JMIR Cancer

Impact Factor (2024): 3.3
Volume 9 (2023) ISSN 2369-1999 Editor in Chief: Naomi Cahill, PhD, RD

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Review

Features of Cancer mHealth Apps and Evidence for Patient Preferences: Scoping Literature Review

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Abstract

Background: Cancer is increasingly being treated as a chronic disease rather than an acute one-time illness. Additionally, oral anticancer therapies, as opposed to intravenous chemotherapy, are now available for an increasing number of cancer indications. Mobile health (mHealth) apps for use on mobile devices (eg, smartphones or tablets) are designed to help patients with medication adherence, symptom tracking, and disease management. Several previous literature reviews have been conducted regarding mHealth apps for cancer. However, these studies did not address patient preferences for the features of cancer mHealth apps.

Objective: The primary aim was to review the scientific literature that describes the features and functions of mHealth apps designed for cancer self-management.

Methods: As the purpose of this review was to explore the depth and breadth of research on mHealth app features for cancer self-management, a scoping review methodology was adopted. Four databases were used for this review: PubMed/MEDLINE, Embase, CINAHL, and PsycINFO. Citation and reference searches were conducted for manuscripts meeting the inclusion criteria. A gray literature search was also conducted. Data extracted from manuscripts included author, title, publication date, study type, sampling type, cancer type, treatment, age of participants, features, availability (free or subscription), design input, and patient preferences. Finally, the features listed for each app were compared, highlighting similarities across platforms as well as features unique to each app.

Results: After the removal of duplicates, 522 manuscripts remained for the title and abstract review, with 51 undergoing full-text review. A total of 7 manuscripts (referred to as studies hereafter) were included in the final scoping review. App features described in each study varied from 2 to 11, with a median of 4 features per app. The most reported feature was a symptom or side effect tracker, which was reported in 6 studies. Two apps specified the inclusion of patients and health care providers during the design, while 1 app noted that IT and communications experts provided design input. The utility of the apps for end users was measured in several ways, including acceptability (measuring the end users' experience), usability (assessing the functionality and performance by observing real users completing tasks), or qualitative data (reports from end users collected from interviews or focus groups).

Conclusions: This review explored the literature on cancer mHealth apps. Popular features within these mHealth apps include symptom trackers, cancer education, and medication trackers. However, these apps and features are often developed with little input from patients. Additionally, there is little information regarding patient preferences for the features of existing apps. While the number of cancer-related apps available for download continues to increase, further exploration of patient preferences for app features could result in apps that better meet patient disease self-management needs.

(JMIR Cancer 2023;9:e37330) doi:10.2196/37330

KEYWORDS

scoping review; mHealth; mobile health; health app; cancer; oncology; disease self-management; self-management; chronic disease; tablet; smartphone; digital health; eHealth; feature

Introduction

Cancer is increasingly being treated as a chronic disease rather than an acute one-time illness [1-3]. Some cancers, such as chronic leukemia and ovarian cancer can be managed, sometimes described as "controlled," in a state where the cancer does not grow but is also not cured for months or years. Additionally, oral anticancer therapies, as opposed to intravenous chemotherapy, are now available for an increasing number of cancer indications [4,5]. These oral treatments are typically self-administered by the patient outside of the clinical setting, presenting challenges (eg, symptom and side effect management) for patients, their families, and their caregivers [6-8].

A 2015 literature review found that health care systems and patients were meeting the challenges of managing self-administered medicines by using mobile health (mHealth) software apps [9]. mHealth apps for use on mobile devices (eg, smartphones or tablets) are designed to help patients with medication adherence, symptom tracking, and disease management [10]. A 2021 analysis found 794 oncology-specific English language mHealth apps [11]. Nasi et al [9] found that patients with cancer mainly used mHealth apps for self-management activities. Self-management can be described as a patient's ability to deal with all aspects of a chronic illness, such as symptoms; treatments; and physical, social, and lifestyle changes.

A wide variety of mHealth apps are available for cancer care (prevention, screening, diagnosis, treatment management, and survivorship) [12,13]. While some apps allow for two-way communication with health care professionals or caregivers, others are solely for the patient to track data such as disease symptoms or physical activity [12,14]. A literature review conducted by Bender et al [15] cataloged mHealth apps providing tools for the self-management of cancer and sorted their features into three groups: appointment tools (eg, reminders for visits with the health care team), self-monitoring functionality (eg, patient tracking of disease symptoms and medication side effects), and communication capability (eg, SMS text messaging with a member of the health care team). With such heterogeneity in functionality, it is imperative to understand what features are preferred by patients to best meet their cancer care needs.

Smartphone ownership in the United States has reached at least 81% according to the Pew Research Center [16], bringing mHealth apps to a majority of the adult population. However, in 2012, a study by Pandey et al [14] showed that fewer than half of cancer care apps were free of cost (42.8%), while the remainder charged fees for downloading. As such, access to mHealth apps remains an important consideration when assessing whether they can aid patients in disease self-management.

Several previous literature reviews have been conducted regarding mHealth apps for cancer. Bender et al [15] conducted a systematic review and content analysis of apps for the prevention, detection, and management of cancer. Nasi et al [9] conducted a literature review regarding the role and use of mHealth technologies during the cancer care process with a particular focus on supportive care. Davis and Oakley-Girvan [13] conducted a literature review to identify apps across the cancer care continuum (from prevention to survivorship) examining patient education and recommendations from randomized studies. Pandey et al [14] evaluated the availability and content of apps for patients with cancer. Finally, Tabi et al [17] reviewed medication management apps for oncology patients. However, these studies did not address patient preferences for the features of cancer mHealth apps.

Our primary objective was to review the scientific literature that describes the features and functions of mHealth apps designed for cancer self-management.

Methods

Overview

This review used a scoping literature review methodology. As stated by Munn et al [18], a systematic review is indicated when the purpose of the research is to compare clinical practices or inform decision-making, whereas a scoping review is indicated when the purpose of the review is to explore how research in the field is conducted and the kinds of literature available. As the purpose of this review was to explore the depth and breadth of research on mHealth app features for cancer self-management, a scoping review methodology was adopted. Guidance was drawn from several sources including the seminal Arksey and O'Malley [19] article, the Tricco et al [20] scoping review guidelines, the McGowan et al [21] PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews), and the Peters et al [22] updates to the Joanna Briggs Institute Guidelines. The reporting in this manuscript follows the PRISMA-ScR extension guidance. This review protocol was not registered. The corresponding author may be contacted regarding the protocol.

Inclusion Criteria

This review included manuscripts related to patient preference studies for cancer self-management using mHealth apps; utilization studies for cancer self-management mHealth apps; utility analyses for cancer self-management mHealth apps; and gray literature from web-based or trade publications related to consumer preference for, use of, or utility for cancer self-management mHealth software apps. Only studies for adults diagnosed with cancer were included. No limits were placed on the type of study considered for inclusion (eg, experimental vs descriptive).

Exclusion Criteria

Manuscripts not written in English were excluded. Pediatric studies were not included. Studies that focused on app development for cancer prevention, diagnosis, palliative care, or survivorship support were not included. Additionally, manuscripts published before 2010 were not included as technology evolutions would likely have rendered previous apps obsolete [23].

Search Strategy

Four databases were used for this review: PubMed/MEDLINE, Embase, CINAHL, and PsycINFO. The database searches were conducted between February 1 and April 1, 2021. A protocol was developed a priori outlining search strategies including databases, websites, and search terms. Exploratory searches were conducted in PubMed and Google Scholar to gather potential search terms. Manuscripts from the exploratory searches were reviewed, and keywords were collated to begin building a search strategy. Once a successful search strategy was built in PubMed, the Polyglot Search Translator was used to build additional searches for the other three databases [24]. The final search strategy for PubMed is presented in Textbox 1. Citation and reference searches were conducted for manuscripts meeting the inclusion criteria. A gray literature search was also conducted across technology trade publications (eg, HealthTech Magazine) and health professional organization publications (eg, American Society for Clinical Oncology and International Society for Pharmaceutical and Outcomes Research).

Textbox 1. PubMed search strategy.

> ("Neoplasms"[Mesh] OR "cancer"[ALL] OR "oncology"[ALL] OR "neoplasm*"[ALL]) AND ("Patient Preference"[Mesh] OR "Patient Satisfaction"[Mesh] OR "acceptability"[ALL] OR "utility"[ALL] OR "patient preference"[ALL] OR "patient satisfaction"[ALL] OR "usability"[ALL]) AND ("Telemedicine"[Mesh] OR "User-computer Interface"[Mesh] OR "mobile health"[ALL] OR "mHealth"[ALL] OR "mobile application"[ALL] OR "smart phone application"[ALL] OR "mobile app"[ALL] OR "smart phone app"[ALL] OR "smartphone application"[ALL] OR "smartphone app"[ALL]) AND ("Self-Management"[Mesh] OR "Self Care"[Mesh] OR "Treatment Adherence and Compliance"[Mesh] OR "Patient Compliance"[Mesh] OR "self-management"[ALL] OR "adherence"[ALL] OR "disease self-management"[ALL] OR "cancer supportive care"[ALL])

Data Extraction

The research team developed title/abstract screening and full-text review forms based on the inclusion and exclusion criteria above. Two independent reviewers (SV and SW) completed the title/abstract screening and full-text review forms for the peer-reviewed and gray literature. If consensus was not reached between the two reviewers, a third independent reviewer (a senior member of the research team) provided arbitration.

Data were extracted from the manuscripts meeting the inclusion criteria and collated in Excel (2017; Microsoft Corporation). Data extracted from manuscripts included author, title, publication date, study design, sampling type, cancer type, treatment, age of participants, features, availability/cost (free or subscription), design input, and patient preferences. One or more members of the research team verified the accuracy of the tabularized data and resolved any discrepancies. Finally, the features listed for each app were compared, highlighting similarities across platforms as well as features unique to each app.

Ethical Considerations

This review was deemed to be not human subjects research by the University of Arizona Internal Review Board.

Results

Overview

The initial search identified 611 manuscripts. After the removal of duplicates, 522 manuscripts remained for the title and abstract review, with 51 undergoing full-text review. A total of 7 manuscripts (referred to as studies hereafter) were included in the final scoping review. The outcomes of the database searches, title and abstract reviews, and full-text reviews (as well as reasons for exclusion) are presented in a PRISMA flow diagram of the manuscript selection process (Figure 1). Data extracted from the scoping review are presented in Table 1 and Multimedia Appendix 1 [25-31].

Figure 1. PRISMA (Prefered Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram of the record selection process. mHealth: mobile health.

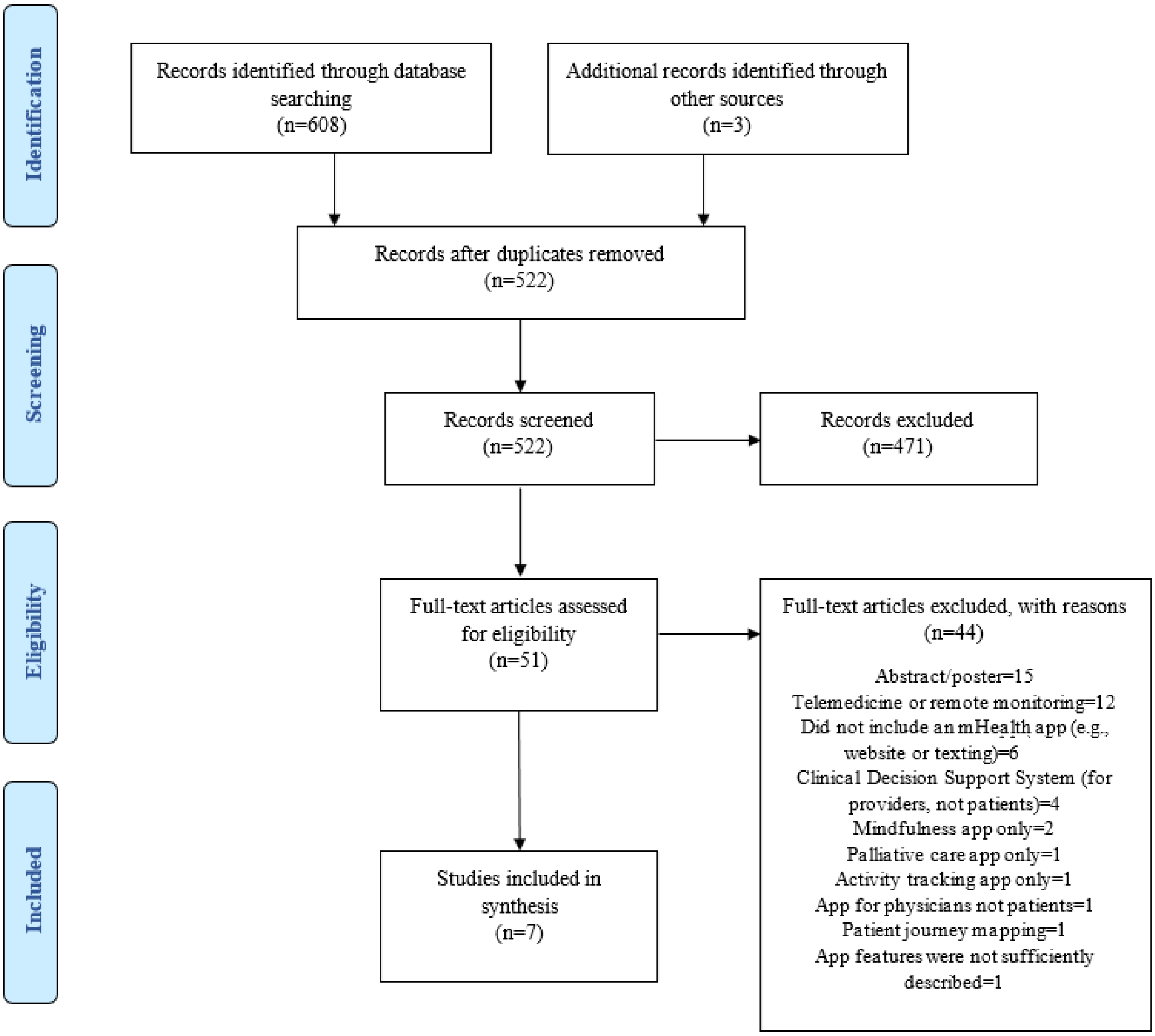

Table 1. Features of mHealth apps in the scoping literature review.

Features	Birkhoff et al [25]	Fishbein et al [26]	Greer et al [30]	Jacobs et al [27]	Kongshaug et al [28]	Tran et al [29]	Wang et al [31]
Symptom tracker	✓[a]	✓	✓		✓	✓	✓
Emotional/social well-being	✓			✓			
Medication tracker	✓		✓				
Reminders		✓	✓		✓	✓	✓
Tools and settings	✓			✓			
Landing page		✓		✓			
Education		✓	✓				✓
Health and fitness		✓	✓	✓			
Calendar	✓				✓		
Medical/treatment information				✓			✓
Privacy/data use		✓					
Notes and questions		✓					
Personalized dose schedule			✓				
Journaling	✓						
To-do list	✓			✓			
Weight tracking	✓						
Patient decision support					✓		
Vital sign tracking	✓						

[a] Indicates presence of the feature.

Study Design and Publication Date

While 5 of the included studies were descriptive [25-29], 1 study was experimental [30] and 1 study was quasi-experimental [31]. The descriptive studies used a variety of methodologies. Three were feasibility studies including combinations of app trials, patient interviews, and expert focus groups [25,28,29]. Two of the descriptive studies were usability tests including measures of acceptability or barriers [26,27]. The experimental study compared the improvement of symptoms and medication adherence between two patient groups (using app vs standard care) [30]. The quasi-experimental study compared patient care needs (eg, psychological support and communications with the care team) between two patient groups, one of which received routine care and one with access to the patient app [31]. Publication dates ranged from 2017 to 2021.

Sample Size

Sample sizes of included studies varied widely, ranging from 11 to 181, with descriptive studies including smaller samples and the quasi-experimental and experimental studies including 100 and 181 patients, respectively. Most studies, including the experimental and quasi-experimental studies, used convenience sampling [25,26,29-31] or did not cite sampling methodology [27,28].

Cancer Type

Four apps were developed to support a single subpopulation of patients with cancer such as breast [27], gastrointestinal [28], oral [31], or prostate cancer [29]. The remaining apps were designed to serve a diverse cancer patient population, including 1 app that was designed to support a wide range of diseases such as asthma and cardiac health [25,26,30]. Three apps were designed to support oral chemotherapy treatment regimens [26,28,30]. Two apps were designed to support mixed treatment regimens [27,29]. One app each was designed to support radiation [25] or surgical treatment [31].

Age of Participants

Four studies reported a mean age for participants (mean age ranged from 52 to 57 years) [25,27,30,31], and 1 study reported a median age of 55 years [27]. One study reported only an age range from 40 to 79 years [28], and 1 study did not specify participant ages [26].

App Features

App features described in each study varied from 2 to 11, with a median of 4 features per app. The most reported feature was a symptom or side effect tracker, which was reported in 6 studies [25,26,28-31]. While there were 5 emotional/social support features reported, they were found in only 2 apps. “Circle of support” and “Healthy dose” functionality were reported by Birkhoff et al [25], and “Social support,” “Emotional support,” and “Local resources” (which provided users with contact information for emotional and social support services in their community) were reported by Jacobs et al [27]. A total of 20 different types of app features were reported ranging from a home page and settings to medication adherence trackers and calendars. A total of 5 features were unique to single apps: notes and questions [26], notices of privacy and data use [26], personalized medication dosing schedule (with optional reminders) [30], vital sign tracker [25], and weight tracking [25].

Availability/Cost

Two apps were noted to be free and publicly available for download [25,27], 2 were only available to study participants or the patients of a particular cancer treatment facility at the time of publication [30,31], and the remainder did not specify availability [26,28,29].

Design Input

Three apps specified the inclusion of patients and health care providers during the design [26,27,30], while 1 app noted that the IT and communications experts provided design input [28]. The remainder did not specify [25,29,31].

Measure of Acceptability

The utility of technology for end users can be measured in several ways, including acceptability (measuring the end users' experience), usability (assessing the functionality and performance by observing real users completing tasks), or qualitative data (reports from end users collected from interviews or focus groups). In the study by Birkhoff et al [25], both usability and acceptability were reported. The overall usability score was 4.69 out of 7, though considerably higher among high school–educated patients (6.38) versus graduate degree–educated patients (3.87). There was no significant difference in reported use over time. In the study by Jacobs et al [27], acceptability was reported as a usefulness score (4.2/5); while engagement with the app over the study period was high, several improvements were suggested qualitatively, such as greater integration with local support services. The study by Wang et al [31] reported acceptability among the intervention group over time. Baseline (odds ratio) scores were reported for intention to use (2.54), perceived usefulness (2.52), and perceived ease of use (2.32) compared to postintervention scores of 3.02, 2.95, and 3.01, respectively, a significant increase in all three aspects. Three studies presented utility as qualitative data [26,28,29]. Fishbein et al [26] noted that usability and acceptability tests were performed but not reported, reporting instead that stakeholder feedback had been incorporated into the design from focus groups and alpha and beta testing, as this was an app design protocol. Kongshaug et al [28] reported that the app provided patients with reassurance regarding correct oral chemo treatment, the app was used as a memory tool for discussing medication adherence and side effects with the health care team, and patients were concerned about reporting less serious side effects. In addition, health personnel expressed a positive attitude to integrate the tool into everyday work. Tran et al [29] reported that patients valued the emotional and well-being support over symptom reporting, requested incorporating patient web-based communities of support (eg, Facebook or Reddit), were concerned with future data use and privacy, and requested data summary features to help them track the information they were entering over time. Finally, Greer et al [30] did not report usability, acceptability, or qualitative data.

Discussion

Principal Findings

In total, 7 studies published from 2017 to 2021 were included for analysis. Studies varied in methodology, from descriptive to experimental, and size, with subject sizes ranging from 11 to 181. Additionally, apps were developed to address the needs of a heterogeneous patient population, some address the needs of a single cancer indication or treatment, and others provide support across the spectrum of cancer diagnoses. Likewise, the number of features per app varied from 2 to 11 with a median of 4—with the most reported feature being a symptom tracker. Lastly, several studies reported patient acceptability or preference data for the app or the features, with acceptability (assessed through survey or interviews) most frequently reported.

Our objective was to review the features and functions of mHealth cancer self-management apps. Symptom tracking, education/information, and medication tracking were three of the most frequently reported features, each of which is discussed in turn below.

A symptom tracker was the most reported feature across the manuscripts in this review, reported in 6 of 7 manuscripts. Cooley et al [32] noted that symptom tracking (particularly with eHealth applications) was relevant to improved patient outcomes in cancer treatment. Similar results were shown by Lu et al [33] who conducted a systematic review to evaluate the use of mHealth apps to track patient-reported cancer outcomes such as symptom reporting. Their search of the iOS Apple Store and Android Google Play identified 11 cancer-specific apps with symptom tracking features. Further details of these features were explored. Some symptom trackers offered the ability for patients to add symptoms not already listed, record symptom severity, add notes, provide a graphical summary, or export data to a caregiver or health professional. Two apps in our review were able to provide symptom trend reports and graphical information [26,28], but only 1 specifically noted the ability to log symptom severity [26]. Further studies may seek to examine patient preferences for symptom trackers, such as the utility derived from displaying symptom reporting trends over time.

This review found that patient education features were reported in 3 studies [26,30,31]. Similarly, Richards et al [34] explored the importance of patient education within mHealth apps, conducting a systematic review to assess how patients used their mobile devices to access information to support outpatient disease management. A total of 14 different interventions were identified across 23 published studies. The education-related features described by Richards et al [34] were related to treatment and did not meet the full range of patient information needs regarding treatments and symptom management. In contrast, the education features identified in our review attempted to meet a broader spectrum of information needs including symptom management and other cancer-related topics (eg, nutrition). Likewise, 3 of the studies included in this review included a home page (at least one of which provided health recipes and news items). Finally, our review identified a total of 5 emotional or social support features that were reported within 2 apps (including information on local patient and caregiver support groups and services) [25,27]. While many of the app features were not described as primarily providing cancer care information, several of the features included information to support patients with disease self-management.

Medication trackers were not typical offerings for cancer self-care apps included in our review, as they were present in only 2 studies. Similarly, Skrabal Ross et al [35] conducted a scoping review to better understand mobile phone apps that were designed to enhance medication adherence to oral chemotherapy. Skrabal Ross et al [35] identified 5 studies with electronic medication adherence interventions; however, only 2 used an mHealth app (the others were SMS text message based). Alarms and reminders were used in both apps to increase patient medication adherence. Likewise, alerts and reminders were identified in 4 apps in our review [28-31]. Like our review, none of the apps included in the study by Skrabal Ross et al [35] were noted to contain a feature for tracking medication-taking behavior trends over time. A study by McNamara et al [36] noted the difficulty in managing patient oral oncolytic medication adherence, and an article by Burhenn and Smudde [37] advocates for tools (eg, smartphone apps) to aid patients in medication adherence. Therefore, further research is warranted to explore whether medication tracking features of mHealth apps aid in medication adherence for patients with cancer treated with oral oncolytic medication.

Despite the growing number of oncology apps, challenges of access do remain for patients seeking to use mHealth for cancer self-management. Our review noted that several apps were available only to patients of a particular cancer center or health system. Similarly, a study by Ana et al [38] noted that, while there are an increasing number of clinical trials aimed at increasing patient medication management through the use of an mHealth app, many of these apps are removed from app stores after the trial ends. Thus potential resources remain out of patient reach.

Limitations

This was a scoping review rather than a systematic review; therefore, a quality assessment was not conducted for the studies meeting the inclusion criteria. Future research could consider conducting a systematic review; assessing the quality of the studies included in the review may lead to further insights. This review specifically sought information on smartphone apps—not SMS text messaging or web-based apps. Accordingly, a narrow range of inclusion dates was used to account for current smartphone operating systems. While not a specific inclusion criterion, patient preference was an area of research interest, and not all studies included reported such.

Future Research

The information found in our review may be of value as cancer apps are continuously developed and updated. Researchers have not always used the preferences of patients in the design of apps. Many of the app features identified in this review included optional calendar reminders, alerts, or trend graphs, although how useful patients find these optional functions is less clear. Additionally, there may be key features that would enhance use that are yet undiscovered.

Further assessment of available features should be conducted among subject matter experts in the fields of mHealth cancer app development and cancer clinical care to explore whether the features currently available are useful and relevant for patients (ie, meet patient preferences). This may enable the development of mHealth apps that better meet patient needs for disease self-management, both from a technical and clinical perspective. Further clarity is needed regarding whether currently available features are used by patients. In addition, some features are heterogeneous across apps. For example, some medication trackers also feature optional alerts when medication should be taken or reminders to track medication adherence, but it remains unclear how many patients use these options or how often. This information could be transformed into a discrete choice experiment to better understand patient preferences for app features. Lastly, this can inform future app development or existing app revision.

Conclusions

While the number of cancer-related apps available for download continues to increase, further exploration of patient preferences for app features could result in apps that better meet patient disease self-management needs. Currently, there is a lack of consensus regarding the presentation of information on patient input into the app design process; reporting best practices may increase the comparability of research. Patient access to cancer self-management apps remains limited. Future research may also include the evaluation of mHealth apps upon development completion from an end user (patient) perspective.

Acknowledgments

This project was not externally funded. We thank Lidia Schapira, MD, FASCO (Stanford University), and Lynne Blasi and Claire Smith (American Society of Clinical Oncology) for generously agreeing to share their knowledge in the field of mobile health.

Authors' Contributions

All authors contributed to the project concept and design. SV and SW provided data collection. SV and TW provided data analysis and interpretation. SV provided manuscript writing. All authors contributed to the manuscript review.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Study characteristics.
[DOCX File , 22 KB - cancer_v9i1e37330_app1.docx]

Multimedia Appendix 2
PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) checklist.
[DOCX File , 32 KB - cancer_v9i1e37330_app2.docx]

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Abbreviations

mHealth: mobile health
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews

Edited by A Mavragani; submitted 15.02.22; peer-reviewed by B Nievas Soriano, A Carr; comments to author 27.04.22; revised version received 28.07.22; accepted 12.12.22; published 28.04.23.

Please cite as:
Vaffis S, Whaley S, Axon DR, Hall-Lipsy E, Hincapie A, Slack M, Warholak T
Features of Cancer mHealth Apps and Evidence for Patient Preferences: Scoping Literature Review
JMIR Cancer 2023;9:e37330
URL: https://cancer.jmir.org/2023/1/e37330
doi:10.2196/37330
PMID:37115587

Review

Effects of Active Video Games in Patients With Cancer: Systematic Review

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Abstract

Background: Physical activity (PA) is now considered an adjuvant therapy in cancer treatment; nevertheless, multiple barriers could reduce PA engagement during treatment. Active video games (AVGs) lead to the achievement of mild- to moderate-intensity PA and represent a promising tool for regular movement and exercise.

Objective: This paper aims to review the current literature and provide updated content on the physiological and psychological effects of AVG-based interventions in patients with cancer undergoing treatment.

Methods: Four electronic databases were investigated. Studies reporting on AVG interventions delivered to patients undergoing treatment were included. A total of 21 articles (17 interventions) were identified for data extraction and quality assessment.

Results: A total of 362 patients with cancer participated in the studies (number of participants 3-70). The majority underwent treatment for breast, lung, prostate, hematologic, or oral or laryngeal cancer. The types and stages of cancer varied in all studies. Participants ranged in age from 3 to 93 years. Four studies included patients with pediatric cancer. The duration of interventions ranged from 2 to 16 weeks, with a minimum of 2 sessions per week and a maximum of 1 daily session. Sessions were supervised in 10 studies, and 7 included home-based interventions. AVG interventions improved endurance, quality of life, cancer-related fatigue, and self-efficacy. Effects were mixed on strength, physical function, and depression. AVGs did not affect activity level, body composition, or anxiety. Compared with standard physiotherapy, physiological effects were lower or similar, and psychological effects were higher or similar.

Conclusions: Overall, our results suggest that AVGs can be recommended to patients undergoing cancer treatment, given the physiological and psychological benefits. When AVGs are proposed, supervision of the sessions should be considered as it can limit dropouts. In the future, it is important to develop AVGs that combine endurance and muscle strengthening, with the possibility of achieving moderate to high exercise intensity, depending on the physical abilities of the patients, as indicated in the World Health Organization's recommendations.

(JMIR Cancer 2023;9:e45037) doi:10.2196/45037

KEYWORDS

exergaming; cancer; physical activity; fatigue; endurance; strength; adjuvant therapy; cancer therapy; cancer treatment; video games; digital health intervention; cancer patient

Introduction

Physical activity (PA) is now considered an adjuvant therapy in cancer treatment [1]. This promising strategy provides psychological (decreased cancer-related fatigue [CRF], decreased anxiety or depression, and improved quality of life [QoL] [2-6]) and physiological benefits (improved fitness, improved muscle strength and function, and normalization of body composition [4,7,8]) in patients with cancer and cancer survivors. Interestingly, a growing body of evidence now suggests that PA is associated with a reduction in cancer-specific mortality [9-11]. Therefore, experts recommended that patients with cancer be as physically active as possible and limit sedentary time [12]. An effective exercise prescription should include moderate-intensity aerobic exercise training at least 3 times per week for 30 minutes combined with 2 sessions of resistance training per week [4].

Unfortunately, 93% of patients with cancer are insufficiently active [13]. Multiple barriers have been identified to support this finding. They can be organizational (schedule of care, location of practice, and availability of therapists and venues) [14,15], physical (pain, lymphedema, CRF, or treatment side effects [14,16-18]), or psychological and social. Abo et al [14] show that the main individual limitations of patients with cancer are lack of motivation and emotional burden. Feeling unable to perform physical exercise or fear of injury is also reported [16]. Therefore, solutions are needed to reconnect patients with cancer to PA and keep them engaged.

New technologies have emerged as a promising tool for regular movement and exercise. Active video games (AVGs), also known as exergames (eg, Just Dance, Wii Fit Plus, and Beat Saber), are becoming increasingly accessible [19]. They are defined as engaging, safe, and fun games in which the players interact in the environment through their movements [19-21]. A few studies have investigated the impact of AVGs in promoting PA in healthy populations [22] or those with disease [23], showing that AVGs lead to the achievement of mild- to moderate-intensity PA [23,24]. These preliminary results suggest that AVGs can help patients reach PA recommendations and thus could provide several health benefits [23,25-27]. Importantly, as described by Tough et al [28], adherence to the AVG intervention is greater than that to standard care in adults with a current or previous cancer diagnosis. Nevertheless, the lack of studies and heterogeneity of interventions and patients hinder conclusions about the real impact of AVGs on health.

In this context, the purpose of this paper is to review the current literature and provide updated content on the physiological and psychological effects of AVG-based interventions in patients with cancer undergoing treatment.

Methods

Study Design

This review was conducted in accordance with the PRISMA (Preferred Reporting Items for Systematic Review and Meta-Analysis) [29].

Search Strategies

Four databases (MEDLINE, PubMed, SPORTDiscus, and Google Scholar) were investigated from inception to February 2023. Keywords were defined with the PICO method [30]. The search strategy was based on the following keywords and their associated synonyms: “Cancer,” “Active video game,” “Exergames,” “Virtual Reality,” “Physical activity,” and “Exercise.” There were no restrictions by date or study location. Additional articles were added manually by searching the references of included studies.

Study Selection

Articles from different databases were combined into a single file, and duplicates were removed. Next, eligibility was assessed by a reviewer (RP) using a 2-step process. At any point, if there was any doubt, a second reviewer (AR) helped to decide.

First, the reviewer screened the title and abstracts of each article. Studies were considered for the second phase if the title or abstract indicated that the intervention was PA based on AVGs in human populations. No age restrictions were considered. The second phase consisted of a full-text review. The inclusion and exclusion criteria for the screening process are presented in Textbox 1.

Textbox 1. Inclusion and exclusion criteria for the study screening.

Inclusion criteria:

- Article type

Clinical trials: research that compared the active video game intervention with healthy controls (ie, cohort and case studies), participants serving as their own control (ie, longitudinal evaluation), and usual physical activity (PA) program or care (ie, randomized control)

- Language

English and French

- Population

Patients with cancer undergoing treatments

- Intervention

Exergames, virtual reality to support PA, and chronic intervention (more than 1 week)

- Outcomes

Physiological or psychological outcomes were reported. Physiological outcomes included PA level, motor functions, endurance, strength, and body composition. Psychological outcomes included cancer-related fatigue, quality of life, self-efficacy, anxiety, and depression.

Exclusion criteria:

- Article type

Reviews and opinions

- Language

Other language

- Population

Healthy population, other chronic diseases, or cancer survivors

- Intervention

Acute virtual reality intervention (less than 1 week), no PA intervention

Data Extraction

A data collection form was developed specifically for this review. It was used to capture the study reference with author, year of publication, study name, and location. We also extracted participant characteristics (sample size, age, and type of cancer), study design, methods used to assess the impact of exergaming, intervention program (frequency, intensity, temporality, time, and supervision), and outcomes (feasibility, adherence rate, and physiological and psychological effects).

Study Quality Assessment

Study quality was assessed by one reviewer (RP) using a Cochrane tool and the Physiotherapy Evidence Database (PEDro) scale.

RoB 2 (version 2 of the Cochrane risk-of-bias tool for randomized trials) [31] was used for randomized controlled trials (RCTs). The risk of bias was assessed across 5 items: randomization process, deviation from the planned intervention, missing outcome data, outcome measurement, and selective reporting. These 5 domains were used to estimate an overall bias: “low risk,” “some concerns,” or “high risk.”

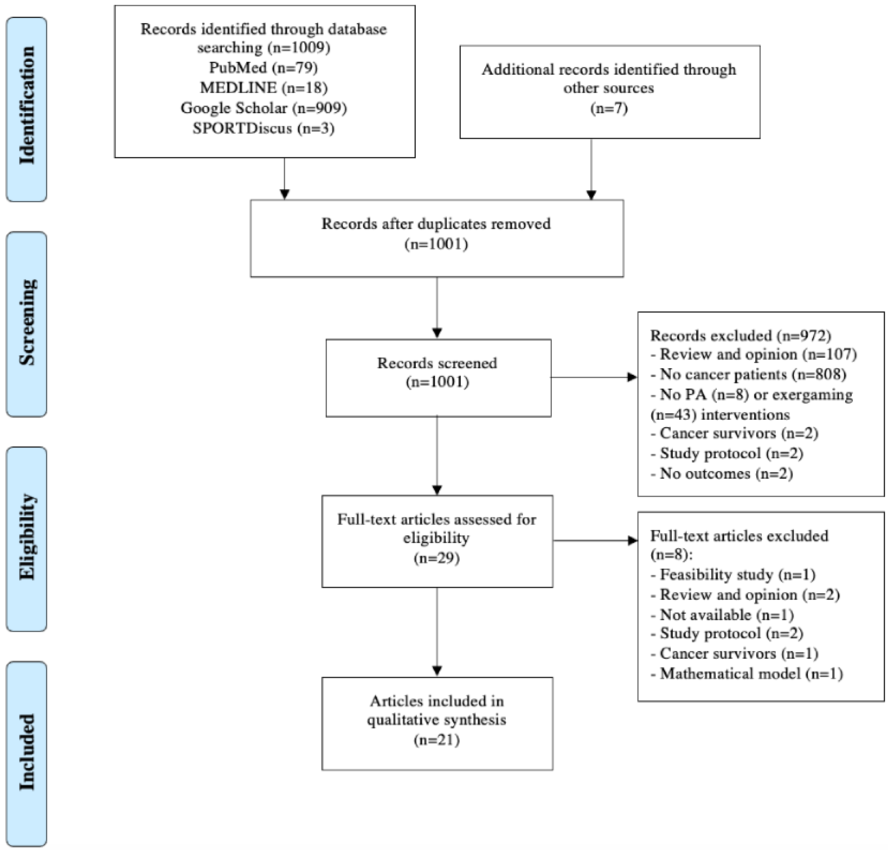
The PEDro scale is a valid scale for assessing risk of bias in clinical studies, regardless of design [32]. This tool provides a 10-point score through 11 “Yes-No” questions. The list of questions is available on the PEDro website. A lower score indicates poor-quality studies, and a higher score indicates high-quality studies.

Results

Study Selection

On February 10, 2023, a total of 1009 articles were identified from PubMed (n=79), MEDLINE (n=18), Google Scholar (n=909), and SPORTDiscus (n=3). A total of 15 duplicates were removed, and 7 articles were manually added from reference checking of recent systematic reviews. Thus, 1001 articles were reviewed, and 972 were deleted after title and abstract screening. Reasons for exclusion were lack of the PA or exergaming intervention, lack of outcomes of interest, no patients with cancer, or patients who did not receive treatment. Review and opinion articles were also excluded. Therefore, after screening, 29 full-text articles were assessed for eligibility and 21 were retained and included in the qualitative synthesis. The 21 articles were combined into 17 trials. The study selection process is described in Figure 1, and the different steps are documented in Multimedia Appendix 1.

Figure 1. Flow diagram [29]. PA: physical activity.



Study Characteristics

No papers were published on the topic before 2013. Studies were published from 2013 to 2023 and conducted in several countries: Egypt, Saudi Arabia, Switzerland, Brazil (n=2), Finland, the United States (n=4), Turkey (n=2), Greece, Germany, Poland, Japan, and Denmark. Different study designs were adopted: 9 RCTs, 2 controlled quasi-experimental studies, 4 single-group studies, 1 case series, and 1 qualitative study.

In total, 379 patients with cancer participated in the studies (number of participants 3-70). The majority underwent treatment for hematologic, breast, lung, prostate, oral, or laryngeal cancer.

The types and stages of cancer varied in all studies. Participants ranged in age from 3 to 93 years. Four studies included patients with pediatric cancer [33-36]. The duration of interventions ranged from 2 to 16 weeks, with a minimum of 2 sessions per week [37,38] and a maximum of 1 daily session [34,39]. Sessions were supervised in 10 studies [33,35-37,39-47], and 7 included home-based interventions [34,38,48-53]. Regarding exergames, 7 trials used Xbox Kinect, 8 trials used Nintendo Wii, and 2 trials created its own exergame and software. The characteristics of the studies and interventions are summarized in Table 1. Data extraction is available in Multimedia Appendix 2.

Table 1. Study characteristics.

Study design, country, reference	Cancer type	Population and age (years), n, mean (SD) or median (minimum-maximum)	System and exergames	Program duration (weeks)	Session frequency and duration	Intensity	Supervision, individual training (IT) or group training (GT)	Comparison group
Quasi-RCT[a], Egypt [37]	Breast cancer	ExG[b]: 15, 54.07 (8.28); SPTG[c]: 15, 53.07 (7.24)	Nintendo Wii: tennis, triceps extension, and rhythmic boxing	4	2×/week for 30 minutes	NR[d]	Yes	SPTG: stretching and PNF[e]
RCT, Saudi Arabia [40]	Breast cancer	ExG: 30, 48.83 (7.0); SPTG: 28, 52.07 (7.48)	Xbox Kinect: Kinect Sports	8	5×/week	NR	Yes (GT)	SPTG: RES[f]
RCT, Switzerland [33]	Pediatric oncology	ExG: 22, 11.81 (2.41); MemG[g]: 23, 10.71 (2.48); CG: 24, 11.13 (2.47)	Xbox Kinect: Shape Up	8	3×/week for 45 minutes	RPE[h]: mean 4.35 (SD 2.23)/10	No	CG[i]: usual care; MemG: memory training
Controlled quasi-experimental, Brazil [41-43]	Various types (gastrointestinal tract, breast, abdominal and pelvic, or oropharyngeal)	ExG: 15, 57.13 (16.74); CAG[j]: 15, 63.29 (7.34); ExGh[k]: 15, 56.73 (11.94)	Xbox Kinect: Your Shape Fitness Evolved (Wall Breaker, Stomp It, and Run the World)	8-10	2-3×/week; ExG: mean 91.84 (SD 11.88) minutes/week; ExGh: mean 90.03 (SD 9.95) minutes/week	NR	Yes (IT)	N/A[l]
RCT, Turkey [38]	Breast cancer	ExG: 19, 50.84 (8.53); SPTG: 17, 51.00 (7.06)	Xbox Kinect: Dance Central and Kinect Sports	6	2×/week for 45 minutes	NR	No	SPTG: END[m] and RES
Controlled quasi-experimental, Brazil [44,45]	Various types (gastrointestinal, breast, abdominopelvic, ovary, uterus, prostate, or oropharynx)	ExG: 10, 61.46 (8.79); ExGh: 10, 57.62 (7.57)	Xbox Kinect: Your Shape Fitness Evolved (Stomp It and Wall Breaker)	8-10	2-3×/week for 20-50 minutes	Light to moderate intensity	Yes (IT)	N/A
RCT, Finland [34]	Pediatric cancer	ExG: 17, 7.8 (3-16); CG: 19, 7.9 (3-15)	Nintendo Wii Fit: Hula Hoop or Jogging, Island Cycling, and Rhythm Kung-Fu	8	7×/week for 30 minutes	NR	No	CG: PA[n] advice: 30 minutes/day
Single group, USA [48,49]	Early-stage non–small cell lung cancer	ExG: 7, 64.6 (6.5)	Nintendo Wii Fit Plus: Walking and balance games	16	Balance: 5×/week; Walking: 5×/week; W1[o]: 5 minutes/session incremented by 5 minutes/session each week if PSE[p] >70%	Light intensity	No	N/A
Qualitative, Greece [35]	Pediatric cancer	ExG: 3, 5.66 (0.58)	Xbox Kinect: Kinect Sports 1 and 2, Kinect Adventures	12	3×/week for 30 minutes	NR	Yes (IT)	N/A
RCT, USA [50]	Prostate cancer	ExG: 8, 77.5 (6.7); SPTG: 6, 75.7 (9.5); CG: 5, 71.8 (5.0)	Nintendo Wii Fit	12	5×/week for 45 minutes	Light to moderate: HRr[q]: 60%-70%; RPE: 3-5/10	No	CG: usual care; SPTG: END and RES

Study design, country, reference	Cancer type	Population and age (years), n, mean (SD) or median (minimum-maximum)	System and exergames	Program duration (weeks)	Session frequency and duration	Intensity	Supervision, individual training (IT) or group training (GT)	Comparison group
Prospective randomized, Germany [46]	Hematologic cancer	ExG: 19, 56 (21-65); SPTG: 23, 56.5 (23-69)	Nintendo Wii Sport, Wii Fit, and Wii Balance Board	4	5×/week for 30-45 minutes	NR	Yes (IT)	SPTG: END and RES
Single group, Japan [47]	Hematologic cancer	ExG: 16, 66 (60-76)	Nintendo Wii Fit: Hula Hoop and Basics Step	Median: 23.5 days	5×/week for 20 minutes	METs[r]: Hula Hoop: 4; Basic steps: 3	Yes (IT)	N/A
RCT, Denmark [51]	Prostate cancer	ExG: 21, 67.6 (4.6); CG: 20, 69.8 (4.4)	Xbox Kinect: Your Shape Fitness Evolved, Sport and Adventure	12	3×/week for 60 minutes	NR	No	CG: usual care
Single group, United States [52]	Oral or laryngeal cancer	ExG: 8, 57.6 (13.3)	Nintendo Wii Fit: Wii Fit U	6	3-5×/week; W1-W3: 36 minutes/week; W4-W6: 40.1 minutes/week	HRpeak[s]: approx. 65%; RPE: 3-6/10	No	N/A
Single group, United States [53]	Advanced cancers	ExG: 4, 63.3 (8.7)	PAfitME (personalized exergame PA)	6	3-5×/week; W1-W3: 47.0 minutes/week; W4-W6: 81.2 minutes/week	RPE: 3-6/10	No	N/A
RCT, Poland [39]	Breast cancer	ExG: 9, 50.6 (12.6); CG: 7, 59.55 (7.85)	Virtual Therapeutic Garden	2	7×/week for 15 minutes	Light intensity	Yes (IT)	CG: usual care

Study design, country, reference	Cancer type	Population and age (years), n, mean (SD) or median (minimum-maximum)	System and exergames	Program duration (weeks)	Session frequency and duration	Intensity	Supervision, individual training (IT) or group training (GT)	Comparison group
Case series, Turkey [36]	Pediatric medulloblastoma	ExG: 5, 10.4 (3.5)	Nintendo Wii Fit Plus: Soccer heading, ski jumping, Penguin Slide, Ski Slalom, Balance Bubble	12	2×/week for 45 minutes	Light intensity	Yes (IT)	N/A

[a] RCT: randomized controlled trial.

[b] ExG: exergames group.

[c] SPTG: standard physiotherapy group.

[d] NR: not reported.

[e] PNF: proprioceptive neuromuscular facilitation.

[f] RES: resistance training.

[g] MemG: working memory training program group.

[h] RPE: Rating Perception of Exertion.

[i] CG: control group.

[j] CAG: remission patients.

[k] ExGH: exergame group with healthy volunteers.

[l] N/A: not applicable.

[m] END: endurance training.

[n] PA: physical activity.

[o] W1: week 1.

[p] PSE: personal self-efficacy.

[q] HRr: heart rate reserve.

[r] MET: metabolic equivalent task.

[s] HR peak: heart rate peak.

Study Quality

Quality assessments of the randomized studies are presented in Table 2 and are available in Multimedia Appendix 3. Overall, the risk of bias ranged from low [40] to some concerns [33,38,39,46,50,51] to high [34]. This assessment depended primarily on knowledge of allocation, number of dropouts, lack of data, and heterogeneity of baseline results.

Quality ratings for nonrandomized studies are presented in Table 3. Scores ranged from 1 to 5. Non-RCTs, missing data, and dropouts limited quality.

Table 2. Risk of bias assessment for randomized trials.

Study	D1[a]	D2[b]	D3[c]	D4[d]	D5[e]	Overall
Basha et al [40]	Low	Some concerns	Low	Low	Low	Low
Benzing et al [33]	Low	Some concerns	Low	Low	Low	Some concerns
Feyzioğlu et al [38]	Low	Some concerns	Low	Low	Low	Some concerns
Hamari et al [34]	Low	High	Low	Low	Low	High
Sajid et al [50]	Some concerns	Some concerns	Low	Low	Low	Some concerns
Schumacher et al [46]	Low	Some concerns	Some concerns	Low	Low	Some concerns
Villumsen et al [51]	Low	Some concerns	Some concerns	Low	Low	Some concerns
Czech et al [39]	Low	Some concerns	Low	Low	Low	Some concerns

[a] D1: bias due to the randomization process.

[b] D2: bias due to deviations from intended interventions.

[c] D3: bias due to missing data.

[d] D4: bias in measurement of outcomes.

[e] D5: bias in selection of the reported results.

Table 3. Risk of bias assessment for nonrandomized trials.

Studies	Q1[a]	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Score
Atef et al [37]	Y[b]	Y	N[c]	Y	N	N	N	Y	N	Y	Y	5
da Silva Alves et al [41], da Silva Alves [42] da Silva Alves [43]	Y	N	N	Y	N	N	N	N	N	Y	Y	3
de Oliveira et al [44] and de Oliveira et al [45]	Y	N	N	Y	N	N	Y	N	Y	Y	Y	5
Hoffman et al [48]	Y	N	N	N	N	N	N	N	Y	Y	Y	3
Hoffman et al [49]	Y	N	N	N	N	N	N	N	Y	Y	Y	3
Nani et al [35]	N	N	N	N	N	N	N	Y	Y	N	N	2
Tsuda et al [47]	Y	N	N	N	N	N	N	N	Y	N	Y	2
Wang et al [52]	Y	N	N	N	N	N	N	N	N	N	Y	1
Wang et al [53]	Y	N	N	N	N	N	N	N	N	N	Y	1
Tanriverdi et al [36]	Y	N	N	N	N	N	Y	Y	Y	Y	N	4

[a] Q1: Question 1.

[b] Y: yes.

[c] N: no.

Feasibility and Adherence to Exergaming Interventions

Feasibility and adherence are presented in Table 4. On the whole, the exergaming interventions were feasible; 53.1% of patients agreed to participate. In addition, no adverse events related to AVG were reported. Regarding dropouts, 12 studies reported a rate of less than 20%, and 5 studies had 26.2% to 60% dropouts. The dropout rate was reduced by session supervision; supervised interventions had an 11.1% dropout rate [33,37-40,46,48,50,54] compared with 25.4% for those without supervision [34,35,41,42,44,47,51-53]. The dropout rate increased with age [41,43,44,46,47,50,52], male gender [50,51], and cancer aggressiveness [44,46,47,52,53]. Other reasons such as lack of time, travel difficulties, and patient death have also been reported [44,47,50,55].

Adherence rates were reported in only 6 studies. Three studies achieved an adherence rate of less than 70% [33,34,47], and 3 obtained a rate greater than 70% [36,48,49,52]. The number of studies is too small to provide convincing evidence of patient adherence to AVGs.

Table 4. Feasibility of intervention, dropouts, and adherence rate throughout intervention.

Study	Feasibility (participants/people meeting inclusion criteria)	Dropouts, n (%)	Adherence rate (total sessions completed [%])
Atef et al [37]	36/51	6 (16.7)	NR[a]
Basha et al [40]	60/112	2 (6.7)	NR
Benzing et al [33]	70/310	6 (8.6)	47.6% reached the desired 20 sessions
da Silva Alves et al [41], da Silva Alves [42], and da Silva Alves [43]	36/105	10 (18.2)	NR
Feyzioğlu et al [38]	40/67	4 (10.0)	NR
de Oliveira et al [44] and de Oliveira et al [45]	38/51	18/38 (47.4)	NR
Hamari et al [34]	36/47	1 (2.8)	50% the first week
Hoffman et al [48] and Hoffman et al [49]	7/10	0 (0)	First 6-week period: mean 96.6% (SD 3.4%, range 90%-100%); second 10-week period: mean 87.6% (SD 12.2%, range 59%-100%)
Nani et al [35]	NR	0 (0)	NR
Sajid et al [50]	19/31	Week 6 = 0 (0); week 12 = 6 (31.5)	NR
Schumacher et al [46]	42/49	11 (26.2)	NR
Tsuda et al [47]	NR	7/16 (43.8)	62%
Villumsen et al [51]	NR	5/46 (10.9)	NR
Wang et al [52]	10/85	2 (20)	First 3-week period: 75%; second 3-week period: 100%
Wang et al [53]	10/60	6 (60)	100%
Czech et al [39]	NR	0 (0)	NR
Tanriverdi et al [36]	NR	0 (0)	83.3%

[a] NR: not reported.

Physiological Effects

Physiological outcomes are summarized in Table 5. The interventions based on AVGs showed varied physiological effects in patients with cancer.

PA levels were assessed in 6 studies using pedometers [48,50], accelerometers and diaries [34], or questionnaires [39,46,51]. Four studies found that AVGs did not significantly improve this parameter [34,46,50,51]. Hoffman et al's study [48] indicated that AVGs could increase PA levels, but the authors did not present statistical analysis, and Czech et al's study [39] indicated that AVGs increased PA levels significantly.

Muscular strength was assessed in 9 studies using hand dynamometers [38,40,46,47,50,52,53], electromyography [41-45], or a power bench [51]. After the intervention based on AVGs, strength was improved in 3 studies [38,40-43]. Five studies reported no significant effect of the AVG intervention [44,45,47,50-53], and Schumacher et al [46] demonstrated that patients had lost strength at the end of the intervention. In addition, 2 studies examined body composition [50,51]. The authors concluded that AVGs did not have a significant effect on body composition.

Aerobic capacity was assessed by a 2-minute walk test [46] or a 6-minute walk test [51-53]. Three of the 4 studies revealed a significant enhancement due to the AVG intervention [46,51-53].

In addition, physical function was assessed in 9 studies using questionnaires such as QuickDASH-9 (Quick Disabilities of the Arm, Shoulder and Hand) [37] and DASH [38,40] and tests such as the German Motor Test [33], Movement ABC-2 (Movement Assessment Battery for Children—Second Edition) [34], SPPB (Short Physical Performance Battery) [50], or Barthel Index [47]. Tanriverdi et al's study [36] is based on the performances achieved in video games (ie, Fit Age in Nintendo Wii Fit Plus). Four studies showed a positive effect of AVGs on physical function [36-38,40], whereas the others did not report a significant effect.

Table 5. AVGs[a] within-group effects on psychological and physiological outcomes.

References	Physiological outcomes					Psychological outcomes				
	PA[b] level	Strength	Endurance	Physical function	BC[c]	QoL[d]	CRF[e]	Anxiety	Depression	SE[f]
Atef et al [37]	N/A[g]	N/A	N/A	+[h] (*P*=.001)	N/A	N/A	N/A	N/A	N/A	N/A
Basha et al [40]	N/A	+ (*P*<.001)	N/A	+ (*P*<.001)	N/A	+ (*P*<.001)	N/A	N/A	N/A	N/A
Benzing et al [33]	N/A	N/A	N/A	=[i] (*P*=.63)	N/A	N/A	N/A	N/A	N/A	N/A
da Silva Alves [41], da Silva Alves [42], and da Silva Alves [43]	N/A	+ (*P*<.01)	N/A	N/A	N/A	+ (*P*<.01)	+ (*P*<.01)	N/A	N/A	N/A
Feyzioğlu et al [38]	N/A	+ (*P*=.001)	N/A	+ (*P*=.001)	N/A	N/A	N/A	N/A	N/A	N/A
de Oliveira et al [44] de Oliveira et al [45]	N/A	+ Right deltoid (*P*=.01); = Left deltoid (*P*=.19)	N/A	N/A	N/A	N/A	+ (*P*=.001)	N/A	N/A	N/A
Hamari et al [34]	= (*P*<.05)	N/A	N/A	= (*P*<.05)	N/A	N/A	= (*P*<.99)	N/A	N/A	N/A
Hoffman et al [48] Hoffman et al [49]	+ (*P*=NR[j])	N/A	N/A	N/A	N/A	N/A	+ (*P*=NR)	N/A	N/A	+ (*P*=NR)
Nani et al [35]	N/A	N/A	N/A	N/A	N/A	+ (*P*=NR)	N/A	N/A	N/A	N/A
Sajid et al [50]	= (*P*=.71)	= (*P*=.69)	N/A	= (*P*=.46)	= (*P*=.25)	N/A	N/A	N/A	N/A	N/A
Schumacher et al [46]	= (*P*=.09)	–[k] (*P*=.02)	+ (*P*=.02)	N/A	N/A	+ (*P*=.001)	N/A	= (*P*>.05)	+ (*P*=.02)	N/A
Tsuda et al [47]	N/A	= (*P*=.28)	N/A	= (*P*=.58)	N/A	N/A	N/A	= (*P*=.05)	= (*P*=.22)	N/A
Villumsen et al [51]	= (*P*>.05)	= (*P*>.05)	+ (*P*=.02)	= (*P*>.05)	= (*P*>.05)	= (*P*=.61)	= (*P*=.15)	N/A	N/A	N/A
Wang et al [52]	N/A	= (*P*=.18)	= (*P*=.07)	N/A	N/A	N/A	+ (*P*=.03)	N/A	N/A	N/A
Wang et al [53]	N/A	= (*P*=NR)	+[l]	N/A	N/A	N/A	+[m]	N/A	N/A	N/A
Czech et al [39]	+ (*P*=.03)	N/A	N/A	N/A	N/A	N/A	N/A	N/A	+ (*P*=.02)	N/A
Tanriverdi et al [36]	N/A	N/A	N/A	+ (*P*=NR)	N/A	N/A	N/A	N/A	N/A	N/A

[a] AVG: active video game.

[b] PA: physical activity.

[c] BC: body composition.

[d] QoL: quality of life.

[e] CRF: cancer-related fatigue.

[f] SE: self-efficacy.

[g] N/A: not applicable.

[h] +: positive effect.

[i] =: no significant effect.

[j] NR: not reported.

[k] –: negative effect.

[l] Cohen *d*=0.6.

[m] Cohen *d*=0.7.

Psychological Effects

Psychological outcomes are summarized in Table 5. Overall, AVG interventions maintained or improved psychological parameters.

Fatigue was assessed in 7 studies using the FACT-F (Functional Assessment of Cancer Therapy: Fatigue) scale, the Brief Fatigue Inventory scale, or the PedsQL (Pediatric Quality of Life Inventory) Multidimensional Fatigue subscale. Five AVG interventions led to an improvement in fatigue score [41-45,48,49,52,53], whereas Villumsen et al [51] and Hamari et al [34] reported no significant change.

Anxiety and depression were assessed in 2 studies using the HAD (Hospital Anxiety and Depression) scale. One study assessed depression through Beck Depression Scale. No significant results were found on anxiety [46,47]. However, Schumacher et al [46] and Czech et al [39] showed an improvement in the depression score.

Regarding QoL, 5 studies examined this outcome through interviews or questionnaires as well as FACT-BMT (Functional Assessment of Cancer Therapy: Bone Marrow Transplantation), FACT-P (Functional Assessment of Cancer Therapy: Prostate), or SF-36 (36-Item Short Form Health Survey). Four of them demonstrated that AVGs improved QoL in patients with cancer [35,40-42,46]. One study found no significant effect on this parameter [51].

Concerning the self-efficacy perception, Hoffman et al [48,49] used the Perceived Self-Efficacy for Fatigue Self-Management for Walking Duration questionnaire and a specific scale for balance activities. They demonstrated that the AVG intervention improved self-efficacy perception in patients with cancer.

Comparison Between AVG and Standard Physiotherapy

Between-group comparisons are presented in Table 6. They revealed that AVGs induced greater benefits on QoL [46] than standard physiotherapy (SPT), as well as on vitality and general health, which are the subcomponents of QoL [40]. Similar results were reported regarding depression [46].

Concerning endurance, physical function, and strength, the data appeared controversial. Some studies mentioned an improvement in endurance [51] or physical fitness with AVGs [40], whereas others indicated the opposite [38] or no difference between these 2 approaches [37,38,46].

Table 6. Between-group comparisons on physiological and psychological outcomes.

References	Physiological outcomes					Psychological outcomes			
	PA[a] level	Strength	Endurance	Physical function	BC[b]	QoL[c]	CRF[d]	Anxiety	Depression
Atef et al [37]	N/A[e]	N/A	N/A	ExG[f]=SPTG[g] (*P*<.05)	N/A	N/A	N/A	N/A	N/A
Basha et al [40]	N/A	ExG<SPTG (*P*<.001)	N/A	ExG>SPTG (*P*<.001)	N/A	ExG=SPTG (*P*<.05); general health: ExG>SPTG (*P*<.001); vitality: ExG>SPTG (*P*=.006)	N/A	N/A	N/A
Benzing et al [33]	N/A	N/A	N/A	ExG=SPTG (*P*>.05)	N/A	N/A	N/A	N/A	N/A
Feyzioğlu et al [38]	N/A	ExG=SPTG (*P*=.30)	N/A	ExG<SPTG (*P*=.02)	N/A	N/A	N/A	N/A	N/A
Hamari et al [34]	ExG=SPTG (*P*=.38)	N/A	N/A	ExG=SPTG (*P*=.77)	N/A	N/A	ExG=SPTG (*P*<.05)	N/A	N/A
Sajid et al [50]	ExG<SPTG (*P*=NR[h])	ExG<SPTG (*P*=NR)	ExG<SPTG (*P*=NR)	ExG<SPTG (*P*=NR)	ExG<SPTG (*P*=NR)	N/A	N/A	N/A	N/A
Schumacher et al [46]	ExG=SPTG (*P*<.05)	ExG=SPTG (*P*<.05)	ExG=SPTG (*P*<.05)	N/A	N/A	ExG>SPTG (*P*=NR)	N/A	ExG=SPTG (*P*<.05)	ExG>SPTG (*P*=NR)
Villumsen et al [51]	ExG=SPTG (*P*>.05)	ExG=SPTG (*P*=.22)	ExG>SPTG (*P*=.02)	ExG=SPTG (*P*=.08)	ExG=SPTG (*P*=.09)	ExG=SPTG (*P*=.61)	ExG=SPTG (*P*=.15)	N/A	N/A

[a] PA: physical activity.

[b] BC: body composition.

[c] QoL: quality of life.

[d] CRF: cancer-related fatigue.

[e] N/A: not applicable.

[f] ExG: exergames group.

[g] SPTG: standard physiotherapy group.

[h] NR: not reported.

Discussion

Principal Findings

AVGs are innovative tools in oncology. Safe, fun, and feasible PA interventions using AVGs have demonstrated beneficial effects on physical and psychological health.

In our systematic review, we reported that AVGs can help patients develop their endurance capacity because 3 of the 4 studies demonstrated an improvement of this outcome [46,51-53]. Increasing peak oxygen uptake values with AVGs could prevent the disease-associated loss of autonomy and allow the patient to live independently as a healthy individual. AVGs, through their repetitive and rapid movements, lead to PA of sufficient intensity to generate adaptations in pathological individuals, demonstrating the relevance of AVGs as a rehabilitation strategy [23,26,56].

AVGs presented mixed effects on patients' physical functioning. When the practice of AVGs did not result in positive effects [34,47,50,51,55], the authors hypothesized that the intensity elicited by the AVGs would not be sufficient, except in the case of very deconditioned patients [46], or that the weekly duration of practice would be too short [46,55]. However, the second hypothesis seems less relevant, as 3 of the 4 studies reporting benefits offered only 2 sessions per week [36-38]. Another explanation could be the deterioration of patients' health due to cancer treatments [44,47,48]. Among the studies reporting benefits [36-38,40], the protocols used differ in terms of frequency (2 [36-38] to 5 [40] sessions per week during 4 [37] to 12 weeks [36]), intensity (light to moderate [36-38,40]), and time (from 30 [37] to 45 minutes [36,38]), which prevents the definition of precise recommendations.

Contrary to SPT, AVGs do not significantly develop muscle mass and strength. In the 6 studies reporting no benefits, the AVGs proposed, whether commercial [46,47,50,51,53] or created [52], do not include muscle strengthening exercises. In the 3 studies reporting strength gain [38,42,44,45], patients used Xbox Kinect, suggesting that the type of movements performed during these AVGs may be advantageous in targeting this goal. Because muscle mass is predictive of patient life expectancy, it is essential to develop new AVGs with a muscle-strengthening component.

Among the psychological components, only CRF and QoL seem to be improved by the use of AVGs [35,40-42,44,46,48,52,53]. This was previously suggested by Ioannou et al [57] in their systematic review. Similarly, Ulas and Semin [2] also showed that virtual reality decreased perceived exercise intensity, reduced exercise stress, and improved perceived self-efficacy, thus helping patients to delay their fatigue threshold [2,58,59]. An improvement in sleep quality could also be achieved, leading to better recovery and less fatigue [2]. In our systematic review, sleep quality was not a primary outcome. Nevertheless, 2 studies evaluated the effects of exergames on this parameter using polysomnography and the Children's Sleep Habit Questionnaire in children with acute lymphoblastic leukemia [60] and the Pittsburgh Sleep Quality Index in patients with breast cancer [39]. Both of these studies demonstrated the positive effects of the AVG intervention on sleep quality.

The physiological and psychological benefits in response to AVGs appear to be independent of increased PA levels. These results are surprising in view of the previous publications, showing that AVGs led to an increase in PA levels in various patients [23,27,56,61]. Several hypotheses can be proposed; wearing connected watches [34] is described as a behavior change technique [62] because it provides goal setting, action planning, and feedback [63] and could temporarily increase PA [58]. Hence, the first week's measurement may be higher than usual because of the motivational dimension of the device. In contrast, at the end of the protocol, the PA level would be less modulated because of a gradual decrease in the motivation, possibly leading to monitor dropout [59,60,64]. This result can also be found with pedometers [48-50]. With respect to measures obtained using PA questionnaires, there may be a social desirability bias [65]. This bias may lead to overestimating the PA level on the initial assessment, but repetition of the measures would gradually reduce it [66]. An alternative explanation would be that participants decrease their home PA as a result of the increased PA achieved with the AVGs. This hypothesis is notably supported by Hoffman et al [48,49], who show that patients reduce their daily PA once they follow a walk program on the Wii Balance Board. Finally, in the study by Schumacher et al [46], patients with cancer complete the PA questionnaire before hematopoietic stem cell transplantation (T1), and then 7 days (T2), 14 days (T3), and 100 (T4) days after. The comparison is only made between T1 and T4, but we can assume that the level of PA drops after T1 in response to the treatments, explaining the lack of a significant difference between T1 and T4.

To sum up, in view of the physiological and psychological benefits observed, the use of AVGs in oncology appears to be relevant, particularly for patients who are far from PA practice sites and who can perform PA at home [13,14,67], and for those who are too weak or isolated because of the constraints of treatments (ie, sterile room). Our systematic review suggests that anticancer treatments [46,47,52-54] and advanced cancers [44,46,47,52,53] negatively influence patient adherence to interventions using AVGs. This result is also found for SPT [68]. Side effects (eg, fatigue, nausea, pain, or postoperative immobilization) may partially explain this finding. Moreover, AVG interventions appear to be better accepted by younger patients than by older patients. Familiarity and ease of use of technology may explain these results; older adults need tailored technology systems [69,70]. These results are reinforced by studies showing the influence of session supervision on patient adherence [33,36-40,48]. It would contribute to support patients in the use of new technologies and would therefore be more necessary than during SPT [67,71]. Finally, among the parameters of PA, intensity and frequency seem to be 2 key factors [38,41,42,49,51]. Based on the findings, the optimal recommendations would be to perform a minimum of 3 sessions of exercise per week at a light intensity.

Study Limitations

Heterogeneity in settings, evaluations, and populations limits the ability to conclude on the effects of AVGs on specific cancer populations; therefore, only trends are presented in this review.

In addition, most of the nonrandomized trials presented low scores on the PEDro scale (from 1 to 5/10). Thus, some results should be viewed with caution because the study did not present statistical analysis [35,36,48,49] and the dropout rate was very high [44,45,47,53].

Perspectives

Additional RCT and high-quality studies will be required to assess AVG feasibility with other patients with cancer and compare AVG intervention with SPT. In addition, further research will help define the optimal parameters of AVG interventions (ie, frequency, intensity, type, time, and supervision) based on patient characteristics and goals to be achieved. Also, future research should evaluate the effects of the AVG intervention combined with resistance training.

Conclusions

The results of our review support the notion that AVGs can be recommended to patients undergoing cancer treatment, given the physiological and psychological benefits. The rates of engagement and adherence are similar to those found with SPT. However, as AVGs have no impact on body composition and muscle strength, we suggest combining AVGs with muscle strengthening exercises. Special attention should be paid to patients with advanced cancers and cancer cachexia to ensure that AVGs do not exacerbate weight and muscle loss.

Acknowledgments

The authors thank Simon Peyrachon for his assistance with the English language.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Screening process.
[XLSX File (Microsoft Excel File), 14 KB - cancer_v9i1e45037_app1.xlsx]

Multimedia Appendix 2
Quality Assessment.
[XLSX File (Microsoft Excel File), 382 KB - cancer_v9i1e45037_app2.xlsx]

Multimedia Appendix 3
Data extraction.
[XLSX File (Microsoft Excel File), 49 KB - cancer_v9i1e45037_app3.xlsx]

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Abbreviations

AVG: active video game
CRF: cancer-related fatigue
FACT-BMT: Functional Assessment of Cancer Therapy: Bone Marrow Transplantation
FACT-F: Functional Assessment of Cancer Therapy: Fatigue
FACT-P: Functional Assessment of Cancer Therapy: Prostate
HAD: Hospital Anxiety and Depression
Movement ABC-2: Movement Assessment Battery for Children—Second Edition
PA: physical activity
PEDro: Physiotherapy Evidence Database scale
PRISMA: Preferred Reporting Items for Systematic Review and Meta-Analysis
QoL: quality of life
QuickDASH-9: Quick Disabilities of the Arm, Shoulder and Hand
RCT: randomized controlled trial
RoB 2: version 2 of the Cochrane risk-of-bias tool for randomized trials
SF-36: 36-Item Short Form Health Survey
SPPB: Short Physical Performance Battery
SPT: standard physiotherapy

Edited by A Mavragani; submitted 13.12.22; peer-reviewed by B Bock, W Bloch; comments to author 07.02.23; revised version received 08.03.23; accepted 09.03.23; published 26.05.23.

Please cite as:
Peyrachon R, Rébillard A
Effects of Active Video Games in Patients With Cancer: Systematic Review
JMIR Cancer 2023;9:e45037
URL: https://cancer.jmir.org/2023/1/e45037
doi:10.2196/45037
PMID:37234028

Review

Perceived Barriers and Facilitators in Using Patient-Reported Outcome Systems for Cancer Care: Systematic Mapping Study

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Abstract

Background: Cancer is a major global health problem. Patient-reported outcome (PRO) systems have been developed to support the treatment of patients with cancer. Although clear evidence of the benefits of the routine use of electronic patient-reported outcomes (ePROs) exists, engaging physicians in using these systems has been challenging.

Objective: This study aims to identify and analyze what is currently known about health care professionals' (HCPs) perceived barriers and facilitators that exist and influence the use of ePRO systems for cancer care.

Methods: We carried out a systematic mapping study by conducting searches of 3 databases (Association for Computing Machinery, PubMed, and Scopus). Eligible papers were published between 2010 and 2021, and they described HCPs' perspectives on using ePROs. The data on the included papers were extracted, a thematic meta-synthesis was performed, and 7 themes were summarized into 3 categories.

Results: A total of 17 papers were included in the study. The HCPs' perceived barriers and facilitators of using ePROs can be summarized into 7 themes: clinical workflow, organization and infrastructure, value to patients, value to HCPs, digital health literacy, usability, and data visualization and perceived features. These themes can be further summarized into 3 categories: work environment, value to users, and suggested features. According to the study, ePROs should be interoperable with hospital electronic health records and adapted to the hospital workflow. HCPs should get appropriate support for their use. Additional features are needed for ePROs, and special attention should be paid to data visualization. Patients should have the option to use web-based ePROs at home and complete it at the time most valuable to the treatment. Patients' ePRO notes need attention during clinical visits, but ePRO use should not limit patient-clinician face-to-face communication.

Conclusions: The study revealed that several aspects need improvement in ePROs and their operating environments. By improving these aspects, HCPs' experience with ePROs will enhance, and thus, there will be more facilitating factors for HCPs to use ePROs than those available today. More national and international knowledge about using ePROs is still needed to cover the need for information to develop them and their operating environments to meet the needs of HCPs.

(JMIR Cancer 2023;9:e40875) doi:10.2196/40875

KEYWORDS

patient-reported outcome system; barriers; facilitators; cancer; health care professionals

Introduction

Cancer is one of the most important health problems, affecting nearly 25 million people globally each year through new cancer incidences [1]. Routine patient-reported outcome (PRO) follow-up of patients with cancer improves long-term treatment outcomes [2,3]. Integrating PRO measures into routine clinical practice has improved symptom monitoring and the detection of treatment complications in patients with cancer [4]. Using PROs has resulted in fewer hospitalizations and emergency room visits, better health-related quality of life, and higher quality-adjusted survival [2]. Furthermore, PROs can improve communication between patients and health care professionals (HCPs) [4-6].

Patient-reported outcome measures (PROMs) are measurement tools used to report PROs. Nondigital and digital PROs (electronic patient-reported outcomes [ePROs]) use PROMs to collect PRO data [7]. ePRO is a software that allows patients to independently answer questions and report on their health using electronic devices, and HCPs can follow their patients' well-being and assessment of symptoms. ePRO provides decision support for HCPs by helping with symptom monitoring and improving patient-clinician communication [8]. Although most physicians agree on the importance of collecting self-reported data of patients with cancer, engaging physicians in using PROs is a key challenge [9]. Furthermore, nurses and physicians have various preferences regarding PROMs in clinical practice [10]. Increasing the awareness of PRO solution providers regarding the barriers and facilitators to using PROs in clinical practice can help inform the design of these tools to support the enhancement of the quality of patient care [11]. Over the previous decade, research has focused on expanding our understanding of the benefits for patients of using PROs in cancer care [12].

The acceptability of PROM is often linked to its perceived benefits [13,14]. HCPs often support the use of PROMs that bring benefits to patients and improve health care [14]. However, formal integration of these tools into the hospital electronic health record (EHR) is infrequent [15], despite evidence that it improves the feasibility of their use [13]. It is important that the PROM is easy to navigate and that HCPs have easy access to computers and sufficient skills and knowledge to use the PROM. The relevance of workflow has also been highlighted as a significant aspect of the feasibility of PROM use [13]. Previous works in the literature also show other barriers and facilitators: patients' limited eHealth literacy [16], lack of friendly interface elements for displaying longitudinal patient-reported symptoms, and integrations with EHRs [9].

At the time of this study, only a few studies have explored the barriers and facilitators of HCPs' experiences when using ePRO systems to support the treatment of patients with cancer. The purpose of this study was to identify and analyze the current landscape on this topic.

Methods

Study Design

The study was carried out as a systematic mapping study to structure, understand, and organize existing research work on HCPs' experience with ePRO systems [17,18]. Systematic reviews provide a synthesis of valuable studies in a particular field of research that is not possible for a practitioner to read on their own [19], while the systematic mapping study aims to structure the research area [18]. A mapping study is a practical method for a researcher who needs to understand and organize the existing research work in an individual domain [17].

Data Exclusion

Keywords for this study included patient-reported outcomes, barriers, and cancer. We also used the MeSH terms neoplasms, patient-reported outcome measures, telemedicine, assessment, and patient outcomes as search terms. These keywords were combined with Boolean, and search results were narrowed by the publication date of the year 2010 onward to identify appropriate studies, as shown in Multimedia Appendix 1.

Selection Criteria

Papers were included if (1) they were written in English, (2) the studies included the use of ePROs, (3) they were published between or during 2010 and 2021, (4) the target population included patients with cancer, and (5) they mentioned HCPs' perspectives (barriers and facilitators) of using PROMs.

Papers were excluded if they were (1) focused on PROM use in clinical trials, (2) review studies, and (3) focused on the implementation of PROM for clinical practice.

For the purposes of this study, we considered the PROMs used in the past 3 months after the implementation period.

Data Screening

Figure 1 illustrates the study selection process and shows the number of included and excluded papers. The papers were imported from 3 academic research databases to Covidence (Covidence.org). Covidence, a systematic review management tool, was used to remove duplicates and manage all the references included in the title and abstract screening, full-text review, and extraction. The searches from the databases were done from August 22, 2021, to September 29, 2021. A total of 152 papers were imported using agreed-upon search terms, and after careful screening, 17 papers remained.

A considerable share of studies excluded during the title and abstract screening stage were studies that used PROs as data sources but did not assess the barriers and facilitators of using the system. Some of the papers dealt with patient-reported data, but the information was obtained through, for example, a survey on paper or an interview. At that stage, studies related to ePRO implementation rather than barriers and facilitators in using ePRO after the implementation period remained for further full-text review. There was a need to decide when the implementation turned into routine usage, and 3-month implementation period criteria were established.

The main author did the data selection independently. A random selection of 23% (n=25) of full-text papers was reviewed by a different researcher to determine interrater reliability. Interrater reliability was determined using Cohen κ and found to be acceptable at 0.63 (SE 0.25; 95% CI 0.14-1.11). The reviewers had divided opinions on the eligibility of one of the jointly evaluated papers. Therefore, there was a need to clarify when implementation became the routine use of PRO. Multimedia Appendix 1 shows the papers selected according to the criteria of this study. Later in this study, the papers are referenced based on the sequence numbers in the *References* section.

As shown in Table 1, papers addressing the perspectives of HCPs on the barriers to and facilitators of using ePRO data in the treatment of patients with cancer have been published in recent years, while there was no publishing in the early 2010s. The table shows that there is a clear minority of papers describing only ePRO systems in 2020-2021 papers compared to papers focusing on both ePROs and nondigital PROMs.

Figure 1. The number of included and excluded papers during the study selection process. ACM: Association for Computing Machinery.

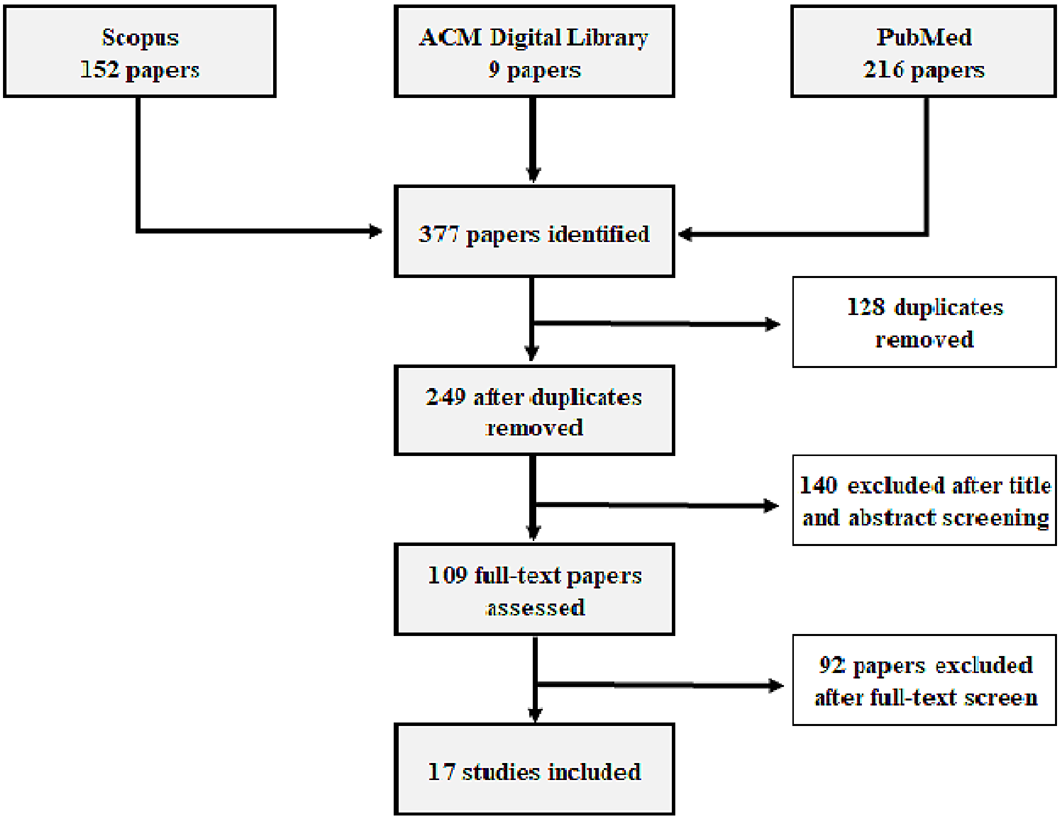

Table 1. The trend of publishing year of included papers.

	2010-2011	2012-2013	2014-2015	2016-2017	2018-2019	2020-2021
All papers	0	0	0	6	1	10
ePRO[a]	0	0	0	5	0	3

[a] ePRO: electronic patient-reported outcome.

Data Extraction and Analysis

The data on the included papers were extracted as follows: authors, title, year of publication, study objective, cancer type, study design, duration of data collection, study population, administered PROM, ePRO name, sole use of ePRO, barriers, and facilitators. Thematic meta-synthesis for the extracted data was performed by adapting the methods for thematic synthesis described by Thomas and Harden [20]. The verbatim findings of these 17 studies were entered into the Excel (Microsoft Corp) file. Each line of text was coded according to its meaning and content. The authors of the paper independently reviewed the data and grouped them into themes. Themes were then discussed and merged. After several rounds of reviewing the coding, the final 7 descriptive themes for the barriers and facilitators were determined. The 7 themes were summarized into 3 categories that united the themes: work environment, value to users, and suggested features.

Results

Overview

Of the total 17 papers, 8 introduced a study in which study participants had used only ePROs [21-28]. In the other 9 papers [29-37], only some of the participants had used ePROs, while others had used nondigital PROMs. The ePRO systems used were AmbuFlex [21,26], OncoQuest [22], Noona [23], the KLIK method [25], and PatientViewpoint [28]. No type of cancer was particularly emphasized, but PROMs were used in different target populations, such as patients with breast, lung, head and neck, prostate, melanoma cancer, and pediatric patients with cancer. The most frequently used PROM was the Edmonton Symptom Assessment Scale (ESAS) [32-34]. Studies were carried out in multiple countries: the Netherlands [22,25,31], Germany [27,29], the United Kingdom [24], the United States [23,28,35,37], Denmark [21,26], Canada [32,34], Australia [33], and 41 other countries [30]. There was no mention of the country where the PROM was implemented in 1 paper [36].

Thematic Analysis

The following themes were identified from the barriers and facilitators presented in the selected papers: clinical workflow, organization, and infrastructure, value to patients, value to HCP, digital health literacy, data visualization and perceived features, and usability.

Clinical Workflow

This theme describes the PROMs' impact on the smooth running of work tasks in a health care organization, both in the work of individual HCPs and in collaboration with a multiprofessional team.

Barriers

The theme was associated with barriers by 8 comments in 13 papers [21-23,25-31,34,35,37]. The lack of integration into EHRs or other hospital systems is highlighted as a barrier in 7 papers [21-23,26,28,29,37]. The impact on the workflow can be a barrier [28] if PROs do not fit into a robust workflow of clinical care [30] and current routines [25]. PROs might delay clinics if it takes too much time for patients to fill them in before physician consultation [27,31,34] or for clinicians to interpret PROMs [31]. The timing of the distribution of the PROM may complicate the clinical workflow [35]. This is especially true if the patient's consultation with the physician is too far removed from the point of PROM reporting, as it may result in the data being no longer relevant [31].

Facilitators

Facilitators of this theme were identified by 8 comments in 7 papers [24,26,29,31,33,35,36]. Easy access to the PROM tool, or data [31,35], specifically via EHR [24,29,33], facilitates the use of PROM. Integration is considered very important [26,36]. The ability of patients to contact the department on time and distribute information automatically to patients is also crucial, which supports the clinical workflow [26]. ePROs are more efficient in data collection, distribution, and preserving data quality than nondigital PROMs [35].

Organization and Infrastructure

This theme refers to the existing support systems available in the health care organization, such as the PROM integration into the hospital's EHR. In addition, the organizational facilitators and barriers to PROM use are discussed under the theme.

Barriers

We identified 6 barriers to this theme in 5 papers [21,24,25,30,36]. The ePRO systems are not implemented as routine [21], or ePROs are not integrated as intended [25]. PROMs might lack integration technology with hospital EHR [36]. Some PROs are not systematically collected at different clinics in the hospital [30]. Another barrier is limited access to computers [24]. A complex hospital system could also potentially influence the use of the ePRO system [24].

Facilitators

This theme was associated with 4 facilitators in 4 papers [25,29,35,36]. The use of PROM is enhanced if professionals think they are expected to use the ePRO system (normative belief) [25] or if coordinating structures are implemented for PRO processes in hospitals [29] or PROMs improve the coordination of care [36]. In addition, PROMs are more used if the hospital benefits financially from the use, receiving more payments for care [35].

Value to Patients

This describes how the use of PROMs affected patient experiences according to HCPs.

Barriers

Barriers to value were captured by 14 comments identified in 6 papers [22,28,33,35-37]. Some HCPs expressed concern that patients may not see the point of using ePRO [36,37]; it may be that it takes too much time [22] and that they end up feeling overburdened [33] or experience fatigue by the process [36]. The lack of home access to ePROs [22] and the lack of feedback from physicians [22] were also mentioned. Patients' inability to complete the PRO can vary based on language [36,37], literacy [35-37], health literacy [33], culture [36], and health status [37]. There can be reporting bias; for example, reporting actual symptoms might not be comfortable for patients [35]. One paper shows that patients might prefer to share their needs directly with HCPs rather than via ePROs [28].

Facilitators

There were 6 papers [25,26,33,34,36,37] with 13 comments on the positive views of HCPs on patients' experiences with PROMs. The perception was that PROM improves patients' quality of life and satisfaction [37] and empowers them [33]. PROMs make it easier for patients to report their symptoms [34], and they think that they increase treatment adherence and patients' awareness of their own needs and the resources available for them [36]. HCPs also perceived patients as being better prepared for consultation and more aware of their symptoms. The tool also allows patients to contact the clinic on time. The PROM is especially valuable for patients who are usually unwilling to contact the clinic unscheduled [26]. Professionals deem patients' opinions important regarding the use of the ePRO [25], and they think it is good that the tool is patient-centered and captures patients' perspectives [34].

Value to HCPs

This theme describes the added value experienced by HCPs in using PROM in their work. In practice, if the comment did not fit other themes identified, it was included in this theme.

Barriers

A total of 7 papers [21,23,25,26,28,32,33] included 6 comments on the barriers to this theme. Some users reported that the use of ePROs or PROMs tends to prolong clinic visits [26,32,33]. Some prefer face-to-face communication rather than looking at the computer [28]. Some HCPs already have electronic ways of communicating with their patients [23], and extensive assessments have already been performed [32]. HCPs are skeptical of the value that ePROs add to their interactions [25], as some clinicians rate the importance of symptoms differently than patients [21].

Facilitators

The theme included 27 facilitating comments in 13 papers [21,22,24-28,31-36]. The potential time saved was highlighted in 3 papers [27,31,36], and 1 paper commented on how the consultation was shorter with ePRO use [21]. The ability to improve communication between patients and clinicians is very important [21,36]; the information seems to be more discussable [25], as it allows for the comparison of symptoms and treatment evaluation [33]. PROMs are perceived as enhancing consultation efficiency [34] and are considered a systematic and measurable method for assessing patient needs [32]. They are sometimes helpful and sometimes confirmatory [28] and have value [32].

PROM appears to stimulate multidisciplinary teamwork [31]. There is an opportunity with ePRO to develop follow-up referrals to better meet the needs of individual patients [22]. ePRO is a useful addition to the clinical management of patients [24] and should be used as a basis for patient-clinician consultation and as an added benefit for the consultation [26]. ePRO helps clinicians understand patients' experiences of recovery and monitoring symptoms [24] and prioritize patients' problems [26]. There is no similar need for explanatory information when looking at patient results [28]. PROM enhances clinicians' awareness of patients' needs [36], patient-centered care [35], and knowledge of patients' health-related quality of life [22,25]. Diagnosis-based ePRO instruments are facilitators for clinicians [35].

Digital Health Literacy

This theme refers to the competence, opportunity to develop, and ability of HCPs to work in a digital workplace.

Barriers

There were 6 papers [21,25,27,28,30,31] with 13 comments associated with barriers to this theme. Barriers ranged from understanding the basics of PROM systems [31] (how to log on, the aim of the system, how the data are presented, and how the ePRO is used in communication with patients [21]) to more systemic issues (lack of support from colleagues [25], management [30], and local PRO experts [30]). The absence of technical support [21,31] and high administrative burden [31] are often present. There is also a lack of knowledge on some assessed data in ePRO [27] and a need to have better indications of what certain scores mean [28]. Uncertainty about how to choose an appropriate PROM is also a barrier [30].

Facilitators

The theme includes 3 facilitating comments in 2 papers [25,33]. Providing sufficient education on the use of ePRO systems [25] and identifying patients' symptoms through PROMs [33] are valuable. For the development of hospital service delivery, PROMs provide information by highlighting the symptom groups of the patient population [33].

Data Visualization and Perceived Features

This theme describes needs regarding the representation of data and information with visual elements, such as charts and graphs, intended to make it easier for the user to understand the data, such as trends and outliers.

Barriers

The theme was associated with 8 barriers mentioned in 6 papers [27,28,30,34-36]. The publications described certain features that are lacking in most cases, such as cost-effectiveness data [30] and automatic referrals to follow-up treatment [36]. More answering options are desired to make the questions appropriate for all patient situations [27]. Some users hope for other symptom options [34], and some prefer features that could flag high symptom scores [28]. More functionalities [28] and well-designed features are needed to avoid information overload [35]. Graphs are preferred over tables [28].

Facilitators

Facilitators of the theme were identified by 9 comments in 8 papers [21,23,25,27-29,31,35]. Good data visualization was mentioned in 2 papers [27,35], and 5 papers placed special emphasis on graphical representation [21,23,25,29,35]. The facilitators include clear reports that are easy to comprehend [29,31] and are done using color schemes and cutoff points [29]. One figure should show all the measured data [29]. Predesigned templates with easy-to-remember phrases [35] and email reminders sent to patients from the system [28] facilitate the use of ePROs.

Usability

This refers to the aspect that affects how easy it is to use a PROM.

Barriers

Two papers [29,34] mentioned barriers to the usability of the PROMs theme. The barriers include a lack of coordinating structures of the PROM between wards [29] and a lack of design specific to the cancer populations [34].

Facilitators

The theme had 6 facilitators identified in 6 papers [21,23,25,31,34,35]. Three studies that presented only ePRO use [21,23,25] raised the issue of being easy to use in 7 comments. Systems are easy to use [21,23] or are not too complicated to use [25]. Two papers that included both ePRO and nondigital PRO use presented the experience of the ease of use of PROM [31,35] and the other one also as an actionable tool [35]. One paper agreed that the PRO tool is a good way to start assessing patients' symptoms [34]. Better customizability of the questionnaire improves usability [35] and displays results in such a way that they are easy to understand [31].

Takeaway Points

Work Environment

- The use of ePRO should be adapted to the workflow of the clinic to ensure the smooth operation of the system.
- The ePRO should be completed by the patient at the time most valuable to the timing of the patient's treatment.
- The use of ePRO should be integrated into all hospital settings so that it works and is in use in all hospital units.
- The ePRO should be interoperable with the hospital's EHR.

Value to Users

- ePRO is valuable to HCPs in symptom management, but it is important to strive to reduce the potential bias between patients' and physicians' symptom assessments.
- It is important to consider the patient's ePRO notes and give feedback to the patient at the clinical visit, and to have a system to capture patients' perspectives.
- ePRO facilitates patient-clinician communication, but it must not limit patient-clinician face-to-face communication. It is valuable for the clinician to check the patient's ePRO entries before the patient visits.
- Providing a means for patients to access the ePRO is very important. Options should be available that take into consideration language, literacy, health literacy, culture, and health status.
- The content of PROMs is more valuable to users if it is designed specifically for different cancer indications.
- Users should understand how to use the system well enough and understand its purpose.
- The electronic format of ePROs enables statistical analysis and visual representation of data, which can lead to decision support and improved patient outcomes.
- HCPs should get technical support and support from colleagues, management, and local PRO experts to use the system.

Suggested Features

- Summaries and overviews displaying measured data can enhance the understanding of PROMs.
- Special attention should be paid to the visualization of data, favoring graphic presentation.
- There should be a feature to flag high symptom scores to make them more noticeable to HCP.
- Color schemes and cutoff points make the user interface easier to comprehend.
- Predesigned templates help select the platform most appropriate to patients' treatment.
- The system should show cost-effectiveness data of the treatment to the HCP.
- The system should automatically create referrals for follow-up treatment.
- Patients should receive reminders to use the system.
- Patients' applications should have more response options for patients in different situations, such as with additional symptoms.

Discussion

Principal Results

This mapping study identified multiple barriers and facilitators to using ePROs for cancer care. The highlights of these are presented in condensed form as takeaway points for easy reading in categories such as work environment, value to users, and suggested features. Our work exposes the need for future studies on the use of ePROs compared to studies on the use of paper PROs.

The findings of this study strongly support the active integration of ePRO into the surrounding work environment. Earlier knowledge emphasizes the importance of functional workflow [12]. This leads to the notion that ePRO's operations should be integrated into the hospital workflow to allow users to experience ePROs' seamless use in the hospital setting. Based on this, it could be valuable to optimize the use of ePRO together with hospital operations at the time of the implementation of the ePRO. This study also revealed the need for ePRO integration in different hospital units. If the same ePRO is in use in different specialties, the system data could be better used in the multidisciplinary care of patients. Further, ePRO integration into the EHR in the hospital was highlighted in 9 of the 17 papers analyzed, which is well-aligned with prior works [9,12,14].

There are different lines of thought regarding the moment in which ePROs are best deployed for patients. The use of web-based ePRO at home may be advantageous, as the memory of the symptoms may be fresher, whereas use during the clinical visit may increase overall use. If patients complete the ePRO at the beginning of the clinical visit, it may help reduce the fear of losing personal contact with professionals and lower digital literacy needs [38]. Allowing patients to choose when to complete the ePRO could be a good compromise. Finally, when the patient is at the doctor's office, patient-clinician face-to-face communication is needed instead of clinicians looking at the computer screen to look at the ePRO information [11]. This is also supported by Gilligan et al [39] in their consensus guideline of patient-clinician communication, where they recommend considering using PROs to prepare the patient visit.

This study emphasizes multiple benefits for patients and the importance of patients' opinions for HCPs regarding the use of PRO systems [25]. These findings are consistent with Roberts et al [14]. Their study demonstrates the desire of HCP to be active in implementing PROMs into routine oncology care if patients benefit from the use and if the use of PROM improves health care. According to these studies, it is important to inform HCPs about patients' views and what facilitates patients' use of ePRO. It may strengthen HCPs' experience of the relevance of ePROs and improve the user experience if patients have positive experiences and feel that they will benefit from using ePRO.

This study highlighted the potential of ePRO systems to help develop the treatment of patients by using the data generated by the system, for example, about the symptom groups of the patient population [33]. A recently published study has also shown the important role of ePRO data in examining the benefits and efficacy of new innovative treatments [40]. Based on this, one can assume that the benefits of ePRO are wider than monitoring the treatment of an individual patient. ePRO data also play an important role in the development of treatments for patients with cancer.

The number of comments on the different themes shows how strongly the ePRO value for patients and HCPs facilitates the use of ePROs. Of 128 comments that presented barriers or facilitators, 60 described the value to patients or HCPs. In other words, for "value to users," 25 of the comments concerned "usability" and "data visualization and perceived features" of the systems. Although this proportion is not as prominent compared to the "value to users" theme, there are some explicit features mentioned that should be considered while developing the system to become more practical for the users.

According to this study (Table 1), only a few studies are available on the barriers and facilitators of ePRO use, including both ePRO and nondigital PROMs. In total, 8 papers described studies that used ePROs alone; the other 9 papers had both electronic and nondigital PRO data. Interestingly, studies on ePRO only have declined in recent years. The smaller number of ePRO studies could suggest that using ePRO has not supplanted the use of nondigital PROs. Thus, there is still a need for the knowledge and development of ePROs.

Limitations

This study has several limitations. As systematic mapping studies rely on the selection process to identify relevant studies, there is a risk of bias that can affect the results and conclusions of the study. Search results are only as current as the date of the last search performed. The quality of the studies included varies greatly, and the limitations of individual studies can affect the overall results and conclusions of the mapping study.

Further, this kind of study does not allow for in-depth analysis of individual studies or a detailed synthesis of the findings. However, systematic mapping studies are helpful to provide an overview of the existing literature, which was the goal of this study.

We decided to focus on the barriers and facilitators experienced by professionals. Patients' experiences were excluded, except when reported by professionals. This resulted in a one-sided perspective on the use of ePRO systems. Other stakeholders' opinions were not discussed. We grouped the barriers and facilitators compiled from the analyzed papers into themes and themes into categories. These themes and categories are the researchers' views on the issue. Some papers included comments from respondents who had never used ePRO systems. We could not ascertain that those responses were different from responses by users who had experience using ePROs.

In the data screening phase, we made efforts to remove the barriers and facilitators identified in the paper version of PROs. Thus, it is possible that the comments from the paper version of PROMs and ePROs were partially mixed.

Studies that demonstrated the barriers and facilitators of the implementation phase of PROM were excluded from the study. The decision to limit the implementation phase to 3 months may have indirectly affected our findings. Although this decision helped in classifying and screening the results, relevant papers might have been excluded.

Conclusions

In this study, we provided a broad overview of the barriers and facilitators affecting the use of ePROs. Our work focused on how the working culture and service integration affects the success of ePRO. A greater understanding of barriers and facilitators is useful to software developers and clinical research organizations to create smoother implementations. We found that there are multiple ways to develop ePROs and their working environments to meet the needs of HCPs. They can be summarized into 3 categories: work environment, value to users, and suggested features. The takeaway points detail the findings of this study.

Future Research

Based on this study, there is still a lack of information on the national and international knowledge of ePROs. Since there are only a few studies on fully electronically completed PRO data, future research should explore the barriers and facilitators of using ePROs, specifically in organizations where users have sufficient experience using ePROs. As this study is limited by the literature currently available in the selected databases, further work may expand on the knowledge by including additional sources and terms. Future work could also focus on exploring how the implementation of ePROs may affect the patient's journey through the health care system. It would also be interesting to understand whether more usability and features are required of an ePRO than of a paper PROM, given that it is possible to implement features beyond those of paper versions.

It would also be interesting to explore in more detail how common it is that patients rate their symptoms differently than physicians treating them and how patients' personal experiences are considered in treatment. Can ePRO be further developed to identify rating differences? Would it help if ePRO were to add more detailed parameters to the symptoms? Concerning challenging symptom descriptions, research may be conducted to determine which symptoms or symptom descriptions differ most in terms of patient and physician perceptions and, based on this, develop an ePRO to highlight a potential bias.

Conflicts of Interest

AML is currently working for a pharmaceutical company (MSD Finland) as a Policy & Patient Engagement Lead.

Multimedia Appendix 1
Searches in databases.
[DOCX File , 21 KB - cancer_v9i1e40875_app1.docx]

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Abbreviations

EHR: electronic health record
ePRO: electronic patient-reported outcome
ESAS: Edmonton Symptom Assessment Scale
HCP: health care professional
PRO: patient-reported outcome
PROM: patient-reported outcome measure

Edited by A Mavragani; submitted 09.07.22; peer-reviewed by Y Chu, D Chrimes; comments to author 22.10.22; revised version received 04.12.22; accepted 12.05.23; published 28.06.23.

Please cite as:
Laitio AM, Giunti G, Halonen R
Perceived Barriers and Facilitators in Using Patient-Reported Outcome Systems for Cancer Care: Systematic Mapping Study
JMIR Cancer 2023;9:e40875
URL: https://cancer.jmir.org/2023/1/e40875
doi:10.2196/40875
PMID:37379076

Original Paper

Categorization and Analysis of Primary Care mHealth Apps Related to Breast Health and Breast Cancer: Systematic Search in App Stores and Content Analysis

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Abstract

Background: Breast cancer is the most common cause of cancer mortality among women globally. The use of mobile health tools such as apps and games is increasing rapidly, even in low- and middle-income countries, to promote early diagnosis and to manage care and support of survivors and patients.

Objective: The primary objective of this review was to categorize selected mobile health apps related to breast health and prevention of breast cancer, based on features such as breast self-examination (BSE) training and reminders, and to analyze their current dissemination. An ancillary objective was to highlight the limitations of existing tools and suggest ways to improve them.

Methods: We defined strict inclusion and exclusion criteria, which required apps to have titles or descriptions that suggest that they were designed for the general public, and not for patients with breast cancer or health workers. Apps that focused on awareness and primary care via self-check were included, while those that focused on topics such as alternative treatments and medical news were excluded. Apps that were not specifically related to breast cancer were also excluded. Apps (in any language) that appeared in the search with keywords were included. The database consisted of apps from AppAgg and Google Play Store. Only 85 apps met the inclusion criteria. Selected apps were categorized on the basis of their alleged interactive features. Descriptive statistics were obtained, and available language options, the number of downloads, and the cost of the apps were the main parameters reviewed.

Results: The selected apps were categorized on the basis of the following features: education, BSE training, reminders, and recording. Of the 85 selected apps, 72 (84.7%) focused on disseminating breast cancer information. BSE training was provided by only 47% (n=40) of the apps, and very few had reminder (n=26, 30.5%) and recording (n=11, 12.9%) features. The median number of downloads was the highest for apps with recording features (>1000 downloads) than those with education, BSE training, reminder, and recording features (>5000 downloads). Most of these apps (n=74, 83.5%) were monolingual, and around 80.3% (n=49) of these apps were in English. Almost all the apps on Google Play Store were free of charge.

Conclusions: Although there exist several apps on Google Play Store to promote awareness about breast health and cancer, the usefulness of most of them appears debatable. To provide a complete breast health package to the users, such apps must have all of the following features: reminders or notifications and symptom recording and tracking. There is still an urgent need to scientifically evaluate existing apps in the target populations in order to make them more functional and user-friendly.

(JMIR Cancer 2023;9:e42044) doi:10.2196/42044

KEYWORDS

breast cancer; breast self-examination; BSE; primary care; mobile applications; mobile apps; breast health; early diagnosis

Introduction

According to an estimation by the International Agency for Research on Cancer in 2020, every minute, about 4 women are diagnosed with breast cancer, and 1 dies of it. Breast cancer is the most common cancer among women and the most common cause of cancer-related mortality (Tables 1 and 2) [1]. Trends have changed significantly over the past few years with more than half of incident cases and deaths due to breast cancer occurring in low- and middle-income countries, which represent 80% of the world's population [2] in comparison to high-income countries [3]. Asia contributes to 45.4% (n=1,026,171) of the new breast cancer cases among the total of 2,261,419 and 50.5% of related deaths (Figure 1) [4].

The World Health Organization's (WHO's) Global Breast Cancer Initiative aims to reduce global breast cancer mortality by 2.5% per year [5]. To meet this goal, the WHO identified 3 pillars that are important for reducing breast cancer–related mortality: awareness to promote early diagnosis, proper screening programs for timely diagnosis, and comprehensive breast cancer management [5]. From a pragmatic point of view, strengthening the screening system and enforcing nationwide comprehensive management essentially depend on women's awareness of breast cancer.

David Forman [3], head of the International Agency for Research on Cancer's Section of Cancer Information, said, "Breast cancer is also a leading cause of cancer death in the less developed countries of the world. This is partly because a shift in lifestyles is causing an increase in incidence, and partly because clinical advances to combat the disease are not reaching women living in these regions."

A survey carried out in Kathmandu Institute of Science and Technology, Kathmandu, Nepal, revealed that 70% of Nepalese women had never heard of breast cancer [6]. Another study carried out in Pokhara, Nepal, reported that the knowledge of breast cancer symptoms is very poor [7]. More than 50%-80% of patients with breast cancer in India, 49% of those in Karachi (Pakistan), and 47% of those in Iraq are diagnosed at advanced stages due to poor awareness and poor screening programs [8,9]. Overall, 62% of breast cancer deaths are due to presentation at advanced stages in low- to middle-income countries [2]. Furthermore, several studies reflect better survival rates among educated women [10-15].

According to Gadgali et al [16], "This emphasizes the need for breast awareness programmes and educational material to be delivered in various local and regional languages in order to reach the less as well as uneducated and underserved women, in order to improve their survival."

Periodic screening, by regular self-checks or through imaging modalities including ultrasonography and mammography, is important in early diagnosis of breast cancer and other breast conditions. Breast self-examination (BSE) is a free and the most convenient modality as it is painless and can be done by oneself without any special equipment or tools. It has been incorporated into international cancer control programs targeting economically disadvantaged low- and middle-income countries [2] as an important tool for early diagnosis. Tara et al [17] reported 68% congruence in findings from BSE carried out by participants and clinical examination performed by health experts. However, BSE results in a high number of false positives and generates anxiety in women.

To tackle the discussed gaps in knowledge regarding breast cancer, its risk factors, and its symptoms, screening programs including BSE and the promotion of both awareness and education are needed. Additionally, providing women with proper tools to learn about BSE or training them will aid in efficiently tackling the potential associated anxiety. Developments in mobile health (mHealth) and growing internet connectivity might contribute to providing appropriate tools to help achieve these goals.

mHealth is broadly defined as mobile and internet-based interventions for health purposes. It can encompass various forms including guidelines, tutorials, games, visual novels. With increasing use of mobile phones and the internet [18], mHealth is now being used in different countries including India [19] and Ethiopia [20] to improve access to health. Success stories, such as that reported by Lin et al [21] about Quit Genius, provide a strong basis for how an mHealth app might result in behavioral changes. Lin et al [21] reported that 36% of Quit Genius users successfully quit smoking, and 59.6% of them reduced the number of cigarettes they smoked per day [21].

There exist several apps on mobile app stores such as Google Play Store and Apple App Store, which aim to promote knowledge about breast cancer. Etege [20] is one such example, designed to aid Ethiopian women in performing BSE and recording symptoms. It has now reached millions of women. Dear Mamma [22] is another very popular breast health app developed by the DEAR Foundation, Switzerland, which teaches women about BSE and allows recording symptoms and setting monthly reminders. Unfortunately, only 13% [23] of all the available breast health–related apps focus on promoting awareness among all women, and these apps have not been scientifically evaluated.

This paper reviewed breast health mobile apps that include features such as BSE training, symptom recording, reminders, and information and educational guides. Categorization of such apps, available to women for self-education about breast health, is also reviewed here. Breast health can be defined as keeping breasts healthy by preventing breast cancer and other benign conditions. Good breast health requires women to be aware of not only symptoms of breast cancer but also other benign conditions. It includes knowledge of BSE, breast cancer diagnosis, and treatment of and correlation among factors such as smoking, alcohol intake, contraceptives, breastfeeding, age at first childbirth, menarche, and menopause, which may affect breast health.

Organizations such as the WHO that are now focusing on using mHealth to promote awareness could also benefit from this study. They could also use this list to choose befitting apps that could be used as educational interventions to educate women about breast cancer. In general, the data collected and analyzed in this study will help in the advancement of mHealth apps related to breast health and result in better apps in the future.

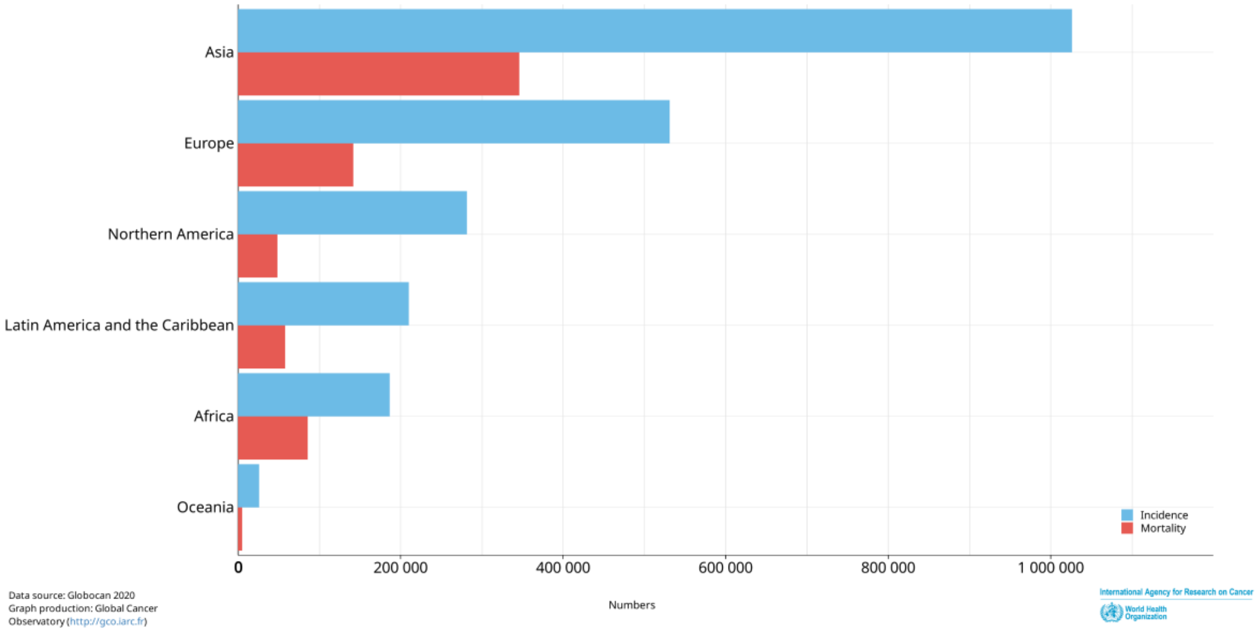
Table 1. Number of new cancer cases among women (according to the 2020 Global Cancer Observatory of the International Agency for Research on Cancer; N=9,227,484).

Cancer type	Individuals, n (%)
Breast	2,261,419 (24.5)
Colorectal	865,630 (9.4)
Lung	770,828 (8.4)
Cervix uteri	604,127 (6.5)
Thyroid	448,915 (4.9)
Corpus uteri	417,367 (4.5)
Stomach	369,580 (4)
Other types	3,489,618 (37.8)

Table 2. Number of cancer deaths among women (according to the 2020 Global Cancer Observatory of the International Agency for Research on Cancer; N=9,227,484).

Cancer type	Deaths, n (%)
Breast	684,996 (15.5)
Colorectal	419,536 (9.5)
Lung	607,465 (13.7)
Cervix uteri	341,831 (7.7)
Liver	252,658 (5.7)
Pancreas	219,163 (4.9)
Stomach	266,005 (6)
Other types	1,637,669 (37)

Figure 1. Estimated number of incident cases and deaths due to breast cancer in women of all ages in different continents. Data were obtained from the International Agency for Research on Cancer [4].



Data source: Globocan 2020
Graph production: Global Cancer Observatory (http://gco.iarc.fr)

Methods

App Search and Data Extraction

An extensive search was conducted on Google Play Store, Apple App Store, and the AppAgg tool using the keywords “Breast,” “Breast health,” “Breast Cancer,” and “Breast Self-Examination.” Search words were limited to English, keeping in mind that the authors’ proficiency is poor in other languages. However, all apps that appeared using these search words were analyzed regardless of the language of the app by translating the content using Google Translate. The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guideline [24] was modified and adapted to guide this review (Figure 2).

Apps were selected using the approach of Bender et al [25], and stringent inclusion and exclusion criteria were defined (see Textbox 1). Apps were selected on the basis of either primary education or early diagnosis (via BSE; or both), including breast cancer guides, BSE training, reminders, and symptom recording. All the other apps (including those focusing on breast workouts, breast shape photo editors, breastfeeding, breast pumping, breast surgery or implants, and breast cancer care) were excluded.

A first round of app search was carried out on AppAgg [26]. AppAgg is a free software that has accumulated large amounts of data about the apps available on all app stores such as Google Play Store, Apple App Store, and Windows. Apps on Google Play Store (n=60) were selected by applying the filter “Android apps” and using the following search keywords: “Breast,” “Breast health,” “Breast Cancer,” and “Breast Self-Examination.” Similarly, apps on Apple App Store (n=29) were selected by applying the filter “iOS apps” and using the abovementioned search keywords.

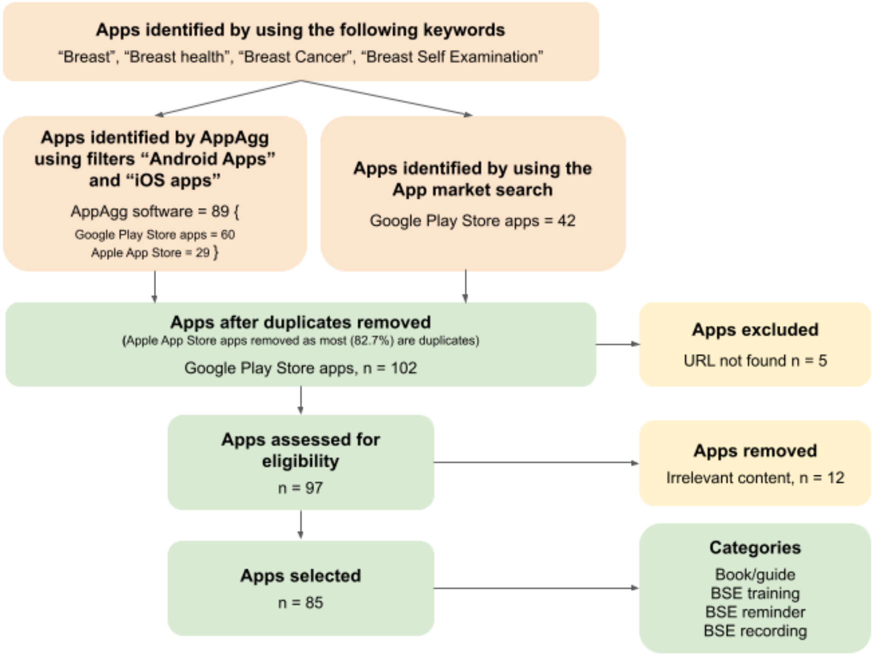
AppAgg provides data in the format shown in Textbox 2. Of these, information regarding the version, developer, subcategory, updates, and release date were removed because it was not informative and of no importance to the study. Information regarding in-app purchase, new, preorder, rating, and vote were discarded because of missing information (97%, 99%, 100%, and 100%, respectively).

Information regarding name, price, category, and downloads was verified manually one by one by comparing it with data available on Google Play Store and Apple App Store. The number of downloads was updated during this process. Additionally, language options available were included while updating information from AppAgg.

A second round of searches using keywords was carried out directly on Google Play Store and Apple App Store. An additional 42 apps from Google Play Store were included in the list. Information regarding name, price, category, and downloads about these additional apps was also recorded in an Excel (Microsoft Corp) spreadsheet.

In total, 131 potential apps were identified (as of October 8, 2021): 29 on Apple App Store and 102 on Google Play Store based on their descriptions and screenshots.

Figure 2. A modified PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flowchart adapted to extensive review of mobile apps. BSE: breast self-examination.



Textbox 1. Inclusion and exclusion criteria met while selecting the apps.

Inclusion criteria

- Apps that appear using the keywords
- Apps can be in any language or can support multiple languages
- The title or description (or both) suggests that the app is related to breast cancer or breast self-examination
- The title or description (or both) suggests that the app has features including educational content (about breast cancer and breast health), self-check reminder, symptom recording (such as notes), or tracking (or history of recorded symptoms)

Exclusion criteria

- The title or description (or both) suggests that the app is related to other cancers or to cancer in general
- The title or description (or both) suggests that the app is related to education on alternative therapy, food habits to prevent cancer, or breast enhancement strategies
- The title or description (or both) suggests that the app is related to risk assessment questionnaires only and serves no other purpose
- The title or description (or both) suggests that the app is related to care management, survivorship, and postcancer standard of living for patients with breast cancer
- Apps intended for patients, health care providers, and caregivers, which track and monitor breast cancer or provide support and care to patients with breast cancer
- Google Play Store apps were retained if they were available on both Google Play Store and Apple App Store

Textbox 2. Data extracted using AppAgg.

- Number
- Name
- Version
- Price
- In-app purchase
- Developer
- Category
- Subcategory
- New
- Downloads
- Updated
- Released
- Preorder
- Rating
- Vote
- Store ID
- URL

Data Refining

Based on app descriptions and screenshots available on the marketplace, 131 apps meeting the inclusion criteria were shortlisted. Google Translate was used to translate the descriptions of the apps if they were in a language other than English. Screenshots of the apps on the app marketplaces (Google Play Store and Apple App Store) also provided information about the features of the apps. In case of poor descriptions and no screenshots, apps were downloaded on a OnePlus 7 device and studied (author SK). These apps were further independently reviewed by author JCT, an MD qualified in gynecology and breast disease, and author KL, a computer scientist with expertise in the digital space, to ensure reliability of the study.

Apps on Apple App Store (n=29) were excluded from the list for the following reasons: (1) use of Android phones is much more widespread than the use of iPhones, (2) most (n=24, 82.7%) of these apps are on Google Play Store and would lead to the inclusion of duplicates, and (3) not much information could be gathered about apps on Apple App Store.

Five out of the remaining 102 apps were excluded as their URL could not be found when reviewed by the 2 reviewers JCT and KL. Twelve apps were further excluded as they were focused on nutrition, alternative therapy, including naturopathy for breast cancer and Ayurveda, and risk assessment surveys or contained frequently asked questions about innovations in treatment and cure—they were considered irrelevant by the reviewers as they did not meet the inclusion criteria.

The remaining 85 apps (highlighted in Multimedia Appendix 1) that met the inclusion criteria were further studied and categorized on the basis of their alleged interactive features.

Categorization of the Selected Apps

To the best of our knowledge, there are no prior reviews on mHealth apps for primary care and awareness of breast health and breast cancer. Hence, we identified features based on which the apps were categorized, in accordance with our understanding and need for primary care and education.

Four important interactive features were identified on the basis of which apps were categorized, namely education (E), BSE training (T), BSE reminders (R), and BSE symptom recording (Re), as shown in Table 3. Some of these features including reminders, BSE training, and education have been recently reported by Nasution et al [27] as important while developing mobile apps for breast health. BSE recording was added as it was deemed important since it helps users keep a note of changes in their breasts.

The E category includes content and information about risk factors, prevention, symptoms, treatment, diagnosis, benign conditions of breasts, or BSE. Category T refers to step-by-step tutorials about how to self-examine breasts via videos, pictures, or text. Category R implies that the app allows users to select a date for monthly check and notifies users on that date every month. Category Re refers to apps that allow users to take notes of changes observed during self-check via audio, video, or text. “Holistic apps” in this study are defined as apps that contain all the discussed features and are categorized as “E,T,R,Re.”

The 85 apps were divided into 10 different categories as described in Table 4 (see Multimedia Appendix 1 for a complete list of apps after categorization). The “category” column was replaced by these functional categories as shown in Table 4. Two independent reviewers analyzed the categorization on the basis of the narrative text corresponding to the description of each app and screenshots provided by Google Play Store. Final categorization was achieved through mutual agreement between the 2 reviewers.

Table 3. Four alleged interactive features used to define the apps (for simplicity in writing, codes are allocated to the different features).

Features	Code	Description
Education	E	Educational—promotes knowledge about breast cancer, symptoms, risk factors, screening and treatments, and benign conditions via text and images
BSE[a] training	T	BSE step-by-step training
BSE reminder	R	Reminders and notifications for monthly BSE
BSE symptom recording	Re	Feature to record symptoms found

[a] BSE: breast self-examination.

Table 4. Categorization of the 85 apps based on the 4 features discussed in Table 3.

Categories	Code	Description
Education	E	Apps that have educational content about breast cancer, symptoms, risk factors, screening and treatments, and benign conditions via text and images
BSE[a] training	T	Apps that have BSE step-by-step training
BSE recording	Re	Apps that only allow recording of symptoms and evaluation of risk from them
Education and BSE training	E, T	Apps that have features including educational content and BSE training
Education and BSE reminder	E, R	Apps that have features including educational content and reminders or notifications
BSE training and reminder	T, R	Apps that have features including BSE training and reminders or notifications
Education, BSE training, and reminder	E, T, R	Apps that have educational content, BSE training, and reminders or notifications
Education, BSE training, and recording	E, T, Re	Apps that have educational content, BSE training, and symptom recording
BSE training, reminder, and recording	T, R, Re	Apps that support BSE training, symptom recording, and reminders or notifications
Education, BSE training, reminder, and recording	E, T, R, Re	Apps that have all the identified interactive features

[a] BSE: breast self-examination.

Statistical Analysis

SPSS (version 29; IBM Corp) was used to analyze descriptive statistics of each of the following parameters: number of relevant apps available on Google Play Store versus those available on Apple App Store, primary characteristics or features, number of downloads, language options, and cost. The median number of downloads was also evaluated against the discussed features and categories; median values were calculated since the data were skewed. For analysis, “Verbose” is defined as the number of words exceeding 20 per sentence in a corpus of text (per the Institute of Medicine’s [IOM’s] guidelines for Health Literate Apps [28]).

Results

Google Play Store or Apple App Store? Which Marketplace Has More Related Apps?

It was interesting to note that there are approximately 300% more related apps on Google Play Store than on Apple App Store. Additionally, 82.7% (24/29) of apps on Apple App Store were also available on Google Play Store.

Primary Characteristics or Features of the Apps

The selected 85 apps were categorized on the basis of their features (as shown above).

As evident from Table 5, most of the apps (n=72, 84.7%) had educational content for users to learn about breast cancer, early diagnosis, treatment, and symptoms. All the E apps exceeded 25 words per sentence, not adhering to the IOM’s guidelines for Health Literate Apps [28].

Less than half of the selected apps (n=40, 47%) focused on BSE training. Very few of them had additional features such as reminders and notifications for monthly scans (n=26, 30.5%) and “notes” features to record symptoms (n=11, 12.9%). Only 7 (8.2%) apps incorporated together all the discussed features (those categorized as “E,T,R,Re”).

Table 5. Number of apps per category (as explained in illustrating how features are distributed among the studied apps.

Category	Apps, n
Education	42
BSE[a] training	4
BSE recording	1
Education and BSE training	8
Education and BSE reminder	2
BSE training and reminder	7
Education, BSE training, and reminder	11
Education, BSE training, and recording	2
BSE training, reminder, and recording	1
Education, BSE training, reminder, and recording	7

[a] BSE: breast self-examination.

Number of App Downloads

Most of the apps (82.4%) had only >1000 downloads, as evident from Table 6. As depicted in Table 7, apps categorized as “E,T,R,Re” had the highest median number of downloads. The median was also extracted from the number of downloads of all the apps with the discussed features: “E,” “T,” “R,” and “Re.” Apps with the Re feature had the highest number of median downloads (Table 8).

One of the apps that had the highest number of downloads was “Breast Cancer Guide”—an E app that promotes knowledge about primary care for breast cancer via videos. Only one app (Dear Mamma) out of 3 apps with >50,000 downloads was a holistic app (E,T,R,Re) with all the discussed interactive features.

Table 6. Number of downloads of the selected apps as determined by Google Play Store.

Number of downloads	Apps, n
1000	70
5000	7
10,000	5
50,000	3

Table 7. Median number of downloads of all apps containing the following features: education, breast self-examination (BSE) training, BSE reminders, and BSE recording.

	Number of downloads, median
Education	500
BSE training	750
BSE reminders	1000
BSE recordings	300

Table 8. Median number of downloads of all apps based on their categories.

	Number of downloads, median
Education	300
BSE[a] training	275
BSE recording	50
Education and BSE training	1000
Education and BSE reminder	5.5
BSE training and reminder	100
Education, BSE training, and reminder	500
Education, BSE training, and recording	1000
BSE training, reminder, and recording	1
Education, BSE training, reminder, and recording	5000

[a] BSE: breast self-examination.

Language Options Available

As clearly depicted in Multimedia Appendix 2, overall, 83.5% (n=71) of the selected apps were monolingual; of them, 80.3% of apps were in English. Only 7.1% of them were multilingual (>5 languages). Apart from English, other common languages in these apps were Arabic, Spanish, German, French, Bangla, and Hindi (Multimedia Appendix 3).

Only 17.08% of people worldwide speak English natively or as a second language [29]. Yet, the most commonly used language in these apps is English (71.8%; Table 8). The Dear Mamma app has 11 language options available and is one of the few apps to have >50,000 downloads.

Cost of the Selected Apps

All of the selected apps on Google Play Store were free of charge.

Discussion

Principal Findings

We conducted a systematic internet search of the existing breast health apps. Five key features of these apps were defined, representing their level of primary care and awareness. A total of 85 apps on Google Play Store were identified and analyzed. Based on the defined features, these apps could be classified into 10 different categories.

Most of the apps (n=72, 84.7%) were clearly educational, containing mainly text (when evaluated against IOM guidelines for Health Literate Apps). The Breast Cancer Guide app, with the highest number of downloads, used videos to provide information; this indicates that videos might be a good way to engage users. Surprisingly, less than half of them (n=28, 38.9% of E apps, accounting for 40, 47% of all apps) had content explaining BSE. Since most of these apps were monolingual (n=71, 83.5%) and in English (80.3% of monolingual apps, 71.8% of all apps), their use remains restricted to women literate in English. Limited accessibility can also be inferred from their rather low downloads (n=70, 82.4% of apps with less than 1000+ downloads). Tables 7 and 8 show that apps categorized as “E,T,R,Re” have the highest number of median downloads and those categorized as “Re” have the highest number of median downloads. This could indicate that users have a selection bias toward apps that help them record their symptoms alongside having BSE training, reminders, and educational material. Unfortunately, only 8.2% (n=7) of apps are holistic (E,T,R,Re) and only 12.9% (n=11) of all apps have the Re feature.

With more than 3 million apps on Google Play Store [30,31] and 2 billion active users [32,33], Android has captured the app market. Most apps on Apple App Store (n=24, 82.7%) were already identified on Google Play Store and studied. Therefore, we decided to focus our study on apps (n=85) available in Google Play Store. Most of the apps were designed to promote knowledge about breast cancer and breast health. Only 40 (47%) apps had visual or textual information about BSE, serving as essential and accessible tools for women to proactively care for their breasts.

Additionally, information about the appropriate timing to perform self-examination in relation to the menstrual cycle, that is, 3 to 5 days after the start of menstruation [34,35], needs to be highlighted in these apps. The reminder feature can be improved through synchronization with period tracking apps. With information regarding period start date at the forefront, selecting dates for monthly BSE will be easier and automatic, resulting in a reliable outcome on BSE.

Another very important addition to these apps can be a well-defined symptom recording feature with all the symptoms enlisted as images or graphics. This will make it easier for users to select their symptoms, if any, especially for low-literacy audiences. Low-literacy populations can also benefit from apps in regional languages with audio aid, for example, integration of text-to-speech modalities such as Siri or Alexa.

Limitations

There are some limitations that need to be discussed. As we observed, most apps were in English. It can be debated that the bias toward English is due to the use of English keywords. However, it is clear from the list that apps in languages other than English were also obtained using these keywords. This can be attributed to the English keywords used by developers while uploading their apps on Google Play Store. To cross-validate, we ran a search with the keywords translated in Mandarin (Chinese) and Spanish (two of the most spoken languages worldwide [36]) and no extra apps were recorded.

“Number of downloads” displayed on Google Play Store indicates the number of unique downloads by different users. Use of “number of downloads” to assess dissemination of the apps might be insufficient. The limitation of this metric is that it does not consider downloads on different devices by the same user (same login ID). Other key retention metrics such as “monthly active users” might be a better proxy.

A general limitation of studies on mHealth apps is that we do not very well understand how the App Stores evaluate apps on their marketplace. Very little to no information is available about that. Also, apps on these marketplaces are not stable. New apps are continually added, and some apps are removed under several circumstances including restricted content, duplication, intellectual property fraud, privacy issues, or if developers choose to remove their app. Thus, reviews on mHealth apps cannot be replicated easily. When we ran our search again, we found the same number of results, but 4 apps in the list were different.

Future Prospects

mHealth apps are increasingly improving the standard of care and health, especially in poor, rural countries such as certain African countries, Nepal, and Bangladesh [37,38]. In countries such as Nepal, most women live in remote, rural areas and do not have access to diagnostic centers, clinics, or hospitals. A minimum of 3 hours of travel [39,40] are required to make a visit to the closest clinic or hospital, which, again, may or may not be well equipped. Breast health apps might provide support to women by aiding them in periodic checks of their breasts [41,42]. Regular breast checks might result in identification of smaller tumors early, resulting in better treatment options and faster recovery.

As we have discussed in this study, current apps are not very user-friendly since they are verbose, have few language options, and lack important features. Customized content factoring in cultural and linguistic differences has been shown to improve accessibility and participation in breast cancer screening [43-45] and might be useful in designing apps for primary care. Well-designed user experience research, followed by a participatory approach for app development (with target audience) [46-48] might help bridge the gap between such apps and their users.

Another approach to make apps more interesting would be gamifying them [47-51]. Gamification is defined as adding game mechanics to nongame environments such as websites and apps. To the best of our knowledge, no breast cancer apps have incorporated game elements yet.

A new direction of research could be the evaluation of mHealth apps. These apps, although useful in primary care, do not seem to have been properly evaluated. There is a need for standard guidelines and protocols [28] that ensure proper evaluation, including those for the design, content, and language of such apps. Prior to launch, pilot and validation studies of these apps might further ensure acceptability and adaptability. These apps can then be usefully integrated into the health care system in the future, seeking to improve the standard of care remotely.

Acknowledgments

The present work is part of the PhD project of SK (under the supervision of Prof Fabien Reyal and Prof Jean Christophe Thalabard as cosupervisor), for which she benefits from a grant from Université Paris Cite.

Data Availability

All data generated or analyzed during this study are included in this published article as Multimedia Appendix 1. Data acquisition was concluded on October 8, 2021.

Conflicts of Interest

None declared.

Multimedia Appendix 1
List of selected apps that have been categorized as discussed in Table 4.

[XLSX File (Microsoft Excel File), 38 KB - cancer_v9i1e42044_app1.xlsx]

Multimedia Appendix 2
Mono-, bi-, tri-, or multi- lingual: the number of languages available on the selected apps. Color gradient from Dark to Light indicating Monolingual to multilingual apps.
[PNG File , 18 KB - cancer_v9i1e42044_app2.png]

Multimedia Appendix 3
Percentage of selected apps available in different languages, namely, English, Hindi, German, French, Spanish, Bangla, Arabic and others. Color gradient from dark to light indicating most used language to the least used.
[PNG File , 14 KB - cancer_v9i1e42044_app3.png]

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Abbreviations

BSE: breast self-examination
E: education
IOM: Institute of Medicine
mHealth: mobile health
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
R: breast self-examination reminder
Re: breast self-examination recording
T: breast self-examination training
WHO: World Health Organization

Edited by A Mavragani; submitted 22.08.22; peer-reviewed by M Fiordelli, M Kapsetaki; comments to author 11.10.22; revised version received 04.12.22; accepted 22.02.23; published 07.09.23.

Please cite as:
Kanodia S, Thalabard JC, Lhoste K
Categorization and Analysis of Primary Care mHealth Apps Related to Breast Health and Breast Cancer: Systematic Search in App Stores and Content Analysis
JMIR Cancer 2023;9:e42044
URL: https://cancer.jmir.org/2023/1/e42044
doi:10.2196/42044
PMID:37676704

Review

The Impact of Digital Technology on Self-Management in Cancer: Systematic Review

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Abstract

Background: Self-management (SM) plays an important role in supporting patients' adaptation to and management of the symptoms of chronic diseases. Cancer is a chronic disease that requires patients to have responsibility in management. Digital technology has the potential to enhance SM support, but there is little data on what SM skills are most commonly supported by digital technology.

Objective: This review aimed to examine the SM core skills that were enabled and supported by digital interventions in people with cancer and identify any predictors of the effect of digital health intervention on SM core skills.

Methods: Three electronic databases (MEDLINE, Scopus, and CINAHL) were searched for papers, published from January 2010 to February 2022, that reported randomized controlled trials (RCTs) involving patients with cancer or survivors of cancer where a digital technology intervention was evaluated and change in 1 or more SM core skills was a measured outcome.

Results: This systematic review resulted in 12 studies that were eligible to identify which SM core skills were enabled and supported by digital intervention. The total number of participants in the 12 studies was 2627. The most common SM core skills targeted by interventions were decision-making, goal setting, and partnering with health professionals. A total of 8 (67%) out of 12 RCTs demonstrated statistically significant improvement in outcomes including self-efficacy, survivorship care knowledge and attitude, quality of life, increased knowledge of treatment, and emotional and social functioning. A total of 5 (62%) out of 8 positive RCTs used theoretical considerations in their study design; whereas in 1 (25%) out of 4 negative RCTs, theoretical considerations were used. In 3 studies, some factors were identified that were associated with the development of SM core skills, which included younger age (regression coefficient [RC]=–0.06, 95% CI –0.10 to –0.02; P=.002), computer literacy (RC=–0.20, 95% CI –0.37 to –0.03; P=.02), completing cancer treatment (Cohen d=0.31), male sex (SD 0.34 in social functioning; P=.009), higher education (SD 0.19 in social functioning; P=.04), and being a recipient of chemotherapy (SD 0.36 in depression; P=.008). In all 3 studies, there were no shared identical factors that supported the development of SM core skills, whereby each study had a unique set of factors that supported the development of SM core skills.

Conclusions: Digital technology for patients with cancer appears to improve SM core skills including decision-making, goal setting, and partnering with health care partners. This effect is greater in people who are younger, male, educated, highly computer literate, completing cancer treatment, or a recipient of chemotherapy. Future research should focus on targeting multiple SM core skills and identifying predictors of the effect of digital technology intervention.

Trial Registration: PROSPERO CRD42021221922; https://tinyurl.com/mrx3pfax

(JMIR Cancer 2023;9:e45145) doi:10.2196/45145

KEYWORDS

self-management; self-management support; self-management core skills; digital technology; digital health; mHealth; mobile health; eHealth; cancer; theoretical frameworks; predictors of effect; chronic disease; skills; decision-making; cancer treatment

Introduction

Self-management (SM) is defined as the ability of an individual to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition. It is an important component of the management of many chronic conditions, including cancer [1]. SM requires patients to apply specific skills such as problem-solving, decision-making, behavioral monitoring and tailoring, setting goals, partnering with health care providers, and using resources [1]. SM support (SMS) provided by the health care system is often necessary to enhance, enable, and support a patient's SM and includes activities, interventions, or programs to promote the patient's skill and confidence in managing their chronic condition [2].

Digital technology, where technological interventions seek to provide improved health care, is one of the means of delivering SMS for people with cancer [3]. It uses a variety of approaches including web-based education, telecommunication with health care providers, delivery of remote rehabilitation programs or monitoring, decision support, and reporting of symptoms [1]. Digital SMS can be provided through a variety of channels such as mobile phone apps, text messages, social media, websites, and wearable devices [4]. The advances in mHealth (mobile health) technology offer a promise of improvement in symptom management on treatment through better SM [5].

To date, there are several reviews on digital health technology interventions that involve SMS for people with cancer [6-12]. These reviews support emerging evidence for improved outcomes with a variety of digital technological interventions supporting SMS in patients with cancer. The focus of these reviews was mainly on patient outcomes such as pain, psychosocial outcomes, and sleep with less attention to specific components of SM. These specific components include (1) problem-solving, (2) decision-making, (3) behavioral self-monitoring and tailoring, (4) setting goals, (5) partnering with health care providers, and (6) risk reduction. In addition, no clear conclusion has been drawn from the reviews as to whether specific patients' characteristics were associated with different outcomes. An exploration of potential predictors of effective SMS such as age, sex, or socioeconomic background could allow greater tailoring of digital technology. This highlights a gap in this literature on how digital technology can enable the specific components of SM and the patients' characteristics may impact the effectiveness of building SM core skills.

A systematic review by Boulley et al [7] reviewed 29 papers from 2001 up to 2017 reporting on cancer-related digital interventions to examine their components, the elements of engagement with digital interventions, and the psychosocial variables targets in the context of SM. The results showed a high level of engagement with digital technology, where it was shown that self-efficacy, psychological symptoms, and quality of life were the most commonly assessed study outcomes. Considerable heterogeneity was noted in components of digital interventions and measures for their engagement [7]. The authors concluded that digital technology could be effective in helping patients cope with the disease but further research into intervention components and engagement was needed to have a greater understanding of the mechanisms underlying the psychological and behavioral changes of patients with cancer or survivors of cancer. They also noted that older patients had high acceptability toward modern and often unfamiliar technology in 3 studies, challenging the perception that modern technology was less likely to be used by older populations [13].

Hernandez Silva et al [6] reviewed 7 papers up to 2017 to assess how mHealth interventions (a subgroup of digital technology where health care interventions can be delivered via personal mobile phone apps) could be used to improve pain, psychological distress, fatigue, or sleep outcomes on a heterogeneous population of survivors of cancer by supporting SM. A total of 3 (75%) out of 4 studies showed improvement in pain and 2 demonstrated improvement of sleep. The results were inconclusive for psychosocial distress and there was no improvement in fatigue [6]. The authors noted a high acceptability of mHealth interventions in older patients equal to that of younger populations, again challenging perceptions that mHealth is less likely to be used by older populations [13].

Kim et al [9] reviewed 37 studies from 2000 up to 2014 to assess the characteristics of web-based SMS interventions in heterogeneous populations in survivors of cancer and to perform a meta-analysis to assess the effect of these interventions. The results indicated that automated and communicative functions were the most popular mode of intervention, where the former produced automated messages and feedback for patients, while the latter allowed patients to communicate to health care workers to receive advice. The effects on diverse outcome measures including fatigue, depression, anxiety, and overall quality of life were small to moderate [9].

Singleton et al [10] reviewed 32 papers to evaluate the effectiveness of digital interventions on patient-reported outcomes (quality of life, self-efficacy, and mental or physical health) in patients who were undergoing breast cancer treatment and in patients who completed breast cancer treatment. The results revealed a significant improvement in quality of life, self-efficacy, and fatigue. The moderator analysis revealed improved quality of life for patients with cancer undergoing treatment compared to patients with cancer after active treatment. Their analysis also revealed that age was not a significant moderator for quality of life, self-efficacy, and mental or physical health [10].

Buneviciene et al [8] reviewed 25 papers to evaluate the impact of mHealth interventions in optimizing the health-related quality of life of patients with cancer. They identified that physical activity or fitness interventions, cognitive behavioral therapy, and mindfulness or stress management were the most commonly studied interventions [8].

Sarbaz et al [11] reviewed 19 papers to evaluate the effect of mHealth interventions in the management of chemotherapy-induced side effects among patients with cancer. They identified that mHealth interventions were capable of producing significant improvement in patients' quality of life and patient satisfaction [11].

Luo et al [12] reviewed 24 papers in a meta-analysis to determine the effectiveness of mHealth-based SM interventions on medical, behavioral, and emotional management in patients with breast cancer. They identified that the interventions can potentially facilitate management and health-related quality of life (functional exercise compliance, self-efficacy, and lymphedema reduction) in patients with breast cancer [12].

To address these gaps, this systematic review aimed to update the evidence with a focus on the impact of digital technology on building SM core skills in patients with cancer. Specifically, the review's objectives were to (1) examine what were the SM core skills that digital interventions enable and support and (2) identify any predictors of the effect of using digital health intervention on SM core skills such as age, sex, and socioeconomic status.

Methods

This systematic review was performed according to the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines, which is described in Multimedia Appendix 1. This review has been registered in the International Prospective Register of Systematic Reviews (PROSPERO; CRD42021221922).

Studies were included if they included participants of any age diagnosed with any type of cancer. The studies had to be randomized controlled trials (RCTs), involving 1 or more digital health technology interventions, published between January 2010 and February 2022, and written in English. The timeframe of 12 years was applied as it coincides with the emergence of research into using digital technology as SMS in the care of patients with cancer [14].

The RCTs needed to compare at least 1 digital technology intervention used to enable SM and SMS of cancer to a control that did not use technology. The design of the study had to measure a change from baseline to postintervention in 1 or more of the 6 SM core skills: problem-solving, decision-making, behavioral self-monitoring and tailoring, setting goals, partnering with health care providers, and risk reduction [1]. The study outcomes of the RCTs needed to explicitly state that there was an investigation of SM core skills or inference could be made that SM core skills were investigated. Papers have been selected based on whether the study outcome matched the definition of any of the 6 SM core skills [1,15].

Studies were selected by searching MEDLINE, CINAHL, and Scopus using the search strategies in Multimedia Appendix 2. This search was performed by 1 author with the aid of a librarian on each of the 3 databases, using search terms related to (1) SM, (2) digital health, (3) cancer, and (4) terms of exclusion. In selecting papers for inclusion in the review, the study needed to investigate the impact of their digital technology intervention on a sample of patients with cancer and measure study outcomes that matched the definition of the SM core skills. When the study did not have features that met these criteria, the study was excluded from the review.

The search results were managed using Covidence (Veritas Health Innovation Ltd) and duplicates were removed. Two reviewers were involved in doing the data extraction independently through Covidence. Each reviewer independently assessed the titles and abstracts against the eligibility criteria. Any disagreements in study selection between the 2 reviewers were resolved through discussion to produce a filtered list for further full-text review. This was followed by a full-text review considered against the eligibility criteria followed by a further discussion to resolve disagreements and to produce a final list of studies for inclusion into this systematic review.

A narrative synthesis of the results was used to assess the aggregate extracted data on digital technology intervention, outcomes, and predictors of outcomes. This approach was selected due to the heterogeneity in the intervention provided by outcomes found.

The quality of the studies was assessed through the Manual for Quality Scoring of Quantitative Studies [16] by the same 2 independent reviewers who performed the data extraction.

Results

Data extraction is summarized in the PRISMA diagram (Multimedia Appendix 3). A search on MEDLINE, Scopus, and CINAHL on March 5, 2022, yielded 2454 studies, of which 1526 (62.2%) studies were selected after removing duplicates. Of these 1526 studies, 246 (16.1%) studies were selected as they met the eligibility criteria after abstract assessment. A further full-text screening was completed for these 246 studies and found that 12 (4.9%) papers reporting on RCTs met the eligibility criteria (Multimedia Appendix 3). A summary of the 12 papers are reported in Multimedia Appendix 4 [17-28].

A total of 4 studies were conducted in the United States [17-20]; 4 were conducted in the Netherlands [21-24]; and there were single studies from Ireland [25], Finland [26], Sweden [27], and China [28]. The most common digital technology studied were web-based applications (8 studies); with single studies examining a combined website and text messaging intervention, text messaging, educational videos, and mobile phone apps. Participants in 7 studies included female participants with breast cancer while the remaining 5 studies included both sexes, with 1 including patients with lymphoma and the remainder including multiple cancer types. In the 12 selected studies, there were 2627 participants in total, where 2143 (81.6%) participants were female and the remaining were male.

The quality assessment scores, using the Manual for Quality Scoring of Quantitative Studies [16], indicated that all studies were of high quality. The summary score of the studies ranged from 19 to 26 points out of 28 points, and the median score was 22 (IQR 2) points. The main reason that the median score was lower than the maximum score was the lack of blinding (9 studies) [17-19,21-25,29,30] due to the nature of the study. A total of 5 studies did not define their outcome variables [22-26]. Three studies had no evidence of consideration of controlling confounding variables [18,19,22] and 2 studies had incomplete control of confounding [17,21].

In assessing the 12 papers, the interventions were analyzed to identify which SM core skills (problem-solving, decision-making, behavioral self-monitoring and tailoring, setting goals, partnering with health care providers, and risk reduction) were being introduced. Across the 12 studies examined, the median number of SM core skills targeted by the interventions was 3 (IQR 2) SM core skills ranging from 1 to 5 SM core skills. A total of 11 studies explicitly stated the SM core skills that were targeted by the intervention.

The most common SM core skill targeted that were explicitly written were partnering with health care professionals [17,22,23,25,27,28] followed by behavioral self-monitoring and tailoring [17,20,23,24] and decision-making [20,24,26,27]. In 7 RCTs, additional SM core skills were identified that were not explicitly named in the study methodology. In these 7 RCTs, the most common SM core skills targeted were decision-making [17,18,23,28] and goal setting [18,19,22,28]. Overall, the most common SM core skills either explicitly identified or inferred by the reviewers were decision-making [17,18,20,23,24,26-28] and goal setting [18-20,22,25,28].

A total of 4 RCTs used a theoretical basis for intervention development including self-determination theory [25], Lazarus and Folkman’s [31] stress and coping conceptual method [19], empowering patient education theory [26], and Bandura’s [32] self-efficacy theory with self-exchange theory [28]. Furthermore, 3 RCTs used input from health care professionals [21,23,27] and 2 RCTs used problem-solving–based protocols [22,24], with 3 RCTs not stating their basis for intervention development [17,18,20].

A total of 8 (67%) out of 12 RCTs demonstrated statistically significant improvement in outcomes including self-efficacy [17,20,22,28], survivorship care knowledge and attitude [18], quality of life [25], increased knowledge of treatment [26], and emotional and social functioning [24]. In these 8 studies, the most common SM skills targeted were decision-making [17,18,20,24,26,28], followed by goal setting [18,20,22,25,28] and partnering with health care professionals [17,18,22,25,28]. A total of 5 (62%) out of 8 positive RCTs used theoretical considerations in their study design [22,24-26,28] whereas 1 (25%) out of 4 negative RCTs used theoretical considerations to design the intervention [19].

Out of the 8 papers that showed improved outcomes with the digital technology intervention, 3 RCTs investigated predictors of effects. In these 3 papers, there were 109 (16.2%) male participants out of 673 total participants. Willems et al [33] had the greatest number of male participants with 93 (25.2%) out of 369 participants, while Siekkinen et al [26] had the least, with 16 (9.1%) male participants out of 176 participants.

Siekkinen et al [26] investigated how a web-based application that gave participants feedback after responding to a knowledge test on radiotherapy increased their knowledge, leading to improved decision-making skills in patients with breast cancer. A significant positive association was observed with younger age and baseline decision-making skills (regression coefficient [RC]=–0.06, 95% CI –0.10 to –0.02; *P*=.002). A significant positive association was also observed between computer literacy and an increase in decision-making skills (RC=–0.20, 95% CI –0.37 to –0.03; *P*=.03).

Willems et al [33] evaluated the short-term effectiveness of a web-based psychoeducational program for survivors of cancer. Patients who were male (SD 0.34 in social functioning; *P*=.009); had higher education (SD 0.19 in social functioning; *P*=.04); aged 56 years and younger (SD 0.44 in fatigue; *P*<.001); or received chemotherapy with or without surgery compared to participants who received surgery only, radiotherapy with or without surgery, or chemotherapy and radiotherapy with or without surgery (SD 0.36 in depression; *P*=.008) showed higher improvement in the following SM core skills: problem-solving, behavioral self-monitoring and tailoring, goal setting and risk reduction, and decision-making skills.

Leach et al [20] assessed the efficacy of a web and text message support application for patients with cancer in managing issues related to long-term and late effects of cancer treatment. There was a statistically significant difference in developing the following SM core skills—setting goals, decision-making, behavioral self-monitoring, and completed cancer treatment (Cohen *d* for self-efficacy in patients that completed cancer treatment=0.31; *P*=.02), but there was no association observed with age (Cohen *d* for self-efficacy in participants over 60 years old=0.25; Cohen *d* for participants under 60 years old=0.29).

Discussion

Principal Findings

This systematic review sought to understand how digital interventions improved SM in cancer by examining what were the SM core skills that digital interventions enabled and supported and any predictors of effect. The review demonstrated that digital technology was associated with improvements in multiple SM skills; however, no study targeted all SM core skills.

The most common SM core skills targeted and improved by the interventions (both explicitly and inferred) were decision-making, followed by goal setting and partnering with health care professionals. In 8 studies that had shown improvement in outcomes, decision-making was the most common SM skill that was targeted, suggesting the importance of this skill in the overall SM process. This is consistent with findings from the systematic reviews that focused on the impact of digital technology on patients with a variety of other chronic diseases [34,35]. Future digital technology interventions should target decision-making, goal setting, and partnering with health care professionals to improve outcomes for patients with cancer given this supportive evidence.

In comparison, fewer studies targeted and observed an improvement in problem-solving [21,24,26,28], behavioral self-monitoring and tailoring [17,20], and risk reduction [24].

These findings imply that there is potential from all 6 SM core skills to build SM through mHealth interventions.

In line with the Corbin and Strauss [36] framework, chronic disease management, including cancer, requires the patient to address 3 distinctive tasks: medical management of their condition such as taking medication or responding to symptoms, managing behaviors and life roles, and dealing with emotional consequences of the illness. These tasks call for the use of diverse skills in the context of how the patient perceives their circumstances and problems. This process of SM can be supported by health system interventions designed to deliver SMS. It is thus perhaps not surprising that the most commonly targeted skills in our study included decision-making, goal setting, and partnering with health professionals.

It Is a little surprising and concerning that problem-solving was not as frequently targeted, given that the nature of SM is addressing problems as defined by patients. It is notable that decision-making contributes to problem-solving with the latter also including the identification of problems, the generation of solutions, and their implementation and evaluation. This lesser attention to problem-solving and similar lesser focus on behavioral self-monitoring and risk reduction may reflect the prevalent medical approach to chronic disease management where the delivery of solutions and interventions rests within the health system rather than the patient. Future research should explore the reasons for less focus on some of the SM skills from the perspective of the patients and the health professionals alike. Furthermore, the design of future interventions should consider the key SM skills required for particular interventions from the users' perspective and ensure that they are adequately supported in the interventions.

This study highlights a number of gaps in the design of studies focusing on SMS of patients with cancer, which are often not grounded in theory and not taking a systematic approach to the "active ingredient" of SM, that is, the core skills that patients use. It is impossible to accurately state why these deficiencies exist in the first place, but they point to some potential strategies to avoid them in future studies, including the support of theory-driven research in SM and consistent standards of reporting of these types of studies.

None of the RCTs in this review targeted all SM core skills. An average of 3 SM core skills out of the total 6 SM core skills were targeted. Lorig and Holman's [15] review of 38 RCTs that have incorporated 1 or more SM core skills as interventions for participants with chronic diseases proposed that there was greater potential in assisting patients with chronic diseases to become self-managers of their disease by using all SM core skills to promote behaviors for good medical management, emotional management, and role management. It is likely that targeting more SM core skills would be beneficial in drawing on a range of skills to manage different tasks involved with cancer management. However, different tasks may not require all the SM core skills for optimal health outcomes.

Future research on digital interventions should target multiple SM core skills explicitly and consider which SM core skills are most required to improve the SM of cancer. A greater understanding and use of behavioral theoretical frameworks of SM may also assist in identifying and prioritizing SM core skills necessary for the tasks involved with cancer management. In doing so, there is potential in producing mHealth technology where patients with cancer are capable of managing their illness and reducing their risk of deterioration leading to hospitalization.

It was notable that 5 (62%) out of the 8 RCTs that used theoretical frameworks in designing an SM intervention produced statistically significant outcomes. This observation is consistent with the findings of the systematic review of SMS inventions in primary care management of chronic diseases by Dineen-Griffin and colleagues [37], who showed that theoretical models produced effective frameworks in SMS and improvements were seen in clinical indicators, health-related quality of life, confidence to self-manage, disease knowledge, and control [29]. These findings emphasize the necessity of including theoretical frameworks in future digital intervention studies design.

Only 3 (25%) [20,26,33] out of 12 studies explored predictors of effect and concluded that younger age, male sex, higher education, computer literacy, completing cancer treatment, and being a recipient of chemotherapy were associated with improving the development of SM core skills. Excluding cancer treatment, each factor was not identified by more than 1 paper as a predictor of effect. As of now, previous reviews have investigated the predictors of the use of eHealth on patients with chronic diseases, showing that younger age was associated with higher eHealth use but there were inconsistent results with regards to sex and education [38,39]. Within the 3 papers, only Leach et al [20] investigated and identified age as an association with building SM core skills for patients with cancer. These findings may suggest that they may play some role in the predictor of effects but there is limited evidence from the current findings of this paper to support this as of now.

Within this systematic review, there was sex bias where 81.6% (2143/2627) of the total participants in the 12 selected studies were female. Within the studies that investigated the predictors of effect, 85.6% (656/766) of the total participants were female. This raises a possibility of limitations to the extent that sex could be a predictor of effect in building SM skills with mHealth interventions. Further research on the impact of predictors of digital intervention effect including sex is needed. There is relatively limited data on specific predictors of intervention effectiveness such as sex and age, with few studies and small patient numbers addressing this issue. Future research should focus on robust examination of predictors of intervention effectiveness.

The study population in 7 (58%) of 12 included studies included patients with breast cancer [17,19,21,25-28], suggesting that the literature may not be representative of other cancers. In 11 (92%) of the 12 papers, the location of the studies was in North America and Europe, suggesting a lack of evidence relevant to populations from other regions and ethnicities.

It is also noteworthy that all studies identified in this review had participants from metropolitan backgrounds despite the growing importance of digital technology in patients from rural areas [40].

The majority (8/12, 67%) of the studies in this review used web-based application interventions in assessing how SM was built in patients with cancer, with less data on other modalities such as telehealth and mobile phone apps. In addition, there are other modalities of technology that have shown improvement in building SM for patients with diabetes including artificial intelligence (AI) [41] and virtual reality applications [42]. There is a growing interest in AI and machine learning as an approach to deliver coaching-like approach to improve behaviors, especially with regards to physical activity, mental well-being, decision-making, and problem-solving, although the data on the mechanisms of how these approaches improve SM skills remain, as yet, limited. Greater adoption of machine learning approaches will likely facilitate greater customization and tailoring of interventions, integration into overall care, and focus on specific patient subpopulations. It is critical that the design process for such interventions is based on sound behavioral models, and factors in consideration of customization, behavioral change, and self-efficacy in its evaluation [43].

Conclusions

Digital technology appears to improve SM core skills including decision-making, goal setting, and partnering with health care partners in patients with cancer with suggestion of greater impact in people who are younger, male, educated, highly computer literate, completing cancer treatment, and a recipient of chemotherapy. These findings should prompt developers or designers of digital health intervention to focus on interventions targeting multiple SM core skills and better identifying predictors of digital intervention effect.

Conflicts of Interest

None declared.

Multimedia Appendix 1
PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) checklist.
[DOCX File , 31 KB - cancer_v9i1e45145_app1.docx]

Multimedia Appendix 2
Search strategies used for CINAHL, MEDLINE, and Scopus.
[DOCX File , 26 KB - cancer_v9i1e45145_app2.docx]

Multimedia Appendix 3
PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) diagram summarizing the searched literature.
[DOCX File , 47 KB - cancer_v9i1e45145_app3.docx]

Multimedia Appendix 4
Summary of the 12 papers that describes the impact of digital technology on building self-management skills for patients with cancer.
[DOCX File , 31 KB - cancer_v9i1e45145_app4.docx]

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Abbreviations

AI: artificial intelligence
mHealth: mobile health
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROSPERO: International Prospective Register of Systematic Reviews
RC: regression coefficient
RCT: randomized controlled trial
SM: self-management
SMS: self-management support

Edited by T de Azevedo Cardoso; submitted 17.12.22; peer-reviewed by A Trojan, P Innominato, A Antonini, XF Zhong, I Naja; comments to author 27.04.23; revised version received 05.08.23; accepted 24.10.23; published 22.11.23.

Please cite as:
Lim DSC, Kwok B, Williams P, Koczwara B
The Impact of Digital Technology on Self-Management in Cancer: Systematic Review
JMIR Cancer 2023;9:e45145
URL: https://cancer.jmir.org/2023/1/e45145
doi:10.2196/45145
PMID:37991831

Original Paper

Use of Online Health Forums by People Living With Breast Cancer During the COVID-19 Pandemic: Thematic Analysis

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Abstract

Background: At the time of the UK COVID-19 lockdowns, online health forums (OHFs) were one of the relatively few remaining accessible sources of peer support for people living with breast cancer. Cancer services were heavily affected by the pandemic in many ways, including the closure of many of the customary support services. Previous studies indicate that loneliness, anxiety, distress, and depression caused by COVID-19 were common among people living with breast cancer, and this suggests that the role of OHFs in providing users with support, information, and empathy could have been of increased importance at that time.

Objective: This study aimed to examine how people living with breast cancer shared information, experiences, and emotions in an OHF during the COVID-19 pandemic.

Methods: This qualitative study thematically analyzed posts from the discussion forums of an OHF provided by the UK charity, Breast Cancer Now. We selected 1053 posts from the time of 2 UK lockdowns: March 16, 2020, to June 15, 2020 (lockdown 1), and January 6, 2021, to March 8, 2021 (lockdown 3), for analysis, from 2 of the forum's boards (for recently diagnosed people and for those undergoing chemotherapy). We analyzed the data using the original 6 steps for thematic analysis by Braun and Clarke but by following a *codebook* approach. Descriptive statistics for posts were also derived.

Results: We found that COVID-19 amplified the forum's value to its users. As patients with cancer, participants were in a situation that was "bad enough already," and the COVID-19 pandemic heightened this difficult situation. The forum's value, which was already high for the information and peer support it provided, increased because COVID-19 caused some special information needs that forum users were uniquely well placed to fulfill as people experiencing the combined effects of having breast cancer during the pandemic. The forum also met the emotional needs generated by the COVID-19 pandemic and was valued as a place where loneliness during the pandemic may be relieved and users' spirits lifted in a variety of ways specific to this period. We found some differences in use between the 2 periods and the 2 boards—most noticeable was the great fear and anxiety expressed at the beginning of lockdown 1. Both the beginning and end of lockdown periods were particularly difficult for participants, with the ends seen as potentially increasing isolation.

Conclusions: The forums were an important source of support and information to their users, with their value increasing during the lockdowns for a variety of reasons. Our findings will be helpful to organizations offering OHFs and to health care workers advising people living with breast cancer about sources of support.

(JMIR Cancer 2023;9:e42783) doi:10.2196/42783

KEYWORDS

online health forum; breast cancer; COVID-19; pandemic; discussion forum; coronavirus; web-based communities; information use

Introduction

Background—COVID-19 and Breast Cancer

COVID-19 had an enormous impact worldwide, as countries struggled to contain and manage the disease. A strategy to manage the spread of COVID-19 was to implement lockdowns at the local, regional, and national levels during the pandemic. During the UK lockdown periods, people other than essential key workers were required to stay at home, except for undertaking essential shopping and physical exercise. Health services for non–COVID-19 conditions were severely reduced, and some health care professionals were reallocated to care for patients with COVID-19. Many support services were also closed. However, one of the few relatively unaffected sources of support for patients was online health forums (OHFs). These are sections of websites where groups of people facing similar health-related issues, life challenges, or difficult circumstances can communicate and provide each other with emotional support; advice; and information, especially experiential information. OHFs are distinct from chat rooms in that they are asynchronous, whereas chat rooms facilitate discussions that occur in real time.

Patients with cancer were greatly affected during the COVID-19 pandemic [1,2]. People with cancer had high risks of COVID-19 (breast cancer was deemed a *moderate risk*) [2-5] and patients undergoing chemotherapy had increased mortality risk from COVID-19 [3,4] because of immunosuppression. Patients experienced delays, cancellations, and alterations both to treatment and their overall care in a time of rapid change and great uncertainty [5].

Interaction with other people with the same disease or condition, going through the same experiences, can be highly beneficial to patients [6-8]. Peer support services can normally be undertaken face-to-face; however, during COVID-19 lockdown periods, this was not possible. Therefore, OHFs became an increasingly important opportunity for patients for support [9].

Web-based options can provide benefits similar to face-to-face interactions [10] and have additional benefits; for example, use is not limited geographically, participants can meet 24/7 [11,12], and there is great anonymity. During the COVID-19 pandemic, women in a breast cancer online support group reported numerous advantages over meeting in person [12], for example, not having to wear a wig and being able to accommodate the meetings with family responsibilities.

Literature Review

Cancer During the COVID-19 Pandemic

As noted previously, COVID-19 had major effects on cancer services and treatment including delays or cancellations in diagnostic and treatment services and restricted access to health services, including screening [2,13-16]. Some patients were also reluctant to visit health care settings [2,17] owing to the increased risk of infection [2,14,15].

COVID-19 also affected patient experience and well-being, including restricting access to psychosocial support from personal or professional networks [16], limiting support during hospital or office visits, and limiting communication with medical personnel. Patients with cancer reported receiving misinformation or insufficient information about COVID-19 during the pandemic [18]. Some also experienced increased levels of isolation and loneliness [18-20], fear, and anxiety [17] and mental health issues [21,22]. However, other studies found that some patients reported being less stressed, lonely, and unhappy than carers of patients with cancer or people without cancer [17,23]. Some patients felt reduced isolation and increased sense of being part of society again, as everyone was at home [24-26].

Breast Cancer During the COVID-19 Pandemic

People living with breast cancer experienced many of the abovementioned negative problems throughout the cancer journey [27-29]. Although many patients were “treated according to pre–COVID-19 guidelines” [30], other studies [19,31] predicted additional avoidable deaths, even up to year 5 following diagnosis.

Increased levels of loneliness and high levels of anxiety, depression, and psychological disorder caused by COVID-19 stressors were reported among people living with breast cancer [32-37]. Their quality of life was affected according to their level of concern about COVID-19 [38], and high levels of fear of cancer recurrence were also associated with COVID-19–related anxiety and distress [39]. Patients also experienced concerns about the risk of COVID-19 when immunosuppressed and distress caused by attending treatment alone, and some patients experienced a great burden of responsibilities at home (eg, because of homeschooling) [40].

OHFs During the COVID-19 Pandemic

Dedicated OHFs were set up during the pandemic, specifically to discuss COVID-19. The most popular topics discussed were symptoms, public health practice, and psychological impacts [41]. Participants mostly provided feedback or opinion, and the most frequently used sources of information were the news and websites.

Discussion about COVID-19 was also found on other OHFs and social media. Users who had great web-based support had better subjective well-being, better mental health, and more prosocial behaviors [42], which led to a sense of belonging and reduced loneliness. A US survey of 28 OHFs for people with chronic illnesses over 13 months found that they were used more during peak lockdown times and the desire for emotional or mental health support increased over time. When moderated well, OHFs can “provide a powerful, intermediate and safe space where conversations about mental and emotional wellbeing can be normalized” [43]. However, potential negative effects include the distress of hearing about others’ negative experiences regarding COVID-19 [44].

Cancer-Specific and Breast Cancer–Specific OHFs During the COVID-19 Pandemic

Cancer OHFs are an effective way of sharing and receiving information and social and emotional support [45-47]. A Cochrane review of online support groups for women with breast cancer did not find studies of sufficient size or quality to determine evidence of improvement or lack of improvement to negative affect (such as anxiety, depression, or distress), through use of the groups. However, it noted the benefits that were clear to women participating in online support groups [47].

Lung and breast cancer were frequently discussed on Twitter and OHFs by people living with cancer during COVID-19 lockdowns, with concerns regarding "delayed diagnosis, cancellations, missed treatments, and weakened immunity" [48]. Forum users were worried about the impact of COVID-19 on treatment, health, everyday life, and finances—they expressed a strong need for information and advice on COVID-19 and self-management [49]. The emotional health of patients with breast cancer was affected by COVID-19, and they desired one-to-one therapies, advice, and emotional support [50]. Social distancing led many patients "to turn to online forums for support" [9].

Comparison With Previous Literature

The literature shows that conversations about the pandemic were not confined to forums specifically dedicated to COVID-19 and that it was deemed a topic suitable for forums for people living with breast cancer. Although the COVID-19–related topics discussed in the forums and the emotions that COVID-19 caused have received research attention, there are only a few studies focusing on what the breast cancer forums were used for and how they were used. Previous studies have not examined in depth how people living with breast cancer shared information, experiences, and emotions in an OHF during the pandemic. Zhang et al [9] conducted qualitative analysis of posts from a US-based forum for people living with breast cancer, focusing only on how the users felt about the treatment delays and their views of treatment, rather than on the role of the forum more generally. Green et al [43] investigated the users of 28 OHFs with varied chronic health conditions at different stages of the COVID-19 pandemic. They compared user responses to a survey over a few days from a selection of months between March 2020 and April 2021, rather than covering 2 lockdown periods as done in this study. Their study was US-oriented, was non–cancer-specific, did not look at data from the forums during these times, and focused on information sources about COVID-19 rather than information needs more broadly. Loeb et al [51] conducted a study of posts on prostate cancer forums, which compared posts from before the pandemic with those at its beginning, not during 2 lockdown periods, as in this study. It is also important to consider how people at different stages of the cancer journey used OHFs during the pandemic, and no previous studies have specifically explored this. Similarly, no previous study has explored how people at different stages of the breast cancer journey may have used OHFs during the COVID-19 pandemic. Therefore, the overall aim of this study was to address these research gaps by undertaking an in-depth qualitative analysis of posts made by people living with breast cancer during the COVID-19 pandemic and, through this, to better understand how people living with breast cancer used OHFs during the COVID-19 pandemic.

Research Questions

The following research questions (RQs) are addressed in the paper:

- RQ1—How did people living with breast cancer share information, experiences, and emotions in an OHF during the COVID-19 pandemic?
- RQ2—How did people's use of OHFs differ during different lockdown periods during the pandemic?
- RQ3—How did people living with breast cancer at different stages of their cancer journey share information, experiences, and emotions during the pandemic?

Methods

Research Design and Approach

This qualitative study explored the use of an OHF for people living with breast cancer during the COVID-19 pandemic. It continues the work of *A Shared Space and a Space for Sharing* project [45,52]. We thematically analyzed posts from an OHF provided by the UK charity, Breast Cancer Now (BCN). This approach enabled us to observe forum use discussion that was uninfluenced by the presence of a researcher and foregrounded the participants' own comments on COVID-19 and its impact on them. In addition, we obtained some basic descriptive statistics to provide some information about the forum users.

Study Setting

Breast cancer is the most common form of cancer in the United Kingdom and can have a wide range of outcomes. For some, it may form an acute individual episode; for some, it becomes a chronic disease that they live with for many years; and for others, the prognosis is terminal. BCN is a charity providing support, information, advice, and help to people living with breast cancer at all stages of their journey. We chose BCN because it is publicly accessible; allows its forum data to be used for research; and had previously been involved in *A Shared Space and a Space for Sharing* project, and thus, a well-established working relationship was already present before this study. The discussion forum part of the site offers 12 boards covering different aspects or stages of breast cancer, for example, *local recurrence or new primary diagnosis*, *top tips and practical support*, and *radiotherapy*.

Sampling Strategy

Forum Boards

We reviewed all 12 boards and identified the most relevant ones. Searches were then conducted on these using key COVID-19–related terms (eg, "Coronavirus," "COVID-19," and "Lockdown") to identify the boards that contained the most discussion about the pandemic. The findings were discussed with BCN, and the boards, *recently diagnosed with breast cancer* (RDwBC) and *chemotherapy monthly threads* (CMTs), which contained a large amount of material on COVID-19, were selected for analysis and to answer RQ3. CMTs are (sometimes very long-lasting) threads designed for all those starting chemotherapy in a particular month. They support small cohorts of individuals experiencing the same process together over a period. In addition, chemotherapy is a highly stressful time involving long hospital visits and very high risks of infection and therefore a time when COVID-19 was likely to be of much concern. We chose the RDwBC board because it was likely to reflect the concerns of individuals immediately following their diagnosis and at the beginning of their treatment, a period that is very stressful and typically involves a high level of contact with health professionals and medical appointments. COVID-19 was likely to be a significant concern for the individuals posting on this board, at a time when they needed considerable support.

Forum Threads and Posts

To answer RQ2, we purposively focused on 2 UK lockdown periods: March 16, 2020, to June 15, 2020 (lockdown 1), and January 6, 2021, to March 8, 2021 (lockdown 3). A short second lockdown in November 2020 was not included in this study. March 16, 2020, was selected because this was when cancellations of appointments began and the UK government instructed “now is the time for everyone to stop non-essential contact and travel” [53]. June 15, 2020, was when nonessential shops reopened in the United Kingdom. January 6, 2021, was the official beginning of the third lockdown, and March 8, 2021, was when restrictions started to lift and schools began to reopen.

We selected 6 CMTs initiated during the relevant time period (March-June 2020) and the previous month and 2 other short threads with titles explicitly about COVID-19–related matters that fell within the time period. For lockdown 3, a total of 7 CMTs that began during the relevant time period (January-March 2021) and the previous month were selected. There were no threads with titles explicitly about COVID-19–related matters during this period.

The final sample of 15 threads was downloaded, pseudonymized, and identifiable material such as photos was removed. Then, we loaded the data into NVivo (version 12; QSR International) and conducted inductive and deductive semantic and latent thematic analyses. Posts referring to COVID-19 and its impact on users or the forum were coded. Comments on the value of the forum that did not specifically relate to COVID-19 were also coded to provide a more complete picture of why the users valued the forum at the time.

We followed the same process for the RDwBC threads, with some modifications. The number of posts per thread was found to be much lower than that for CMTs; therefore, we included threads that started before the chosen time period but contained posts within it. The time period was also extended to the end of June 2021, which was the point at which full unlocking occurred in the United Kingdom for lockdown 3. In total, 35 threads were identified for lockdown 1 and 48 threads for lockdown 3.

Data Analysis

Qualitative Analysis

We analyzed the data using the original 6 steps for thematic analysis by Braun and Clarke [54] but by following a *codebook* approach [55]. This started with in-depth familiarization with and reflection on the data. The team agreed on deductive codes based on the initial readings and then manually coded the data sets in NVivo (version 12) with the unit of coding being the whole post. Codes were also added inductively and reflexively throughout. Codes were regularly discussed and preliminary themes were generated through ongoing team discussions.

To help identify areas of analysis where different understandings could be explored and which could benefit from deep reflection or reflexivity on our part, a coding comparison test was conducted on a subset of posts using the coding comparison query function in NVivo. In total, 50 randomly selected posts from each of the 2 data sets were coded independently by 3 members of the research team using NVivo. The coding comparison query was run among the researchers. Coding consistency was high, with approximately 80% agreement. The exercise was primarily valuable in generating discussions about codes and development of themes. Then, we recoded all data using the final set of agreed codes and checked data extracts to ensure that they were coded appropriately. The final thematic map was developed through discussion within the entire research team.

Quantitative Analysis

Quantitative analysis was performed using data extracted from the posts from both lockdowns in both CMT and RDwBC data sets. We extracted the date, time, user pseudonym, and user type from each post to analyze the number of users and posts and their distribution across the lockdown periods. Posts that had been coded during qualitative analysis and were therefore deemed COVID-19–related were extracted, transformed, and loaded into MATLAB (MathWorks), and descriptive statistics were derived using MATLAB.

Ethics Approval

Ethics approval was obtained from the University of Sheffield (application 043811) in January 2022. We obtained permission from BCN to access the data, consistent with good practice [56].

Confidentiality

We pseudonymized the data after downloading them, by replacing usernames with pseudonyms and removing identifying details, such as names and photos. Quotations from the forums were carefully altered to protect participants’ identities, while ensuring that the post’s meaning was retained [57]. Idiosyncratic or rare words and spellings, which were likely to be found easily owing to their infrequent occurrence, were changed to more common alternatives with the closest possible meaning.

Results

Background—COVID-19 as a Topic of Conversation

Quantitative Data

We found that COVID-19, especially in relation to cancer, was a frequent topic of conversation during both lockdown periods. It clearly interested group users, and the forum was considered as an appropriate venue for discussion. To understand the context of use of the forum for COVID-19 as a topic of discussion, we looked at the number of users and posts and their distribution across the lockdown periods, as described in the *Methods* section.

In total, at least 1053 posts were related to COVID-19 across the RDwBC threads and CMTs during lockdowns 1 and 3. Of these 1053 posts, 719 (68.28%) were in the CMTs and 334 (31.72%) were in the RDwBC threads. There were some differences in the frequency of posts between the RDwBC and CMTs during the 2 time periods. In the RDwBC thread, the number of posts was higher during lockdown 1 (196/334, 58.7%) than during lockdown 3 (138/334, 41.3%), whereas the CMTs were more evenly split across lockdown 1 (381/719, 52.9%) and lockdown 3 (338/719, 47%). This may be owing to the reduced immunity of those undergoing chemotherapy, which meant that COVID-19 remained as a matter of great interest to them for longer than it did among people coping with a recent diagnosis in 2021 who were not immunosuppressed.

The distribution of COVID-19–related posts across lockdowns 1 and 3 was analyzed to determine if there were changes in the frequency of posting across lockdown periods. In the CMT during lockdown 1, there was increased activity at both the beginning (March 15, 2020, to April 10, 2020) and the end (May 10, 2020, to June 14, 2020) of the lockdown period. However, during lockdown 3, activity did not increase at the beginning of the lockdown, but a large spike of activity occurred toward the end (February 15, 2021, to March 9, 2021). The RDwBC threads had no initial spikes in activity; instead, during lockdown 1, there was increased activity in the middle period (April 16, 2020, to May 16, 2020), and there were no clear spikes during lockdown 3. This highlights how users used the forum for both immediate information around COVID-19 and continued to use the forum for information throughout the lockdowns.

Finally, we analyzed individual forum users who posted across threads and lockdowns. Although there were more posts in the CMT (719/1053, 68.28%), there were only 80 different users compared with the RDwBC group (334/1053, 31.72% of posts), which had 106 different users. To identify frequent users, searches were performed for people posting ≥20 posts on a thread. There was a high number of such users in the CMTs (16/80, 20% of users) compared with those in the RDwBC threads (5/106, 4.7% of users). These frequent users accounted for 43.97% (463/1053) of the total posts around COVID-19, suggesting that there are groups of superusers who post frequently. However, a substantial number of users were discussing about COVID-19, highlighting the importance of the forum for many users.

Qualitative Data

Specific aspects of COVID-19 and breast cancer that were discussed in the forums included the following:

1. The impact of COVID-19 on the treatment and experience of cancer, for example, changes, cancellations, or delays to treatments and having no visitors during inpatient care
2. The impact on cancer services, including professional support services, such as those offered by the UK charity, Macmillan Cancer Support
3. The increased risk that COVID-19 posed to patients with cancer, especially those undergoing chemotherapy
4. COVID-19's impact on the patient's support network of family, friends, and neighbors, both in terms of how they supported the patient and the effect on their own lives
5. COVID-19's impact on the forum users' daily life including work; education; and social activities, for example, holidays, exercise, and shopping
6. COVID-19–specific topics. Forum users exchanged information and advice on topics ranging from shielding to booking vaccinations, from dealing with COVID-19–related anxiety to where to get items in short supply because of the pandemic. They asked questions that they may not have wanted to bother their oncology team with, such as the following example:

> *Anyone had the jab already? Wondering where they inject it...Just asking cos I have a line in one arm and my surgery scar on the other.* [Ethel; lockdown 3]

This illustrated a practical problem that patients with cancer could face regarding COVID-19 because of the nature of cancer treatment. Another example is the timing of receiving the vaccine in relation to the chemotherapy cycle. These forum conversations provide an interesting picture of the impact of COVID-19 on the life of people with breast cancer.

We observed that the people posting in the forums quickly adopted terms and expressions that had come to have COVID-19 associations in UK society in general. This includes COVID-19–specific terms such as "LFT" (lateral flow tests), phrases such as "we're all in it together" and being on the "frontline" (signifying National Health Service [NHS] COVID-19 wards), and commenting on living in "strange," "difficult," or "scary" times. There were references to the "current state of the world" or "current climate" used as euphemisms for the pandemic, and the injunction to "stay safe" was a recurrent slogan, frequently used in the forums as it was in wide conversation, especially during the first lockdown.

Themes

Overview

We identified four main themes from the analyses under the overarching first theme of *COVID-19 amplifies the forum's value to users*:

1. Using the forum to meet special information needs
2. Using the forum to share emotions generated by cancer during COVID-19
3. Using the forum to reduce isolation
4. Using the forum to raise each other's spirits

The following sections discuss the themes individually.

Theme 1—COVID-19 Amplifies the Forum's Value to Users

Although the forum was highly valued by its users in ordinary times for providing access to others who understood them (because they had been through the same experiences), this value acquired an extra dimension in the lockdown periods. To grasp this fully, it is necessary to appreciate the unique nature of the users' situation at that time—they were the first people in UK history to be diagnosed with cancer or undergoing chemotherapy during a nationwide lockdown caused by a pandemic. People who had had breast cancer before could, and did, still offer peer support that was appreciated. For example, several forum users commented very positively on the BCN *someone like me* service, which matched people to trained volunteers with similar experiences. However, no previous patients with cancer had experienced cancer at the same time as a global pandemic causing lockdowns. Their unique circumstances led to some special information needs (refer to theme 2) and situation-specific emotions (refer to theme 3) in the context of which the forum acquired additional value. In the forums, people living with breast cancer could connect with others in this unique position, who fully understood this:

> *This is my first post. I was recommended this forum as a way to connect with others going through such a scary experience at such a crazy time.* [Tina; lockdown 1]

This was particularly the case during lockdown 1—people who were diagnosed or treated at that time formed a small group that could support those during lockdown 3:

> *You've found the right place to be with people who understand. I was in my fifties and single when I was diagnosed in early 2020 and went through treatment in the pandemic, you can get through it too.* [Donna; lockdown 3]

During the lockdowns, there was a lack of alternative ways to connect with peers because of COVID-19. Most customary sources of peer and professional support and information about cancer were either closed, difficult to access, or reduced in quality:

> *It's been very hard that so many support services have had to close. This forum has been a lifeline for me. So a huge thank you. It is so good to be able to connect with people going through this.* [Joanne; lockdown 1]

> *I was fortunate I got to go on a...course before the pandemic and lockdown...Now they can only offer online courses.* [Gretchen; lockdown 1]

Personal support networks, for example, friends and family, were also difficult to access other than via the web:

> *A diagnosis of breast cancer is hard enough in "normal" times, but SO much harder for anyone during COVID-19, who can't easily and physically access their network of family and friends for much needed support.* [Cheryl; lockdown 3]

Therefore, the forum's value was amplified as a rare source of peer support and information. Its value was further increased as it was available 24/7, which made it more accessible than peer support meetings that had moved online:

> *I took part in an online support group this morning...recommended if you like that kind of thing - although, it's only once a month which isn't enough for me...here we have our wonderful little team of lovely women.* [Maeve; lockdown 3]

The forum was also a place where members could support others, even if COVID-19 meant that they could not help at work. There were several mentions of guilt from key workers who were unable to help their colleagues "on the frontline":

> *I totally understand how you feel about this horrendous situation we are in. I also work for the NHS and my team are working so hard helping as many patients as they can. I wish I could be well enough to help.* [Philippa; lockdown 1]

Another individual had replied by saying the following:

> *All you people in the NHS are amazing - even though you can't be there, please know that you're certainly helping here.* [Megan; lockdown 1]

Therefore, the forum acquired additional value to its participants above and beyond the already high value in which it was held, as it gave continuous access to others going through the unprecedented situation of living with breast cancer during the COVID-19 pandemic.

Theme 2—Using the Forum to Meet Special Information Needs

During lockdowns 1 and 3, when discussing about COVID-19, users used the forum in 2 main ways: first, to recount or compare their experiences or both, and second, to ask questions and exchange information and advice. These often went together because forum members used their experiences to answer questions, pooling their knowledge to create a store of information. These were not novel ways of using the forum, as discussions around breast cancer were also largely in this format. However, what was different was that these periods were times of particular uncertainty around information, with UK Government and NHS guidance about COVID-19 and cancer changing rapidly. There were also geographical variations across the UK nations and regions and NHS Trusts, which complicated what information was valid where. Information at these times was confusing or absent:

> *When you're self-isolating it's hard to know what's best to do - advice from the government keeps changing.* [Roberta; lockdown 1]

> *Rebecca - I hope you get your appointment. I think hospital policies are changing daily. Hopefully things will continue for now.* [Nancy; lockdown 1]

As before the pandemic, forum users frequently referred each other for information to their NHS breast care team members, especially the nurses [49]. The resulting experiences were mixed, suggesting that COVID-19 changes may have rendered acquiring information from these sources difficult for some people:

> *I found having this during COVID-19 has been hard as in hospital everyone has to keep their distance and many of my appointments have to be over the phone so it feels like there's less support and it's hard to ask all those questions over the phone.* [Lauren; lockdown 1]

> *My Breast Cancer Nurse got transferred to the coronavirus team early on too.* [Joan; lockdown 1]

The forum was needed as a source of information more than ever:

> *I know just how you feel as I've been booked in for my surgery with very little information or preparation. However, everyone here has been so helpful, it's made all the difference to me and to my family who have*

> *been reading some posts here too.* [Rowan; lockdown 1]
>
> *Is it alright for me to still come here as this is the only place I am getting answers to my questions?* [Stephanie; lockdown 3]

Forum users shared practical tips and ideas about COVID-19 and cancer. They shared resources, for example, websites for homeschooling, information about support services that were still open, and numbers to access priority shopping slots. During lockdown 3, they helped each other with booking vaccinations, including managing information systems to get a response. Responding to Tara, who described her frustrating attempts over several days to book, "Alexa" offered a tip that had worked for her:

> *Check out all the NHS sites...One of them asks if you are happy with the info...I clicked "no" and that sent me right to the actual booking site.* [Alexa; lockdown 3]

This did not work for "Tara," and "Alexa" then asked a family member to help:

> *The great thing about this forum is that somebody somewhere always has an answer.* [Alexa; lockdown 3]

This is very practical informational support based on experience that would not be available through more conventional sources. The forum provided them with a wide range of people to consult with during the COVID-19 pandemic. It became a place where they could ask "Is it like this where you are?" and "Has anyone else been told this – is it normal?":

> *My partner rang oncology and was told that my consultant has changed my treatment...He asked why and it's so I'm not there as long! I don't understand, it's only going to slightly reduce the time I'm there. If it makes no difference why were we to have it in the first place? Feel very confused...has anyone else been told this?* [Philippa; lockdown 1]

Through this, they could also check rumors and share potentially useful news about COVID-19:

> *Really anxious with this virus and what it means for future treatments. I've heard some have been cancelled, and that the cold cap option isn't available, is this right? Or does it vary by area? Also heard can't have anyone with us while getting chemo. All speculation for me right now.* [Rebecca; lockdown 1]
>
> *When I went last week they said they are planning to send some NHS patients to private chemo units to keep some NHS space free so I don't think they're planning to stop chemo.* [Joanne; lockdown 1]

Comparing experiences in the forums and finding what was happening elsewhere, at a time of confusing and conflicting information, gave them useful information and a route to some sense of normality and reduced isolation.

The author, Case [58], identified 2 types of information needs: objective needs, which relate to facts and are driven by rational judgment, and subjective needs, which arise from a need to make sense of the world and are driven by feelings and emotions [58]. During the COVID-19 pandemic, the forums showed both types of needs being expressed, sometimes intermixed. For example, "Diane" introduced herself as "feeling pretty low at the minute! and confused, angry etc etc." She described her medical situation and the difference in her experience with NHS cancer services at a recent appointment because of COVID-19. She concluded by saying the following:

> *I feel so lost and isolated. My nurse did not ring. this did not surprise me as I had been in the breast unit, it was empty, normally bursting at the seams! and this virus! I just do not know what to expect. I was told that if the cancer spread to my lymph nodes treatments meant I had a good chance of 5 years.* [Diane; lockdown 1]

She mixed specific questions with the need to make sense of her situation (feeling lost). In return, she received much encouragement and accounts of other people's experiences, and she stated the following:

> *Thank you for the responses. I will ring my key worker tomorrow and see if there is an update. It's really good hearing positive outcomes.* [Diane; lockdown 1]

Other forum users had provided specific advice to help answer her question, but they had also addressed her more general anxiety through accounts of their experiences.

Theme 3—Using the Forum to Share Emotions Generated by Cancer During the COVID-19 Pandemic

As is customary with OHFs, the forum was a place where members could share their emotions and support each other. The overriding emotions related to living with breast cancer during lockdown 1 of the COVID-19 pandemic were anxiety and fear, felt most frequently at the beginning of the pandemic in March 2020:

> *These are frightening times so not surprising you are anxious about going for treatment and scared of catching something. I think it's totally normal to be worried about it all. We should be, as we have to be careful.* [Joanne; lockdown 1]
>
> *My anxiety levels are sky-high and I hate to say it but I feel like the hospital has abandoned me a little [I feel very guilty for even thinking that at this difficult time]. I feel lost and absolutely terrified about what the next few months will bring.* [Sara; lockdown 1]

The anxiety expressed on the forum at this stage was largely related to the risk of infection, impact that COVID-19 would have on treatment, possibility of delays or cancellations, and other general worries about COVID-19. A conflict between the desire for treatment and the fear of infection was common:

> *We have to self-isolate but at the same time we have to go to hospital for treatment. Aaaargh!* [Joanne; lockdown 1]
>
> *My hospital has just been identified as one of the biggest COVID hot spots in the country. Although I*

> *desperately want to proceed with treatment I feel very frightened.* [Roberta; lockdown 1]

In the RDwBC threads, anxiety was primarily voiced about changes to treatments because of COVID-19, and there was great uncertainty among users, as they did not yet have a definite plan. In CMTs, anxiety was primarily shared around vulnerability to SARS-CoV-2 infections. This is likely to reflect that people posting in the RDwBC threads had not yet started treatment, whereas people posting in CMTs had started and had reduced immunity.

Sharing feelings of anxiety reduced during lockdown 1 and had greatly reduced by lockdown 3 (although it remained as the most commonly expressed emotion). During lockdown 3, COVID-19 was no longer a terrifying unknown, and help was on the horizon in the form of vaccines. The cause of the shared anxiety shifted to include new reasons, for example, the lifting of lockdown and the resulting increased likelihood of coming into contact with others:

> *I completely agree with you about the lockdown easing. I am terrified, haven't been anywhere for months...The thought of sitting next to people on any kind of transport, - ick!* [Alexa; lockdown 3]

During lockdown 3, within the CMTs, mentions of stress were approximately as prevalent as comments on anxiety.

The forum was a place where users could share these emotions with people other than loved ones who could be affected by their feelings. They could vent; complain; and receive reassurance, empathy, and comfort:

> *I wanted to try and share my experiences so far to give some reassurance or comfort that you will be well looked after. Yes this is scary, particularly so right now with everything else going on, but we're in this together and we can share our journeys here and support each other.* [Greta; lockdown 1]

Reassurance came to the fore in comments from users about the forum's value when they specifically connected this to COVID-19. It was less prevalent in general comments about the usefulness of the forum, with no reference to COVID-19.

COVID-19 also caused some distinctive emotions specific to the time, which group members used the forums to cope with. This was presumably because other members were uniquely placed to understand these, whereas outsiders and even family members may be negatively affected. The first could be summed up as "it's bad enough having cancer without COVID-19 as well!" (or the converse). This situation was frequently acknowledged empathetically ("it's not surprising you are anxious with COVID-19 as well") or to explain the extreme anxiety and fear experienced:

> *This is a really difficult time isn't it. I feel that the pandemic situation has me constantly on high alert, which makes it even harder to deal with the natural anxieties to do with treatment.* [Joan; lockdown 1]

> *I just wanted to say I feel exactly the same, I start my chemo very soon and like you I feel frightened and so anxious, while this lockdown makes it so much worse.* [Edie; lockdown 1]

Sometimes, there was also a sense of unfairness, unreality, and almost disbelief regarding the extraordinary circumstances they found themselves in:

> *I'm feeling your worries too, it's like we've all been handed one of the biggest battles to deal with, and they pile the end of the world on top.* [Megan; lockdown 1]

This was especially common during lockdown 3, when exasperation, empathy, and sympathy were evident, perhaps because COVID-19 had become annoying and worrying:

> *Totally get where you are coming from. As if having breast cancer isn't bad enough we all have to go through it during a pandemic! Terrible timing.* [Letitia; lockdown 3]

> *I can't believe you're having so much hassle with the jab!!! You'll get there but you SO don't need that right now.* [Maeve; lockdown 3]

A second distinctive emotion was annoyance or being upset at people without breast cancer complaining about COVID-19 when they did not have breast cancer:

> *It does irritate a bit when people complain about having to stay in or not taking this seriously. Grr! I suspect we'll be doing this for a lot longer than most so we have more to complain about!* [Yvonne; lockdown 1]

> *My parent friends don't really understand why I'm being so careful or how dangerous it could be if I sent my child back to school and they brought the virus home.* [Gretchen; lockdown 1]

The forum is the perfect place to offload this feeling without giving offense or causing distress. Lou et al [59] also noted that "participants receiving active treatment reported...greater concern that the general public does not adequately understand the seriousness of COVID-19."

Thirdly, there was emotional upset at COVID-19 "eclipsing" cancer, potentially reducing its seriousness and importance to others:

> *For a few days last week I felt like the cancer had been eclipsed by coronavirus which was really upsetting but then I became pro-active in reaching out...* [Ruth; lockdown 1]

Some members simply did not reach for support outside the forum because of COVID-19:

> *I've not felt able to tell my parents yet. They've been ill, they're shielding because of the virus and I know they will struggle to cope with the news and knowing that they can't do anything to help.* [Gina; lockdown 1]

> *...It's a strange time, with others suffering with COVID-19 to the point that I feel guilty talking about my cancer.* [Erica; lockdown 1]

People with breast cancer may have deferred going to their physician or had tests delayed because of COVID-19:

> *I found a lump just before lockdown. Waited a couple of weeks due to the madness that was happening with COVID-19.* [Noreen; lockdown 1]
>
> *I've convinced myself that it's going to be advanced cancer and that it's spreading massively every day I am waiting for surgery. All made worse [because] my routine mammogram was delayed for several months because of COVID-19.* [Trisha; lockdown 3]

Interestingly, COVID-19 was seen by some as providing others with an excuse for not being supportive or understanding. The following comment was about health care professionals:

> *Some people I click with, some I feel wary of or they seem to not be bothered. The pandemic seems to help them not bother too much either.* [Bethany; lockdown 1]
>
> *I do wonder if some hide behind the mask and COVID-19 is an excuse...* [Alexa; lockdown 3]

Thus, the forum was a place where emotions could be expressed and empathy received without stressing loved ones and with the assurance that the forum user would be understood. For the emotions that were specific to cancer during COVID-19, there were very few other places to discuss this.

Theme 4—Using the Forum to Reduce Isolation

Isolation is an important theme when discussing cancer OHFs in general, as many users come to them because they feel alone with their condition and want to meet someone in the same situation. For those receiving chemotherapy, shielding from contact with others may have been necessary to avoid infection, even without the pandemic [39]. However, clearly, lockdowns seriously exacerbated the isolation of many individuals:

> *Cancer feels lonely however much support you have as it's so very difficult for others to understand what it is like, and even more difficult with all this chaos around.* [Iris; lockdown 1]

As noted in theme 1, COVID-19 removed or altered access to both professional and personal support networks. Close contact (including hugs) was not advised, and cancer services (eg, consultations) moved to the web, which suited some people but not others. There was an added dimension of isolation in that people (even if present) could not be seen well because of masks and other personal protective equipment (PPE; eg, "It's really strange when you can't see people's faces because of masks. It does make me feel even more alone") Social distancing sometimes made it difficult to talk to fellow patients, and no visitors were allowed in wards or at home. As far as possible, people were kept away from health care settings to reduce infection risk.

People who lived alone became particularly isolated because of lockdowns:

> *I do live on my own, which is usually fine, but with COVID-19 it's pretty isolated as I can't see people properly...Couple of doorway visits...I do miss visits and people coming to cheer me up.* [Maeve; lockdown 3]

As noted in theme 1, the forum's value was increased because of this situation:

> *It's all so strange right now not being able to see anyone – I'm so grateful for this forum and all of you here.* [Andrea; lockdown 1]
>
> *I think that while we are isolating this [forum] will be more helpful than ever.* [Nancy; lockdown 1]

However, interestingly, lockdown could also help with isolation in some ways, as everyone was in the same situation. The person living with breast cancer was not missing out on anything, as they would be under normal circumstances:

> *At least for those of us currently going through chemo – the rest of society is joining us now in lockdown so we are not missing out on much.* [Zoe; lockdown 1]

For others, lockdown could be the opposite of isolation, as family members may have been around all the time. This could be annoying, for example, interfering with work or requiring demanding homeschooling of children. Visits for cancer treatments or tests even became a source of relief:

> *Having first round of chemo in a few days...several hours with no company...not sure if that sounds dreadful or wonderful after being stuck in the house with hubby and toddler lol!!* [Chris; lockdown 1]

By lockdown 3, comments on excitement over mundane errands had become a recurrently shared joke:

> *Just had my best day in months...guess what I did...I LEFT MY HOUSE AND WENT TO THE GARDEN CENTRE!! WHOOP-WHOOP!! It was fantastic!* [Maeve; lockdown 3]
>
> *Heading out to get my picc line flushed today. I'm getting a trip out! Yay!* [Amanda; lockdown 3]

When lockdowns lifted, the sense of isolation could intensify, with users having mixed feelings about this:

> *I know it's mean but this isolation felt better because everybody had to do it. Now I reckon I will feel a bit jealous if restrictions are lifted. I feel bad for feeling this way.* [Francesca; lockdown 1]
>
> *We are all going through such a hard time, lockdown in a very selfish way has helped massively. No one can go anywhere right now so bad though it is, I dread the unlock when I will still have to remain inside.* [Alexa; lockdown 3]

It seems plausible that this sentiment would be difficult to share outside the group. It suggests that users may have extra need for forum support and the understanding of others in the same situation at the end of lockdowns, similar to the beginning.

Theme 5—Using the Forum to Raise Each Other's Spirits

Members used the forum to lift each other's spirits in various ways specific to the time.

First, they identified and shared other positive aspects of having cancer during the COVID-19 pandemic, in addition to those described previously. The most commonly mentioned aspect in the CMTs was that there was no need to worry about losing hair as no one would be able to see it:

> *One positive thing - there's no one to see my ever increasing baldness.* [Henrietta; lockdown 1]

Other positive aspects that were shared on the forum to raise spirits included the following:

1. Few demands on people as they were not having to go to work
2. Being able to save money for postcancer or post-COVID-19 treats
3. Coming alone to chemotherapy meant that they could meet other patients and talk to the staff (if social distancing rules permitted)
4. Having more time with the family could be enjoyable (and this also meant that there were people at home to look after the person living with breast cancer)
5. Working from home and homeschooling had their positive aspects, including providing distraction from thinking about cancer

In RDwBC, there were fewer examples of forum users describing the positives of cancer during the COVID-19 pandemic than in CMT. This may be because potential positives were overshadowed by the shock of diagnosis and concerns about when treatment would start.

Second, as noted in the CMTs, users shared small pleasures that had replaced large ones during the COVID-19 pandemic:

> *I never thought I'd find a trip to [supermarket] something to look forward to so much! Lol!* [Chris; lockdown 1]

Third, throughout the pandemic, and particularly during lockdown 3, forum users also used the forum to daydream and plan what they would do after cancer and COVID-19:

> *One day soon we'll be able to enjoy those glasses of wine with our friends again and all this will be over! Xx* [Leah; lockdown 3]
>
> *Those good times are ahead of us, we just have to be very patient and enjoy dreaming about it in the meantime xx* [Maude; lockdown 3]

Finally, they also raised one another's spirits through humor, which was seen as an important function of the forum:

> *My bins have been out more than me...I might start calling myself "Dusty," I might have more chance of getting out...and seeing "men"!!!! or even just people or another human being without full PPE on.* [Alexa; lockdown 3]

The forum clearly played an important role in raising spirits and allowed expressions of humor, which outsiders may not have fully appreciated.

Discussion

Summary

This study has developed a better understanding of how people living with breast cancer used the BCN OHF during the COVID-19 pandemic. The study shows that people living with breast cancer found the OHF to be a helpful form of support for sharing and discussing information, experiences, and emotions about COVID-19 and related topics during the pandemic (RQ1). The topics discussed during the 2 lockdown periods we studied had much in common; however, some differences in forum use were found, for example, regarding the topics discussed and levels of emotions experienced (RQ2). Some differences in use depending on the forum user's stage of their journey were found; however, overall, the similarities were more striking, suggesting common interests regarding COVID-19 throughout the pandemic (RQ3).

Principal Findings

We found that group members frequently used their forum (RQ1) to talk about COVID-19, particularly its impact on the experience of cancer, its treatments and services, and its effect on social activities and support. This focus was practical and personal—there was little theoretical discussion about the pandemic. For example, in the threads studied, there were no discussions about the latest statistics (other than a passing mention that they were "scary") and any of the government's approaches or how COVID-19 developed and spread. There was little discourse on COVID-19 symptoms, unlike forums dedicated to the pandemic [40]. During lockdown 3, there was only passing mentions about conspiracy theorists, such as "anti-vaxxers" and COVID-19 deniers. This suggests that users saw this forum as a place for practical help around COVID-19 rather than for theoretical discussion. This may be because they were accustomed to using it for practical help with cancer.

Forum users found additional value in sharing information, experiences, and emotions in the OHF (RQ1) for various reasons. The pandemic exaggerated emotions and situations that may be occurring anyway because of breast cancer, for example, anxiety, fear, and loneliness. Participants were in a situation that was "bad enough already" and COVID-19 amplified this. In addition, COVID-19 created some special information needs and emotions that its users were uniquely well placed to fulfill. It was also valued as a place where loneliness may be relieved and spirits lifted in ways specific to the time. Overall, COVID-19 amplified the value of the forum to its users.

Isolation was found to be an important theme, both in the physical, literal sense of being alone and the emotional sense of feeling lonely and as a synonym for *shielding*. Cancer is described as a lonely experience, because those who have not had it do not know what it is like. Even fewer people understood what it was like to have breast cancer during the COVID-19 pandemic. The value of the forum increased as it was one of the few remaining options for communication and support when other sources were missing or limited, for example, owing to social distancing or PPE. However, group users' views of the isolation caused by COVID-19 were nuanced—in some ways, it helped them to feel better about the cancer experience as they were not missing out, with everyone being in the same situation [19,25].

The 2 lockdown periods studied had much in common, but some differences in use were found regarding the topics discussed and levels of emotions (RQ2). During lockdown 1, COVID-19 was unknown, with no good treatments and no vaccine; therefore, it is unsurprising that accounts of fear and anxiety were more prevalent. During lockdown 3, these were reduced—by then, COVID-19 was more familiar and less threatening.

Both the beginning and end of the lockdown periods had particular challenges that the forums could be used to express. There were several unknowns and uncertainties at the beginning of both lockdowns (during lockdown 1, COVID-19 was completely new, but even during lockdown 3, eligibility for early vaccination was a new issue). The end of lockdowns potentially increased the sense of isolation, as patients saw everyone else resuming normal life, whereas they had to remain cautious. Although in the future, there may be few, if any, full lockdowns, COVID-19 remains as a great problem for patients with cancer, especially those undergoing chemotherapy, than for those without cancer. This means that some of the questions and issues raised, especially around shielding-related matters, will still be relevant to patients today, particularly with episodic surges in COVID-19 cases, and potentially for any future pandemics.

Overall, some differences in use were observed between the 2 boards studied (RDwBC and CMT), and it was shown that there are plausible reasons why we may expect this (RQ3). However, the degree of commonality was more striking. This suggests that the findings may also be transferable to other boards within the forum; however, this would require further studies to test this.

Comparison With Previous Studies

This study contributes to the limited body of work using OHF post analyses to illuminate aspects of cancer during the COVID-19 pandemic [1,9,48]. It confirms these works' findings about the topics related to COVID-19 (such as treatment delays and changes to the cancer experience) that are discussed in cancer OHFs. It also supports their findings about the dominant negative emotions (notably fear and anxiety) that COVID-19 engendered in group users. However, this study differed in several ways from the other studies. For example, this study covered a longer period of the first lockdown than the study by Colomer-Lahiguera et al [1], and this study compared it with the third lockdown and thus was able to comment on the changes in topics between the 2 periods.

Colomer-Lahiguera et al [1] focused on describing people's experiences of cancer and did not examine COVID-19's effect on the way the forum was used. It analyzed only 230 posts and selected only the first post of each thread, rather than analyzing ongoing discussions during the period. Moraliyage et al [48] also analyzed the topics discussed rather than the use of the forum, as did Zhang et al [9]. Loeb et al [51] compared posts on a prostate cancer forum during and before the pandemic, found low rate of misinformation (7%), and again focused on topics of concern. This study is the first to focus on the impact of COVID-19 on the use of a breast cancer OHF.

Hulbert-Williams et al [16] noted the positive aspects of COVID-19, as did Kassianos et al [23] and Schellekens and van der Lee [24]. This study extends the understanding of the ways in which forums contributed to positive well-being, through its analysis of the different ways in which people used the forum to lift each other's spirits.

Our study supports that of Patel et al [60] and Zhang et al [9], who noted that forums were used the most at the beginning of the first lockdown. It also supports the finding by Green et al [43] that interest in COVID-19 had decreased substantially by later lockdowns. There was less discussion about it by RDwBC users, and there were no threads specifically for COVID-19 in the CMT forum. Changes in the topics discussed between the periods were noted.

Finally, this study contributes to the debate about the value of self-help groups to users, as seen, for example, in the editorial by Cordero [44], which asked whether such groups were "a necessity or an added calamity" during the COVID-19 pandemic. Cordero [44] focused on groups dedicated to COVID-19, particularly groups in the Philippines. We would echo his suggestions for user protection on the web, but dispute the predominantly negative assessment, at least in the UK context. This study clearly shows that the value of the forum increased for BCN users as a consequence of the way in which COVID-19 amplified existing information needs, negative emotions, and sense of isolation.

Strengths and Limitations

The study analyzed users' own conversations, which were unaffected by the researchers. The conclusions are based on users' interests and perspectives and thus indicate their priorities and interests as expressed during peer support. The study also benefited from the ongoing collaboration and discussions with the forum provider, BCN.

This study was limited in only focusing on 1 cancer OHF and 2 stages of the cancer journey. It did not include other BCN threads, for example, those for radiotherapy or other treatments, secondary diagnosis, or end of life. The fact that there was much commonality across the 2 stages analyzed may suggest that similar issues may be found in other stages; however, it is also plausible that there would be additional issues and differences.

The findings presented in this paper are not intended to be generalizable to specific groups but may be transferable to other online support groups during the COVID-19 pandemic, particularly other cancer and breast cancer forums.

Recommendations for Breast and Other Cancer OHFs for Similar Situations

Some of the recommendations in this section apply if COVID-19 escalates again or if other similar health emergencies or pandemics arise, necessitating lockdowns. Other recommendations are for the groups regarding the continuing impact of COVID-19.

Support During Societal Transition Points

There was increased anxiety and fear at the beginning of lockdowns; therefore, particular attention from moderators (or their equivalents) is warranted at that point, with provision of reassurance. Groups also need to be aware that users may feel great anxiety and isolation at the point when lockdowns lift. This is not intuitive; therefore, it is important that cancer support services are aware of this and offer extra support, if possible. Even when services are moving offline again, the question remains whether people living with breast cancer will feel safe to take them up or prefer to use the web. Therefore, groups may want to consider their short-term service plans.

Providing Other Ways to Connect With Peers

Groups are in a unique position in facilitating access to multiple others going through cancer during lockdown. Therefore, they may like to investigate other ways to facilitate connection among these peers, for example, live chat rooms. The users spoke highly of BCN's *someone like me* service, and it would be useful for other groups to consider developing a similar service.

Special Services for Individuals Living Alone

Those living alone may be at particular risk of loneliness, and groups may consider whether they would benefit from a specific board or a thread for them; however, people living alone are particularly vulnerable and additional precautions should be considered.

Raising Awareness of How COVID-19 Can Eclipse Cancer

There may be a need to raise awareness among cancer professionals that "COVID-19 eclipsing cancer" can be a cause of distress. Previous literature has shown that it can lead to actions that are not in the patients' best interest, for example, staff or patients delaying diagnostic tests or treatments. However, this study demonstrates that it can also extend to users hiding cancer from their personal support networks of family and friends, thus becoming very isolated.

Future Studies

The transferability of our findings to other breast cancer groups or breast cancer sections on general cancer websites should be explored. Identifying differences from other site-specific cancer OHFs would be valuable to health care professionals, patients, and researchers.

Studies have shown that people also benefit from *lurking* in OHFs—only reading posts, rather than posting themselves. Future studies could examine whether the number of *lurkers* on the BCN forums increased during the lockdowns. This would indicate another population that may have turned to forums owing to the lack of other sources and whose interests require exploration; however, identifying and recruiting people to such a study could be challenging.

This study does not explore whether there was anything that reduced the usefulness of the forum or acted as a barrier to its use during the lockdowns. Interviews with *posters* and *lurkers* could explore whether there were issues that they felt they could not talk about in the forums regarding cancer during COVID-19, and, if so, where they went to discuss those issues. It could explore whether, for example, they ever felt that there were topics they could not raise on the web or that they had to word certain topics more carefully. This would be very useful to OHFs supporting people with breast cancer.

Finally, according to Dhada et al [2], "...the evidence base relating to caregivers (about COVID-19 and cancer) is limited, with only two studies reporting their perspectives. Further research in this key population is warranted."

Given that caregivers of people living with breast cancer found COVID-19 to be very difficult [16,23], future studies are needed to explore their use of BCN or other forums during the COVID-19 pandemic.

Conclusions

As well as the COVID-19 pandemic continuing, there may be similar pandemics in the future, and people living with breast cancer remain very vulnerable. Although, for the rest of society, life may return to normal following COVID-19 and future pandemics, people living with breast cancer remain at great risk. The evolving nature of global pandemics, as we have learned from the COVID-19 pandemic, means that there are times of greater risk than during the periods we studied; for example, tests are no longer free, and legal requirements for people with COVID-19 to self-isolate are removed. Under these circumstances, there are more opportunities to come in contact with the virus, and there may be less support for shielding people. Moreover, waiting lists for cancer diagnosis and treatment remain affected by COVID-19, with much longer waiting times than before the pandemic. In short, people living with breast cancer are still likely to be experiencing a high level of concern about COVID-19 and the accompanying anxiety and distress. Therefore, OHFs are an important source of support and information for their users, both during the COVID-19 pandemic and future pandemics.

Acknowledgments

The authors thank Breast Cancer Now for their support in giving them permission to access their web-based forum—in particular, they thank Susanna Glover, Patient Experience Manager at Breast Cancer Now, for their advice and support in conducting the study. This study was funded through COVID-19 recovery funding and policy quality–related funding awarded to the University of Sheffield. The authors are grateful to the anonymous reviewers, who provided helpful feedback for improving the paper.

Data Availability

All data generated within the study were derived from the Breast Cancer Now online health forum, and, similar to previous studies [45,52], we will not be able to provide access to these data ourselves. Breast Cancer Now should be contacted directly to request access to their data.

Conflicts of Interest

None declared.

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Abbreviations

BCN: Breast Cancer Now
CMT: chemotherapy monthly thread
NHS: National Health Service
OHF: online health forum
PPE: personal protective equipment
RDwBC: recently diagnosed with breast cancer
RQ: research question

Edited by A Mavragani; submitted 18.09.22; peer-reviewed by D Frohlich, C Yuan; comments to author 31.10.22; revised version received 24.11.22; accepted 05.12.22; published 07.02.23.

Please cite as:
Sanger S, Duffin S, Gough RE, Bath PA
Use of Online Health Forums by People Living With Breast Cancer During the COVID-19 Pandemic: Thematic Analysis
JMIR Cancer 2023;9:e42783
URL: https://cancer.jmir.org/2023/1/e42783
doi:10.2196/42783
PMID:36473015

Original Paper

Remote Monitoring of Colorectal Cancer Survivors Using a Smartphone App and Internet of Things–Based Device: Development and Usability Study

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Abstract

Background: Patients with colorectal cancer who undergo surgery face many postoperative problems. These problems include the risk of relapse, side effects, and long-term complications.

Objective: This study sought to design and develop a remote monitoring system as a technological solution for the postdischarge care of these patients.

Methods: This research was conducted in 3 main steps: system feature extraction, system design, and evaluation. After feature extraction from a systematic review, the necessary features were defined by 18 clinical experts in Iran. In the next step, the architecture of the system was designed based on the requirements; the software and hardware parts of the system were embedded in the architecture, then the software system components were drawn using the unified modeling language diagrams, and the details of software system implementation were identified. Regarding the hardware design, different accessible hardware modules were evaluated, and suitable ones were selected. Finally, the usability of the system was evaluated by demonstrating it over a Skype virtual meeting session and using Nilsen's usability principles.

Results: A total of 21 mandatory features in 5 main categories, including patient information registration, periodic monitoring of health parameters, education, reminders, and assessments, were defined and validated for the system. The software was developed using an ASP.Net core backend, a Microsoft SQL Server database, and an Ionic frontend alongside the Angular framework, to build an Android app. The user roles of the system included 3 roles: physicians, patients, and the system administrator. The hardware was designed to contain an Esp8266 as the Internet of Things module, an MLX90614 infrared temperature sensor, and the Maxim Integrated MAX30101 sensor for sensing the heartbeat. The hardware was designed in the shape of a wristband device using SolidWorks 2020 and printed using a 3D printer. The firmware of the hardware was developed in Arduino with the capability of firmware over the air. In evaluating the software system from the perspective of usability, the system received an average score of 3.8 out of 5 from 4 evaluators.

Conclusions: Sensor-based telemonitoring systems for patients with colorectal cancer after surgery are possible solutions that can make the process automatic for patients and caregivers. The apps for remote colorectal patient monitoring could be designed to be useful; however, more research regarding the developed system's implementation in clinic settings and hospitals is required to understand the probable barriers and limitations.

(JMIR Cancer 2023;9:e42250) doi:10.2196/42250

KEYWORDS

eHealth; telemedicine; colorectal cancer; cancer survivor; IoT; mHealth; patient monitoring; remote monitoring; postdischarge care; cancer; patient care; cancer care; postoperative complications

Introduction

Cancer is one of the leading causes of death worldwide. According to reported statistics by the World Health Organization in 2021, this disease was the cause of nearly 10 million deaths worldwide [1].

Among the types of cancer, colorectal cancer (CRC) has the highest incidence of new gastrointestinal cancers globally. CRC includes the colon and rectal cancers [2]. New CRC cases are 19.7 per 100,000 people globally and 12.9 in Iran [3]. In a review conducted in 2019, CRC was reported to be one of the most common cancers among Iranian men and women in the whole review investigation period (2004-2009) [4]. In 2020, CRC accounted for 10% (1.9 million cases) of global cancer incidence and 9.4% (0.9 million deaths) of cancer deaths. CRC is the third-most deadly cancer in both genders worldwide. The international number of new CRC cases, based on population growth, aging projection, and human development, is predicted to reach 3.2 million in 2040 [5].

Strategies of treatment for CRC vary according to the stage and type of cancer. Some treatment procedures include endoscopy for macroscopic intramucosal carcinoma, surgical lymph node dissection, laparoscopic surgery, palliative chemotherapy, radiotherapy, extensive surgery, and local ablative therapies for metastases [5,6].

In the meantime, CRC surgery is associated with many different complications that affect the efficacy of the surgery and patients' overall health and survival [6]. The most frequent postoperative surgical complications after colorectal resections are surgical site infection, anastomotic leakage, intra-abdominal abscess, ileus, and bleeding. These complications have different influences on the outcomes and have to be diagnosed accurately. Monitoring and standardization of postoperative care to minimize these complications are essential [7].

Most of these complications usually occur in the first week [8] to the first month [9] after surgery. Therefore, these patients need continuous care during this period. Due to the lack of specialized personnel and their high workload [10], on the one hand, and the high costs of health care for patients with cancer [11], on the other, the importance of technology-based intervention to monitor the condition of surgical patients after discharge is increasing.

In addition, the 5 most common factors in admitting patients with cancer to the intensive care unit include sepsis, respiratory failure, heart failure, cardiopulmonary resuscitation, and surgical complications [12]. Monitoring the patients could help early detection of these complications. Moreover, patient monitoring can give the physician a clear vision of the discharged patient's health status. If patients are not monitored and followed after discharge, different events may occur, including emergency conditions, unplanned readmission to the intensive care unit, unplanned resurgery, or specific complications such as infection [13].

Telemedicine services have become a powerful solution for providing health services. Studies show the impact of telemedicine services on time savings, patient transportation, and cost savings. The use of these technologies can satisfy patients and health care providers and facilitate their affairs [14]. Since it has been estimated that patients tend to use mobile apps in the postsurgery period [15], it is possible to create a platform to facilitate communication between the patient and the care team using mobile technologies [16], especially smartphones. Health care providers make decisions based on laboratory tests, reports, and self-reported data and according to the patient's symptoms [17]. So, mobile apps have been developed to monitor patients' postdischarge and recovery duration [17,18].

In this regard, similar previous studies were accomplished for remote care, self-management, and telemonitoring of patients with cancer after surgery by applying telephone calls, messaging systems, web portals, and mobile apps [19-21].

Also, more specific studies have been carried out for postoperative telemonitoring, education, and self-care in CRC [22-25]. For example, Keng et al [26] developed an integrated discharge monitoring system based on a mobile app to support patients at home after colorectal surgery. Their study included 106 participants, and 93 of them used the designed apps. Another study by Miller et al [22] developed a remote monitoring application to support and improve the care of patients with CRC for the first 30 postoperative days. Their study included 9 clinicians and 10 patients in phase 1 of their study, which was conducted to identify the views of patients and clinicians regarding the remote monitoring app. Phase 2, which included 15 clinicians and 8 patients, was conducted to evaluate the views and usability of a paper-based version of the app. Sun et al [23], in a pilot study, developed a wireless outcomes monitoring program for major abdominal cancer surgery. The study evaluated their system on 20 patients. In a recent study by Salmani et al [25], a smartphone-based app for the self-management of patients with CRC was developed. In another former study, Kim et al [24] developed and assessed a mobile web-based educational program for patients with CRC undergoing enhanced recovery after surgery. In their study, 59 colorectal patients were assigned to the treatment group that received mobile health intervention, and 59 patients were assigned to the conventional care group.

Despite the research conducted on remote monitoring apps for CRC survivors, there has still been a research gap in the development of a system for telemonitoring patients with CRC after surgery equipped with sensors that can collect the data on time and give the patients suitable messages based on the situation. These multiuser mobile-based monitoring systems could provide the ability to collect, analyze, and give proper feedback to both patients and health care providers simultaneously.

Due to the issues raised and the lack of electronic systems for remote monitoring of patients with CRC in Iran, there is a need to develop such a monitoring system. Therefore, the study's purpose is to design and evaluate a remote monitoring system for patients with CRC undergoing surgery.

Methods

Ethics Approval

The clinician experts evaluated the proposed software system for proof of concept; no patient data were used in this study. The Research Ethics Committees of the School of Public Health and Allied Medical Sciences, Tehran University of Medical Sciences approved the current research ethics with the approval ID IR.TUMS.SPH.REC.1399.270.

System Development

In the first step, the requirements of such a system were gathered from the literature and the opinions of experts. This step is explained in detail in our previous research [27]. After this step, a system architecture containing software and hardware was designed to fulfill the requirements. The software and hardware were developed based on the available technologies and tools.

Software Design

To design the software, use case diagrams are designed and evaluated for this system. After this step, the suitable tools to create the software systems were chosen, and the software was created. The REST (representational state transfer) architecture was used to develop the web service, and the PWA (progressive web application) approach was used to enable the software to run offline using cached data.

Due to the diversity of users' devices (Android [Google Inc]–based and iOS [Apple Inc]–based phones) for developing client-side software, the Ionic software development kit on the Angular framework was used to develop a mobile hybrid app. After the client-side programming (in Visual Studio Code v1.52 [Microsoft]), the outputs were generated as PWA and Android-based software. The output of the Java code was generated and then compiled by the Android Studio 4.1.1 Integrated Development Environment (IDE).

Hardware Design

Due to the need for hardware customization, hardware was designed and created. The hardware is designed to be a wristband with the capability of sensing the heartbeat and body temperature. For this purpose, photoplethysmography (PPG) sensors, temperature sensors, Internet of Things (IoT) modules, batteries, and display modules were selected among the available options. To select the appropriate PPG sensor, due to the elimination of ambient noise and higher accuracy requirements, MAX30101, a ready-made module, was selected. Next, an IoT module, the Wemos D1 mini development board (based on the ESP8266mod), was selected based on its appropriate capabilities and price. An MLX90614 infrared thermometer is used as the temperature sensor. Other components, such as the battery and the display, were chosen in the next step. After selecting the hardware modules, the hardware prototype circuit was created on a breadboard. The firmware was developed in Arduino and then finalized by designing and printing the circuit on a printed circuit board. A wristband enclosure for the board is designed in SolidWorks 2019 software (SolidWorks Corp) and printed using a 3D printer.

System Usability Evaluation

After creating the system, to perform usability evaluation, explanations of the system were provided to 4 experts (this number corresponds to the number of evaluators (3 to 5 people) proposed by Nielsen [28]) in a virtual session through Skype software (Skype Technologies, a division of Microsoft). By providing the username and password to log in to the system, they were asked to evaluate the system's usability by completing an online questionnaire. This questionnaire was designed based on Nielsen's 10 principles [29]. Finally, 4 experts evaluated the system.

Results

System Development

The set of eHealth system capabilities related to patients with CRC and survivors obtained from the categorization of requirements is given in Textbox 1.

Textbox 1. The set of eHealth system capabilities related to colorectal cancer patients and survivors.

Patient information registration

- Registration of patient social and demographic information
- Registration of the details of diagnosis and preoperative treatments
- Registration of surgical specifications and postoperative treatments

Periodic monitoring of health parameters

- Weight monitoring
- Side effects monitoring

Education

- Cancer information
- Common issues and problems for colorectal cancer patients and survivors
- Information about medication
- Information about chemotherapy
- Nutrition information
- Information about rehabilitation
- Information about the treatment process
- Informing about postdischarge care
- Information on pain management
- Information on emergency management

Reminders

- Reminders of hospital referrals
- Reminder for drug use
- Patient-tailored information

Assessments

- Quality of life assessment
- Nutrition status assessment
- Physician-patient relationship assessment

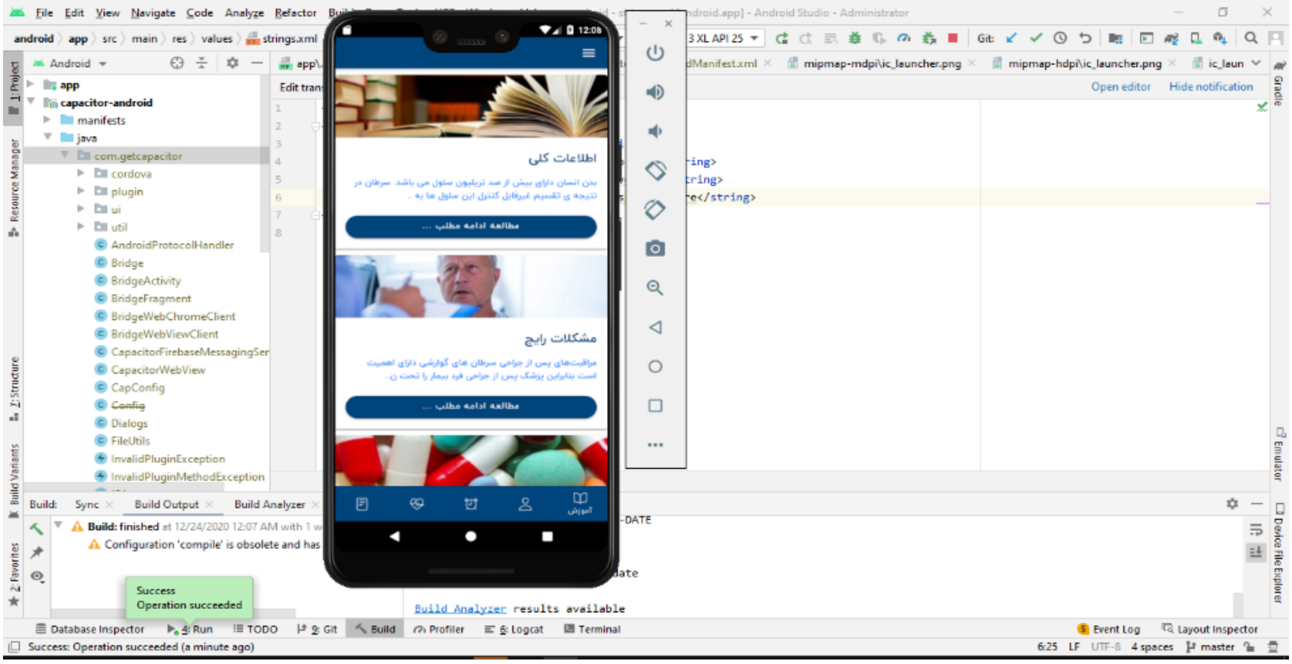
According to the expected capabilities of the system, the general architecture of the system consists of 3 software parts: client-side application, web service, and database. A hardware part containing a smart wristband has also been embedded in the architecture (Figure S1 in Multimedia Appendix 1).

Software Design

The Microsoft Visual Studio 2019 IDE and Microsoft SQL Server 2019 were used to develop server-side software (back end) and database, respectively. The web services were implemented with the ASP.NET Core framework (Microsoft). The Visual Studio Code v1.51.1 IDE was used to develop the client-side software (front end). As a mobile hybrid app, Ionic software development kit and Angular framework were used for software development.

The output of the Android-based app was created (Figure 1). The system data items were designed to be flexible so that the specialist could add the required data item to the system if not by default. The client-side app includes 3 panels for survivors, clinicians, and admin, as shown in Figure 2.

Figure 1. The “Behyar” Android app.



اطلاعات کلی

بدن انسان دارای بیش از صد تریلیون سلول می باشد. سرطان در نتیجه ی تقسیم غیرقابل کنترل این سلول ها به ..

مشکلات رایج

مراقبت‌های پس از جراحی سرطان های گوارشی دارای اهمیت است بنابراین پزشک پس از جراحی فرد بیمار را تحت ن..

```
Build: finished at 12/24/2020 12:07 AM with 1 w
Configuration 'compile' is obsolete and has
```

```
Build Analyzer results available
```

Success
Operation succeeded

Success: Operation succeeded (a minute ago)

Figure 2. Behyar app. (A) A page in the survivor panel for entering the side effect. The drop-down shown on top is for selecting the side effect. The slider shown with a fire icon is for choosing the intensity of that side effect, and the last input is for selecting the date and time of occurrence. (B) A page in the clinician panel to monitor the side effects of the survivor. The figure shows the intensity of appetite loss on multiple dates. (C) A page in the Admin panel for managing clinicians in the system. The page shows the information of 2 clinicians and a form for adding a new clinician to the system.

دکتر ۰۹۱۲۱۱۱۱۱۱۱ محمد شیرخدا

دکتر ۰۹۱۳۱۵۱۳۲۱۳ عباسعلی دهقان

Hardware Design

The hardware block diagram of the designed device is shown in Figure 3.

The MAX30101 PPG signal obtained from the wrist is shown in Figure 4A. The red, blue, and green colors show the PPG signals from RED, IR, and GREED LEDs, respectively. For smoothing the signal obtained from the MAX30101 module, the fast Fourier transform technique was used. The frequencies greater than 4 Hz and less than 0.5 Hz were filtered (Figure 4B).

Figure 3. Hardware block diagram of the wristband. PPG: photoplethysmography.

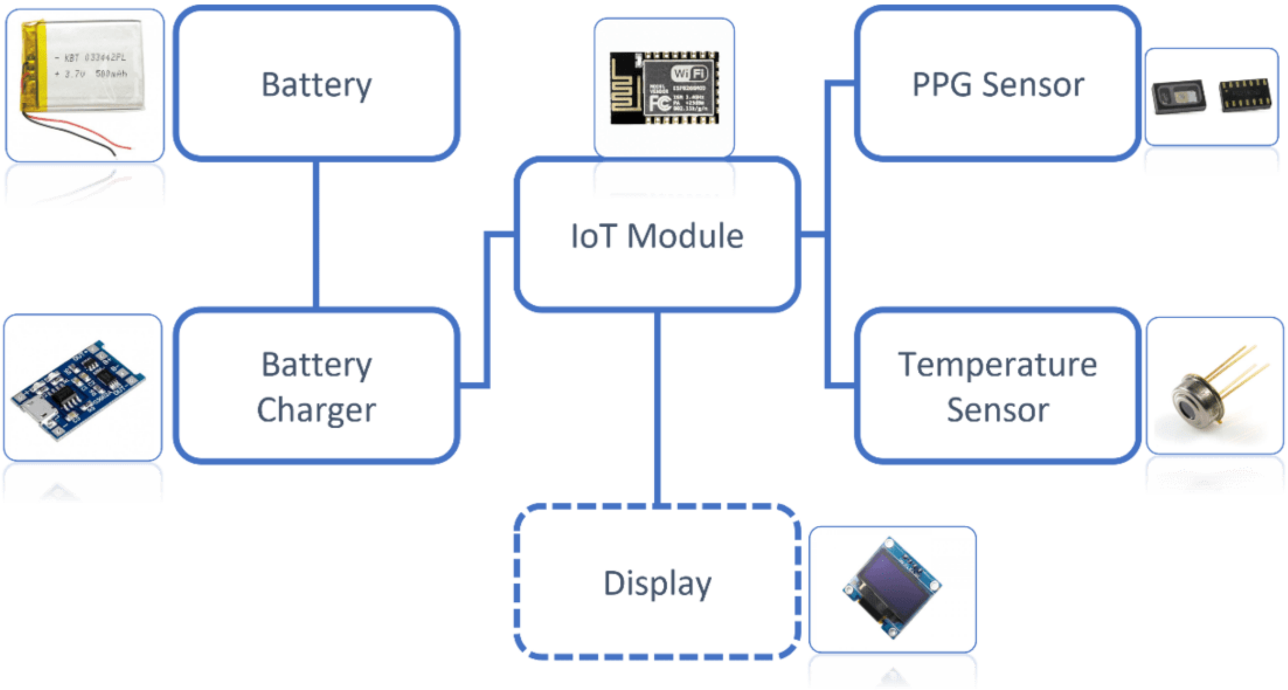
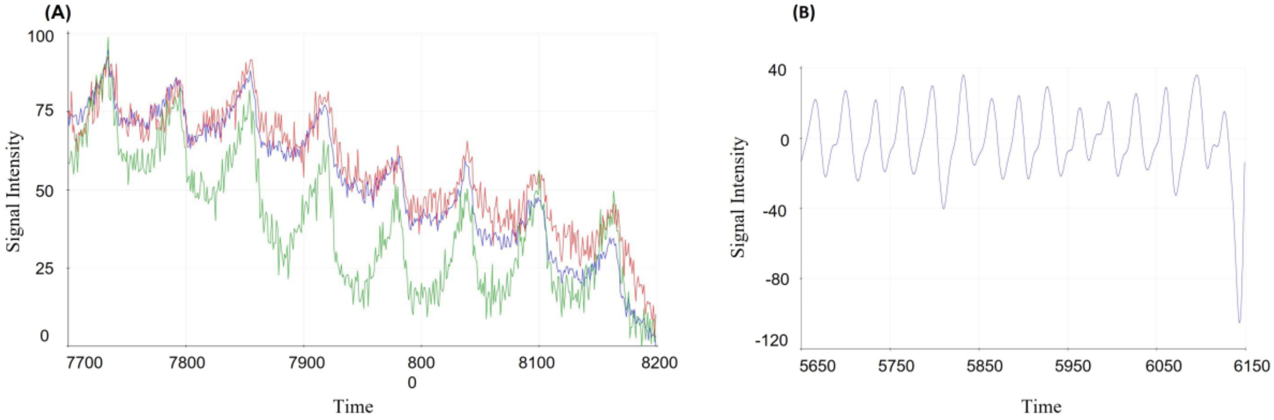


Figure 4. Photoplethysmography (PPG) signal retrieved from the MAX30101 PPG sensor. (A) Raw PPG signal from the wrist. (B) PPG signal after applying a filter.



The prototype of the circuit was developed with modules on the breadboard (Figure S2A in Multimedia Appendix 1), the firmware code was written in the Arduino IDE, and the firmware was uploaded to the Wemos D1 mini development board. The soldering of parts was performed on a printed circuit board (Figure S2B in Multimedia Appendix 1). The assembled hardware is shown in Figure S2C in Multimedia Appendix 1. The hardware's firmware was developed to have the capability of being upgraded remotely (FOTA: Firmware Over-The-Air).

The enclosure was designed to fit the dimensions of the circuit shown in Figure S3A in Multimedia Appendix 1. After the 3D design of the frame, the 3D prototype of the enclosure was printed. Finally, the wristband was created, as shown in Figure S3B in Multimedia Appendix 1.

The Arduino IDE was used for hardware programming. Altium Designer 2020 (Altium Limited) and SolidWorks 2019 were used for designing the printed circuit board and the frame, respectively.

System Usability Evaluation

The 4 male experts finally evaluated the current software of the system in terms of usability based on Nielsen's 10 principles. The experts included cancer surgeons, radiation oncologists, and blood and cancer subspecialists with a mean age of 45 years and an average of 12 years of clinical experience. According to the results presented in Table 1, this system generally gained an average score of 3.8 out of 5 in terms of usability.

Table 1. Result of system usability evaluation based on Nielsen’s 10 principles.

Items	Score 1	Score 2	Score 3	Score 4	Score 5	Average score
Visibility of system status (very confusing to very clear)	0	0	1	1	2	4.25
Match between the system and the real world (irrational to very logical)	0	1	2	1	0	3
User control and freedom (this is not possible to this is very convenient)	0	0	0	4	0	4
Consistency and standards (vague to clear)	0	0	1	3	0	3.75
Error prevention (never to always)	0	0	0	4	0	4
Recognition rather than recall (from inappropriate to appropriate)	0	1	0	0	3	4.25
Flexibility and efficiency of use (very inappropriate to very appropriate)	0	1	1	1	1	3.5
Aesthetic and minimalist design (very inappropriate to very appropriate)	0	0	1	1	2	4.25
Recognize, diagnose, and recover from errors (never to always)	0	1	0	2	1	3.75
Help and documentation (inadequate to appropriate)	0	1	1	2	0	3.25

Discussion

Principal Findings

In this study, the system for remote monitoring of patients undergoing surgery due to CRC was designed according to the identified priorities. The architecture was considered front end and back end separately for modular designing and creating multiple program versions to run on different platforms [30].

Based on the overall architecture of the system, suitable tools were applied to create the system. ASP.NET Core 3.1 was used because of its open-source, multiplatform capability, and flexibility in development. Security and access levels were defined based on the roles defined in the system and access tokens on the web service.

Client-side software was designed to be hybrid to run on different platforms. PWA and Android software have been used in various fields of health care [31-33]. Secure Sockets Layer protocol was installed on the webserver for communication security. Since the core of the current system’s software is designed as a web service, it is possible to integrate it with other software systems.

Off-the-shelf commercial wristbands with the ability to measure heart rate along with body temperature were not found in the Iranian market at a reasonable price. Thus, the wristband device is designed. The detection of the heartbeat was enabled on the hardware device by PPG technology. PPG technology is a noninvasive technology for measuring various indicators such as heart rate [34] and blood pressure [35]. It is used by a ready-made module (MAX30101) to eliminate noise and reach the signal with higher accuracy.

The findings show that green light has a better PPG signal than red and infrared light due to its greater penetration power in the wrist tissue. This is also mentioned by Fortino and Giampà [35]. The filter (fast Fourier transform algorithm) was used to remove noise, improving signal quality.

It is noteworthy that the price of the sensor selected to measure body temperature following the COVID-19 pandemic and the high demand for this sensor to measure body temperature were about 15 times the price increase, making it difficult to provide.

The use of IoT technologies to design system hardware was considered in this study. The whole system could be considered a Medical Internet of Things system. Medical Internet of Things refers to IoT applications in medicine [36]. The 4 IoT core modules were selected and evaluated for suitability. However, the modules that can communicate via General Packet Radio Services require minimal user intervention (there is no need for a pairing process). Due to the requirements of the electronic components for proper operation, especially in conditions with a weak signal antenna, these modules were not used. The ESP8266MOD module with Wi-Fi capability was selected. This module is suitable for connecting sensors and sending sensor data to the central server [37]. Other modules have also been used in studies. For example, in the study of Onubeze [38], the nRF51822 with the MAX30100 module was used to design a wireless heart rate monitor. IoT-based hardware can measure temperature and the PPG signal. This hardware can also be used to measure blood pressure and blood oxygen saturation [39]. If monitoring physical activity is a priority in other diseases, this feature can be added to the wristband by adding accelerometer and pedometer sensors. An intelligently integrated model of the health care system for cancer care is presented in the Onasanya and Elshakankiri study [40]. This model provides 4 layers of cancer care, hospital, data, and service layer, which are designed hardware that can be used in the cancer care layer.

In this study, the wristband enclosure was designed in SolidWorks software and printed using a 3D printer. Due to the high speed of preparation, 3D printing is recommended as a suitable method for making the prototype.

In this study, web software technologies and mobile apps were used. In similar studies, Mayer et al [41], Cheong et al [42], Keng et al [26], and Miller et al [22] used mobile and web applications were used. In the Maxwell-Smith et al [43] study, there is no reference to the technology applied in the system software.

Concerning the hardware presented in this study, the ability to measure heart rate and body temperature was considered. In the study of Miller et al [22], the health professionals for future apps proposed applying wearable outcome measures for detecting increased heart rate and temperature as the key measures that would be helpful in clinical assessments and remote monitoring of CRC surgery.

In other studies related to the monitoring of patients with cancer, for example, Maxwell-Smith et al [43] and Jonker et al [21] applied a commercially available wearable activity monitor (Fitbit) to monitor physical activity, and in another study by Cheong et al [42], hardware was used to monitor physical activity and heart rate. In Sun et al’s [23] study, commercially available wristband pedometers were used to capture data on daily steps for functional recovery monitoring after major abdominal cancer surgery.

In general, based on the advantages expressed in most studies [21,23,44], novel approaches and technology-based solutions to postoperative assessment based on subjective and objective measures and timely intervention in the surgical oncology setting are beneficial. This could improve long-term outcomes and facilitate providing health services. So the development and evaluation of these systems for various cancer surgeries are recommended.

Strength and Limitations

The system designed in this research was the first monitoring system designed for CRC survivors in Iran, which could be assumed as the strength of this research.

A major limitation of this study was the initial evaluation of the software’s usability. The evaluation of the proposed system should be performed in multiple aspects with the involvement of more experts and patients. Due to the resource limitations in this study, we decided to limit the study’s scope in the initial usability evaluation. Another limitation is the availability of hardware sensors and modules in the Iranian market, which limits the choice of sensors in the hardware design.

Conclusions

The results showed that the use of a mobile health app could be used to monitor CRC patients. By including features such as the possibility of changing information items by the expert, the system can be provided with the necessary flexibility in different conditions. Additionally, creating hardware for monitoring vital signs along with system software in terms of creating customization capabilities can help obtain quantitative and qualitative data from patients and survivors to possibly provide better care. From the specialists’ perspective, user interface evaluation of monitoring systems for surgical patients with CRC can achieve an acceptable score. To better understand the usefulness of such systems, in addition to evaluating the user interface, continuous surveys of the system’s effects on indicators such as patients’ quality of life, improving their complications, their nutritional status, and their satisfaction with using the system should be considered.

Acknowledgments

This work was supported by the Tehran University of Medical Sciences (Grant number 26299).

Data Availability

The data sets generated and analyzed during this study are available from the corresponding author upon reasonable request.

Authors' Contributions

MS, SRNK, and SMA contributed to the study conception and design. Material preparation and analysis were performed by SMA. System evaluation was done by KR, RG, FM, and AJ. The first draft of the manuscript was written by SMA. TB contributed to organizing and writing the final version of the manuscript, and NM was the advisor of the project. SRNK and MS supervised the project, and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
The system architecture and hardware.
[PDF File (Adobe PDF File), 640 KB - cancer_v9i1e42250_app1.pdf]

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Abbreviations

CRC: colorectal cancer
IDE: Integrated Development Environment
IoT: Internet of Things
PPG: photoplethysmography
PWA: progressive web application

Edited by A Mavragani; submitted 29.08.22; peer-reviewed by J Agnew, M Kapsetaki, X He; comments to author 27.09.22; revised version received 12.10.22; accepted 31.10.22; published 15.02.23.

Please cite as:
Ayyoubzadeh SM, Baniasadi T, Shirkhoda M, Rostam Niakan Kalhori S, Mohammadzadeh N, Roudini K, Ghalehtaki R, Memari F, Jalaeefar A
Remote Monitoring of Colorectal Cancer Survivors Using a Smartphone App and Internet of Things–Based Device: Development and Usability Study
JMIR Cancer 2023;9:e42250
URL: https://cancer.jmir.org/2023/1/e42250
doi:10.2196/42250
PMID:36790851

Original Paper

The Patient Experience of Acute Lymphoblastic Leukemia and Its Treatment: Social Media Review

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Related Article:

This is a corrected version. See correction statement: https://cancer.jmir.org/2023/1/e54665

Abstract

Background: Adult patients with acute lymphoblastic leukemia (ALL) report substantial disease- and treatment-related impacts on their health-related quality of life (HRQOL). Patient-reported information (PRI) shared on social media may provide a distinct opportunity to understand the patient experience outside of formal research contexts and help inform the development of novel therapies.

Objective: This qualitative social media review aimed to assess PRI shared on social media websites to gain a better understanding of the symptom, HRQOL, and treatment impacts on individuals with ALL.

Methods: We identified English-language posts on 3 patient advocacy websites (Patient Power, The Patient Story, and Leukaemia Care) and YouTube that included PRI about experiences with ALL or ALL treatments shared by adults (aged ≥18 years) with a self-reported ALL diagnosis. Patients' demographic and disease characteristics were extracted from posts (where available), and the posts were analyzed thematically. A network analysis was conducted to delineate possible associations among ALL symptoms, HRQOL impacts, and treatment-related symptoms and impacts.

Results: Of the 935 social media posts identified, 63 (7%) met the review criteria, including 40 (63%) videos, 5 (8%) comments posted in response to videos, and 18 (29%) blog posts. The 63 posts were contributed by 41 patients comprised of 21 (51%) males, 18 females (44%), and 2 (5%) whose gender was not reported. Among the patients, 13 (32%) contributed >1 source of data. Fatigue (n=20, 49%), shortness of breath (n=13, 32%), and bruising (n=12, 29%) were the symptoms prior to treatment most frequently discussed by patients. Patients also reported impacts on personal relationships (n=26, 63%), psychological and emotional well-being (n=25, 61%), and work (n=16, 39%). Although inpatient treatment reportedly restricted patients' independence and social functioning, it also provided a few patients with a sense of safety. Patients frequently relied on their doctors to drive their treatment decisions but were also influenced by family members. The network analysis indicated that disease-related symptoms were primarily associated with patients' physical functioning, activities of daily living, and ability to work, while treatment-related symptoms were primarily associated with emotional well-being.

Conclusions: This social media review explored PRI through a thematic analysis of patient-contributed content on patient advocacy websites and YouTube to identify and contextualize emergent themes in patient experiences with ALL and its treatments. To our knowledge, this is the first study to leverage this novel tool to generate new insights into patients' experiences with ALL. Patients' social media posts suggest that inpatient care for ALL is associated with restricted independence and social functioning.

However, inpatient care also provided a sense of safety for some patients. Studies such as this one that capture patients' experiences in their own words are valuable tools to further our knowledge of patient outcomes with ALL.

(JMIR Cancer 2023;9:e39852) doi:10.2196/39852

KEYWORDS

acute lymphoblastic leukemia; health-related quality of life; qualitative research; social media; leukemia; lymphoblastic; adult; disease; treatment; therapy; symptoms; independence; functioning; social; well-being; emotional

Introduction

Acute lymphoblastic leukemia (ALL) is an aggressive cancer of the blood and bone marrow that rapidly progresses and affects immature blood cells rather than mature ones [1]. ALL is the most common childhood cancer (ie, in patients under 18 years of age, the median age of diagnosis is 15 years), but it also accounts for approximately 20% of adult leukemias [2,3]. Childhood ALL has a cure rate as high as 90%, but the cure rate for adults is substantially lower, ranging from 20% to 40% [1,3,4].

Along with a poor prognosis, patients with ALL experience a significant symptom burden that impacts their physical, social, and emotional functioning [5,6]. This symptom burden is often compounded by significant chemotherapy-associated toxicity as well as frequent and extended hospital stays [1,4,7]. As novel therapies for adult ALL are developed and their uptake increases, a greater insight into patients' experiences with ALL and the impact of ALL symptoms and treatments on patients' health-related quality of life (HRQOL) is needed.

Patient-reported information (PRI) uploaded to social media websites provides a rich source of unsolicited data to facilitate a better understanding of how patients experience a disease and its treatment outside of the formal research context [8]. PRI data include information shared on social media as either single micronarratives (eg, video logs) or interactive micronarratives generated as part of discussions with other patients, caregivers, or stakeholders (eg, chat room discussions [8]). Both the US Food and Drug Administration and European Medicines Agency encourage the exploration of social media as a tool to better understand patient perspectives on disease symptoms and impacts [9,10].

Accordingly, this social media review explored PRI through a thematic analysis of patient-contributed content on patient advocacy websites and YouTube to identify and contextualize emergent themes in patient experiences with ALL and its treatments. To our knowledge, this is the first study to leverage this novel tool to generate new insights into patients' experiences with ALL.

Methods

Search Strategy and Data Sources

The social media review was conducted in October 2020. A pragmatic Google search was performed by experienced qualitative researchers (authors RC, RM, and HC) to identify patient advocacy websites that hosted patient-contributed content. Google's advanced search function was used to identify webpages that included any of the following key search terms: "acute lymphoblastic leukemia," "acute lymphoblastic leukaemia," "patient narratives," "patient stories," "patient advocacy," and "patient organization." The results were then reviewed to identify websites that might contain PRI describing the patient experience of ALL and its treatment, including patient ALL organization websites. PRI was defined as information reported by patients (or caregivers) relating to their experience of disease and its treatment outside a formal research context [8]. The contents of the websites were reviewed to ascertain whether they contained relevant PRI, and websites without relevant PRI were excluded from the review. The Research Triangle Institute (RTI) Health Solutions staff who reviewed the website content were both male and female researchers who had experience with qualitative research methods.

Five relevant websites were identified: Cure Today, Patient Power, Patients Rising, The Patient Story, and Leukaemia Care [11-15]. These patient advocacy websites provide information and support for people affected by cancer and include interviews conducted with patients, caregivers, and patient advocates that focus on specific cancers and treatments. Therefore, these websites were considered to contain the relevant PRI for data collection. Of the 5 websites, 3 (60%) contained PRI related to the patient experience of ALL and ALL treatments (Patient Power, The Patient Story, and Leukaemia Care). Permission was sought from the websites to use their content for this study. A YouTube search using similar search terms as the Google search for identifying websites was also conducted to identify additional ALL-related PRI. YouTube is a global online platform where registered users can easily upload and share videos. Videos uploaded with "public" privacy settings, which can be viewed by any internet user, were the focus of this search.

The review of the patient advocacy websites and YouTube targeted PRI uploaded by social media contributors with a self-reported diagnosis of ALL who discussed their experience with ALL and/or its treatment. Posts were considered eligible for inclusion if they were shared by adults (≥18 years of age) with a self-reported ALL diagnosis, if the adult patient contributed the PRI themselves and not by a proxy (eg, caregiver, physician, or relative), if the post was in English, and if the content was relevant to the patient experience of ALL and/or its treatment. All video footage and blog posts were manually reviewed by RTI-trained researchers to determine eligibility for inclusion in the review. Specifically, 2 RTI researchers reviewed the blogs/posts and created a data record that included search terms, date of search, and the number of views. They also noted the PRI associated with symptoms, HRQOL impacts, and demographics. Blog posts were excluded if they did not meet the following inclusion criteria: not specific to the target disease (ie, ALL), adult patient–focused, written in English, and patient report.

Data Extraction and Analysis

Patient Characteristics

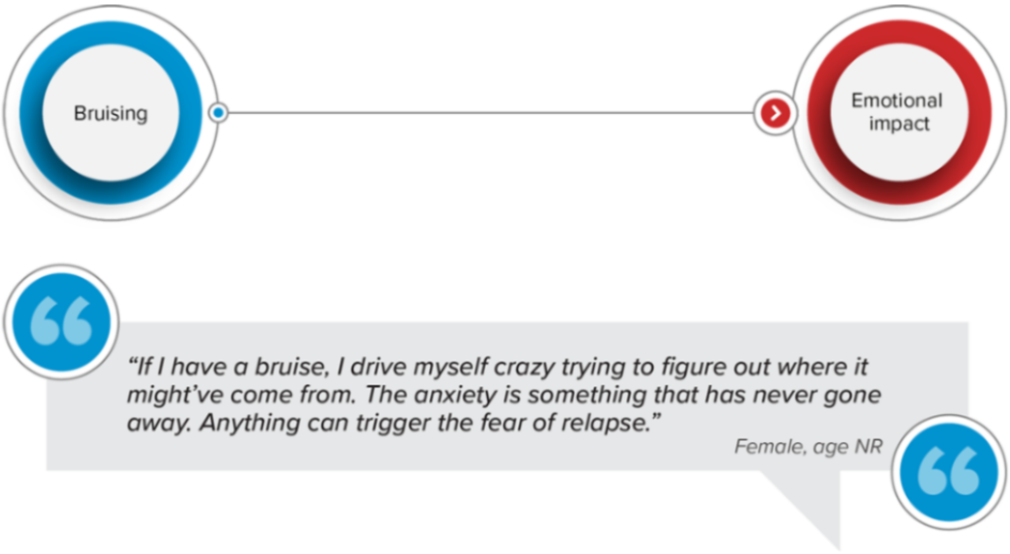
Patients' demographic information (ie, age and sex) and disease characteristics were extracted from social media posts and were assumed to represent their characteristics at the time they uploaded the post. The posts were transcribed, and key data from the posts were extracted into a data record by 1 of the 3 RTI Health Solutions researchers (authors HC, RM, and RC). Since PRI exists outside of the traditional research context, key demographic and disease characteristics were not always available. Where possible, the demographic data available in posts were cross-checked with the patient's username/handle on the same website, their profile associated with the post, or a photograph of themselves that they uploaded to the website. The number of distinct social media posts that each patient contributed was recorded, as well as key parameters for video data, such as upload date, video duration, and type of video publisher/poster (eg, independent patient, medical organization, or pharmaceutical company). Individual posts were cross-checked, when possible, to identify whether the same patient had contributed to more than 1 social media post (eg, if they contributed to both a blog post and a video).

Thematic Analysis

A thematic analysis of the aggregated PRI data extracted from the social media posts was conducted. In this type of analysis, a theme is described as content that captures data relevant to the research question and appears as a patterned response [16]. Specifically, relevant sections from the blog/posts were transcribed, and key themes such as symptoms and HRQOL impact (ie, physical, emotional, relationships, social life, activities of daily living, and work) related to the patient experience of ALL and themes related to treatment, such as treatment history, current treatment, treatment expectations, preference, side effects, impact, time spent receiving treatment, and decision-making, were identified and summarized with quotes. All data were coded by 1 of the 3 RTI researchers (authors HC, RC, and RM) into the key theme categories of symptom, HRQOL, and treatment impacts.

A network analysis was also conducted to identify potential associations between ALL symptoms, HRQOL impacts, and treatment-related symptoms and impacts. The analysis was informed by the network approach to psychopathology, which conceptualizes mental disorders as a network of interacting symptoms [17]. In the analysis, nodes represented distinct ALL symptoms, HRQOL impacts, and treatment-related symptoms and impacts. Edges represented patient-indicated associations between 2 concepts. The edges were directional to indicate sequential associations (eg, frequent bruising preceded anxiety). To illustrate an example (Figure 1), the nodes for ALL symptoms represent 1 theme, the HRQOL impacts nodes represent a second theme, and the edges that connect the 2 themes demonstrate how they could be related or associated based on patient-reported experiences with ALL.

Figure 1. Example of network analysis relationship. NR: not reported.



Ethical Considerations

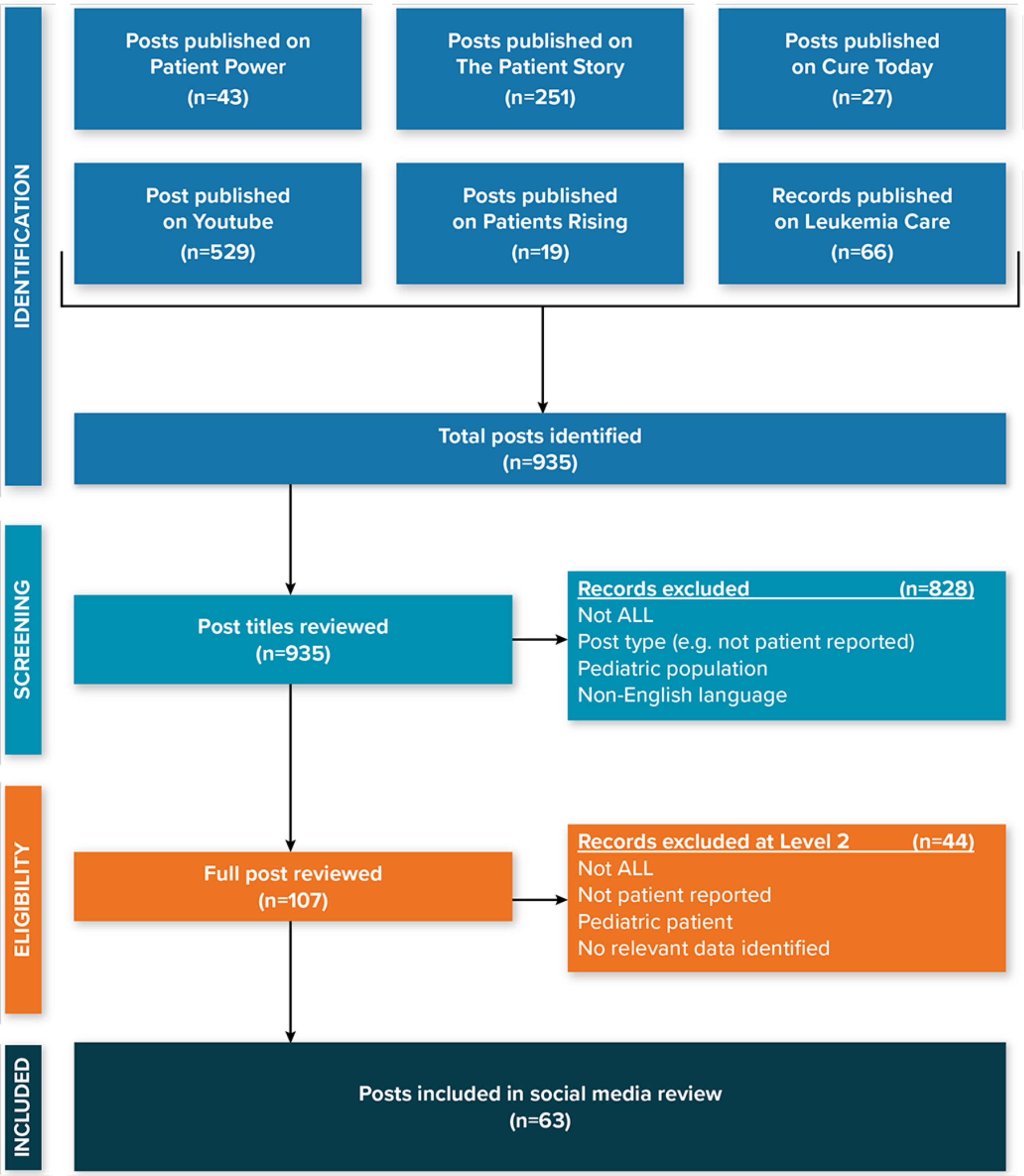
The RTI International Institutional Review Board determined that this study did not constitute research with human participants (STUDY00021294). The contributor quotes used to illustrate the key findings from the social media review are deidentified to maintain contributor confidentiality. No relationship existed between the researchers and the patients prior to conducting this study.

Results

Social Media Posts

A total of 935 social media posts were identified and assessed in terms of the prespecified review criteria. Of the 935 posts, 63 (7%) were included in the final review from Leukemia Care (n=12, 19%), The Patient Story (n=6, 10%), Patient Power (n=4, 6%), and YouTube (n=41, 65%) (Figure 2, Multimedia Appendix 1). The 63 posts included 40 videos totaling 6 hours, 5 minutes, and 27 seconds of footage (mean 9 minutes, 8 seconds; range, 58 seconds to 1 hour, 14 minutes, and 12 seconds); 5 comments posted by patients on 3 of the videos; and 18 blog posts. The posts were uploaded between 2014 and 2020, with most (n=55, 87%) uploaded in 2018 or later.

Figure 2. Social media post identification flowchart. ALL: acute lymphoblastic leukemia.



Patient Characteristics

The 63 social media posts included PRI from 41 individual patients. Table 1 provides the sample characteristics (gender, age range, and country or origin of the contributor post). Among the 41 patients, 13 (32%) contributed to more than 1 post. Most (n=34, 83%) of the patients were identified as located in either the United States (n=19, 46%) or the United Kingdom (n=15, 37%). The remaining 7 patients included 3 patients located in Australia (n=1, 2%), Canada (n=1, 2%), and South Africa (n=1, 2%) and 4 (10%) whose locations were indeterminable based on the available data (all 4 provided comments on YouTube videos). Identities were cross-checked against other content the patients had uploaded to the same website (ie, username/handle, profile, or photograph) for all but 3 patients (7%) who posted relevant PRI as comments on YouTube videos. Approximately half (n=21, 51%) of the patients were male, and 2 (5%) did not report their gender. Age was available for 26 (63%) of the 41 individual patients and ranged from 19 to 59 years.

Table 1. Summary of social media contributor sample characteristics[a].

Contributor characteristics	Value, n (%)
Gender	
Male	21 (51)
Female	18 (44)
Not reported	2 (5)
Age (years) at SM[b] post	
18 to <30	13 (32)
30 to <40	11 (27)
40 to <50	1 (2)
≥50	1 (2)
Not reported	15 (37)
Country of origin	
United States	19 (46)
United Kingdom	15 (37)
Australia	1 (2)
Canada	1 (2)
South Africa	1 (2)
Not reported	4 (10)

[a] Percentages are based on nonmissing data.

[b] SM: social media.

Patient Symptom Experience and Impacts on HRQOL

Patients generally commented on the ALL symptoms they experienced before their initial diagnosis. They most frequently discussed fatigue (n=20, 49%), shortness of breath (n=13, 32%), and bruising (n=12, 29%) in their social media posts. Their symptoms impacted their physical functioning, such as difficulty climbing stairs or walking up an incline (n=5, 12%), getting out of bed (n=4, 10%), and walking short distances (n=3, 7%). Patients' symptoms also interfered with their ability to live a normal life. Nearly half (n=16, 39%) of the patients reported impacts on their ability to work, and many (n=11, 27%) reported impacts on their usual daily activities, including difficulty with basic self-care (n=4, 10%), daily tasks such as chores and shopping (n=9, 22%), and hobbies and leisure activities (n=3, 7%). Two (5%) patients also noted limitations on their social functioning, such as having to practice social distancing at public venues (n=1, 2%) and missing social occasions (n=1, 2%).

Over half (n=26, 63%) of the patients reported a change in their relationships as a result of their ALL. For some (n=5, 12%) patients, their relationships reportedly improved and were strengthened by coping with their ALL symptoms. For others (n=2, 10%), their ALL symptoms were associated with a deterioration in their relationships. They lost touch with friends, and their relationships with their partners changed. For example, 1 patient described how she felt her ALL symptoms changed her relationship with her husband:

> *I felt like he was more my caregiver than my husband.* [Female, age not reported]

Over half (n=25, 61%) of the patients reported that their ALL had a deleterious impact on their psychological and emotional well-being. Patients reported a range of emotional and psychological impacts, including low mood (n=3, 7%), anxiety at the prospect of relapse (n=4, 10%), and loneliness (n=2, 5%).

Moreover, 2 (5%) patients described feeling betrayed by their body:

> *I felt a deep anger towards my own body; I felt betrayed by it.* [Female, 27 years]

Several also expressed fears about the future, such as mortality (n=4, 10%) and uncertainty about their ongoing disease (n=2, 10%). As 1 patient explained,

> *Not knowing at all what my life would look like was traumatizing for me.* [Male, 33 years]

Patient Treatment Experience

Patients experienced a range of treatments for ALL, with nearly half (n=20, 49%) reporting experience with multiple types of treatment (Table 2). Fatigue (n=11, 27%), hair loss (n=11, 27%), and nausea (n=9, 22%) were the most frequently reported treatment-related side effects. These treatment side effects were reportedly often long lasting and had a negative impact on the patients' physical functioning, including eating (n=4, 10%), fine motor skills (n=1, 2%), activities of daily living such as showering (n=1, 2%), and future reproductive abilities (n=1, 2%). These issues had a negative impact on the patients' psychological well-being.

Table 2. Self-reported experience with acute lymphoblastic leukemia (ALL) treatment.

Treatment type	Self-reported experience, n (%)
Chemotherapy	31 (76)
Bone marrow transplant/stem cell transplant	16 (39)
Radiation therapy	5 (12)
Immunotherapy	4 (10)
Steroid treatment	4 (10)
Blood transfusion	1 (2)
Umbilical cord blood transplant	1 (2)

As 1 patient reported,

> *One night, um, my neuropathy and my hands were so bad and one of my…one of my kids wanted a peanut butter and jelly sandwich and to take the twist tie off the bread hurt so bad because my neuropathy was so bad, and I just broke down in the kitchen.* [Female, 30 years]

Furthermore, another patient concluded that the treatment for ALL was worse than the cancer itself:

> *The treatment made me feel worse than the cancer ever did. Eventually, I ended up fainting from exhaustion whilst attempting to shower.* [Female, 27 years]

Overall, three key themes emerged from the analysis of patients' social media posts related to their treatment experience: (1) perceptions of inpatient treatment, (2) treatment expectations and preferences, and (3) treatment decision-making.

Perceptions of Inpatient Treatment

Over a quarter (n=11, 27%) of patients reported their perceptions of inpatient treatment. Several (n=4, 10%) patients commented that inpatient treatment restricted their freedoms and independence. For example, 1 patient explained that when given the option, he chose to leave the hospital:

> *It was a situation where I could've stayed in the hospital, but I just want[ed] to be a little more independent and do things on my own. I much preferred that.* [Male, 36 years]

Some (n=4, 10%) patients also commented on how inpatient treatment impeded their social functioning:

> *I felt like I had lost total control of everything, not being able to see my family, friends, have fun. Nothing was normal anymore; the hospital became my new home.* [Male, 34 years]

The restrictive requirements of inpatient care were also a source of anxiety for 1 (2%) patient who was concerned about her ability to care for her children:

> *You can't keep me here [the hospital], I just got here, I have no clothes, no toiletry bags, I didn't get to say bye to my kids, I didn't kiss them, who's going to watch my kids?* [Female, 30 years]

In contrast to the negative patient perceptions of inpatient care, some (n=4, 10%) patients also highlighted the perceived benefits of inpatient treatment, such as its sense of safety. One patient reported that he felt afraid when leaving the hospital after a 6-week stay:

> *After 6 weeks in hospital, I could go home. I cried a bit at this point, as I was scared to leave the safety of the hospital.* [Male, age not reported]

Another patient expressed anxiety about losing the regularity of care provided in an inpatient setting:

> *If my consultant tells me he'll see me again in 2 or 3 weeks, my first emotion is always disappointment, followed by apprehension at the prospect of going so long without a check-up.* [Female, 27 years]

One patient also appreciated having his treatment adherence controlled by the hospital staff:

> *When you're in the hospital you don't have to worry about anything like that [treatment adherence]. There's going to be nurses that are going to be coming in…You pretty much do whatever they tell you to do.* [Male, 36 years]

Treatment Expectations and Preferences

Over one-third (n=15, 37%) of patients discussed their treatment expectations and preferences in their social media posts. Patients reported that they often anticipated treatment side effects (n=4, 10%) but that the side effects were not always as severe as they expected (n=3, 7%). For example, 1 patient explained:

> *I want to tell leukemia and lymphoma patients to not be so afraid of transplant. I was super afraid.* [Female, 29 years]

Another patient described how his excitement about the potential positive outcome from a bone marrow transplant outweighed his concerns about the treatment burden:

> *I heard so many stories about having a [bone marrow] transplant, so I was excited to start the newest journey of my life, to get better, to be rid of ALL. It was a hard road ahead, but I had every faith.* [Male, 34 years]

In general, patients preferred treatments with minimal impact on their HRQOL. One patient preferred immunotherapy for this reason:

> *The beauty of immunotherapy is how little it affects your quality of life. Although side effects are possible, mine were minimal. [Male, 23 years]*

Another patient explained his desire for a treatment that allowed for an independent lifestyle:

> *I know that I'm getting treated, but at the same time, I have the freedom to coach my kids every day, to go about life, be able to drive my own car, and to go to work and be able to not have to have hospital food.* [Male, 59 years]

In contrast, 1 patient described the inevitable pain associated with chemotherapy:

> *[Intrathecal chemotherapy] was painful. That hurt. There's nothing you can really do for it.* [Female, 30 years]

Treatment Decision-making

Several (n=9, 22%) patients described their decision-making process in their social media posts. Of these patients, the majority (n=7, 78%) reported that their doctors drove their treatment decisions. As 1 patient explained,

> *Although things were always explained to us and I had to sign consent for treatments, I wasn't really taking it in or paying real attention. I was just going along with it.* [Female, age not reported]

Another patient described his shock at the diagnosis and how this impacted his decision-making:

> *I was a little bit, um, obviously shocked because I didn't know anything about leukemia…[I] didn't know anything about chemotherapy or treatment, just sort of believed what the doctor told me.* [Male, age not reported]

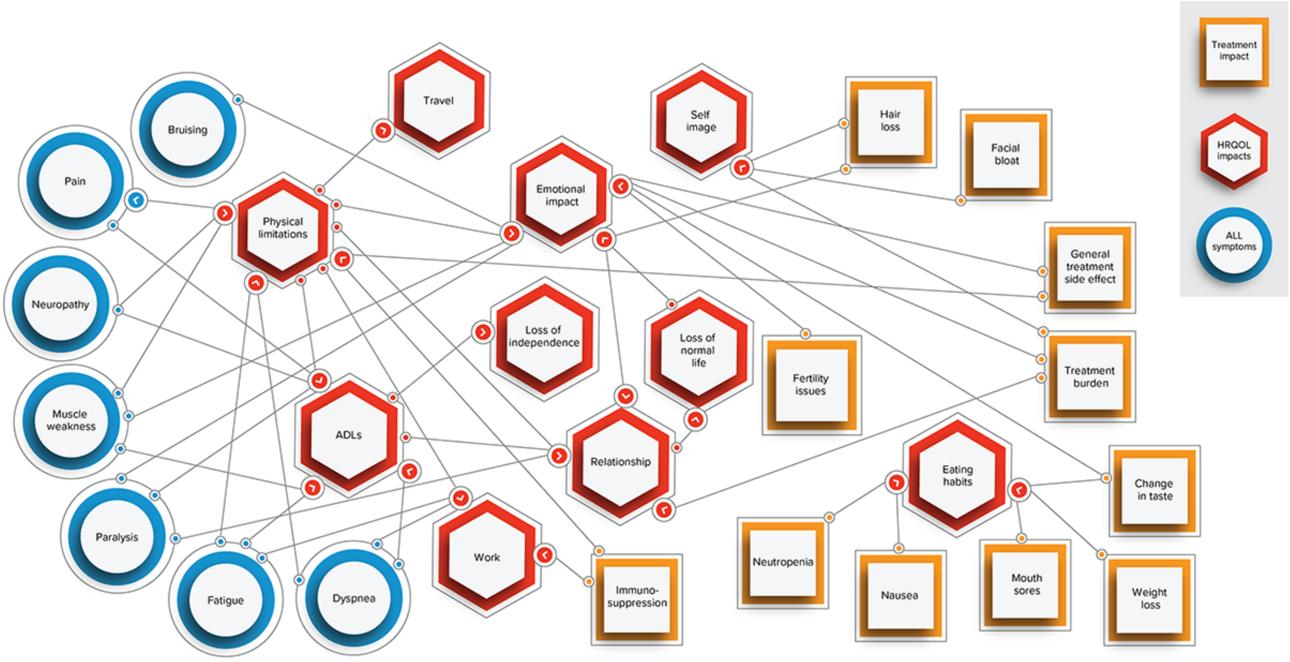
However, a few (n=3, 7%) patients reported that their treatment decisions were also influenced by their parents:

> *She [mother] was also the one that was head honcho in all the research. She looked up everything. She looked up scientific studies on everything that was happening and all the treatments I was on.* [Male, 23 years]

Network Analysis

Distinct associations among ALL symptoms, HRQOL impacts, and treatment-related symptoms and impacts were identified in the network analysis (Figure 3). ALL symptoms primarily affected patients' physical functioning, activities of daily living, and ability to work. In contrast, treatment-related symptoms and impacts primarily affected patients' emotional well-being. A cluster of treatment side effects (ie, neutropenia, change in taste, nausea, and mouth sores) was associated with changes in patients' eating habits, which were in turn associated with weight loss. Three instances of this relationship were attributed to chemotherapy, while 1 instance was associated with a stem cell transplant. Physical limitations played the most central role in the HRQOL component of the network, impacting other aspects of patients' HRQOL (ie, activities of daily living, work, travel, emotional well-being, and relationships).

Figure 3. Acute lymphoblastic leukemia concept network. Concepts are connected based on patient-reported experiences. For example, bruising is connected to emotional impact based on the following quote: "If I have a bruise, I drive myself crazy trying to figure out where it might've come from. The anxiety is something that has never gone away. Anything can trigger the fear of relapse." (Female, age not reported). ADL: activity of daily living; ALL: acute lymphoblastic leukemia; HRQOL: health-related quality of life.



Discussion

Principal Findings

This social media review explored PRI through a thematic analysis of patient-contributed content on patient advocacy websites and YouTube to identify and contextualize emergent themes in patient experiences with ALL and its treatments. To our knowledge, this is the first study to leverage social media websites to generate new insights into patients' experiences with ALL. A network analysis of PRI also provided a distinct view of the connections among patients' experiences with ALL symptoms, HRQOL impacts, and treatment-related symptoms and impacts. In our qualitative network analysis of patient-indicated associations among ALL symptoms, HRQOL impacts, and treatment-related symptoms and impacts, we found that ALL symptoms primarily affected patients' physical functioning, activities of daily living, and ability to work, while treatment-related symptoms and impacts primarily affected patients' emotional well-being. Overall, patients' social media posts detailed the substantial HRQOL impacts they experienced due to their ALL symptoms and treatment side effects.

While studies of HRQOL among adult patients with ALL are limited, the substantial impacts of ALL on patients' social, emotional, and physical functioning identified in this social media review are consistent with prior findings [5,6,18]. For example, Kantarjian et al [6] measured baseline symptom burden and functional impairment in patients with ALL using the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core Module (EORTC QLQ-C30) and found that fatigue, insomnia, pain, appetite loss, and dyspnea had the highest mean symptom scores (ie, worst symptom experience). In addition, a study evaluating HRQOL among adult ALL survivors found that pain and fatigue were the most commonly reported symptoms, and these symptoms were inversely correlated with social, cognitive, emotional, and physical function scores on the EORTC QLQ-C30 [18]. Similarly, our study found that patients frequently described experiencing ALL-related fatigue, difficulty breathing, and bruising in their social media posts. Patients also commented on their need for help from caregivers and how this impacted their relationships with their family members. These issues were identified in a recent review of peer-reviewed literature focused on the needs of family caregivers in the context of both adult and pediatric leukemia [19]. Given the complex care needs of adult patients with ALL and the substantial impacts on their HRQOL, there is an increasing focus on the need to balance treatment goals between achieving remission and maintaining or improving HRQOL [20]. Our findings further demonstrate this need for balance in the development of adult ALL therapies.

Three key themes emerged from our analysis of PRI about the treatment-related impacts of ALL: (1) patients' perceptions of inpatient treatment, (2) their treatment expectations and preferences, and (3) their treatment decision-making. Most patients who commented on inpatient treatment felt that it restricted their independence and social functioning. Treatment-related hospitalization is common in adult ALL [21]. Therefore, it is important to understand how frequent inpatient stays impact patients' HRQOL. For instance, patients' social media posts demonstrated how extended hospital stays were particularly challenging for patients with children or grandchildren who relied on them for care. Interestingly, a few patients commented on the perceived benefits of inpatient treatment, noting that hospital routines and monitoring reassured them that they were receiving the necessary care.

As expected, patients who commented on their treatment preferences preferred treatments with minimal HRQOL impact. They expressed enthusiasm for treatments such as bone marrow transplant and immunotherapy, but they also commented on the inevitable pain of chemotherapy. When making treatment decisions, patients commented that they primarily deferred decision-making to their doctors. Their choice to defer treatment decisions to their doctor may have been influenced by their cognitive state (eg, shock, denial) at the time of diagnosis. For some patients, treatment decisions were also influenced by their parents, further highlighting the complex role of caregivers of adults living with ALL [19]. These 3 themes demonstrate the varied ways in which ALL treatments impact patients' HRQOL and further highlight the need to minimize these impacts when developing ALL therapies.

Our analysis also showed that physical limitations were most central in the HRQOL component of the network, and they impacted patients' ability to work, their relationships, and their emotional well-being. Elucidating the links among disease-related symptoms, treatment-related symptoms, and HRQOL impacts is critical to informing how clinicians treat patients, as illustrated by Wilson's [22] conceptual model of the relationship between HRQOL and patient-reported outcome measures. Their model highlights the impact of symptoms, social context, and individual characteristics on functional status, which can then have downstream effects on the overall quality of life [22]. Therefore, our findings support the importance of minimizing the treatment burden for adult patients with ALL, as such treatment-related symptoms may have an additive effect alongside ALL-related symptoms that substantially impact patients' HRQOL.

Limitations

This social media review had several limitations worth noting. Social media data exist outside of the formal research context and are unregulated, so there is an inherent reliance on patient self-identification and self-report. There is also a risk of self-selection and publication bias. Patients who have a positive mindset may be more likely to submit their stories, and patient advocacy websites may be more likely to post inspirational content. There is also limited availability of patient demographic and clinical characteristics when relying on social media data. For example, age was not available for all patients included in the study, which limits our ability to identify potential age-related aspects of patients' ALL experiences. Age may have been a key factor in determining how aggressive patients' ALL treatment was since younger patients tend to receive more aggressive treatment than older patients. The social media data also lacked information on the stage of patients' treatment journeys at the time of their post (eg, whether they were undergoing first-line treatment) as well as detailed information about other key clinical characteristics (eg, their Eastern Cooperative Oncology Group performance status). This is a new and growing field that requires strict adherence to terms and conditions for host websites, which can impact the type of information available to researchers. As the use of social media reviews to understand patient experiences becomes more common, guidelines will likely need to be developed to provide rigorous frameworks for these studies. Despite these limitations, this study provided valuable and rich insight into adult patients' experiences with ALL through a novel analysis of PRI shared on social media. Patients reported that their ALL- and treatment-related symptoms had substantial impacts on their HRQOL, yet our findings indicate that ALL- and treatment-related symptoms impact different aspects of HRQOL. Treatments were burdensome for patients' emotional well-being, while ALL symptoms primarily affected patients' physical functioning. Inpatient treatment was particularly restrictive of their independence and social functioning but provided some patients with a sense of safety and security. Overall, patients desired treatments that minimized the impact on their HRQOL.

Conclusion

The findings from this social media review suggest that inpatient care for ALL is associated with restricted independence and social functioning. However, inpatient care also provided a sense of safety for some patients. The PRI indicates that treatment- and ALL-related symptoms are associated with different HRQOL impacts, showing an explicit link between treatment-related symptoms and emotional well-being. A deeper understanding of patient experiences, especially disease-related symptoms, treatment-related symptoms, and HRQOL impacts, is critical to informing the development of new treatments and the utilization of current treatments. Studies such as this one that capture patients' experiences in their own words are valuable tools to further our knowledge of patient outcomes with ALL. Information about this study in a plain language format is available in Multimedia Appendix 2.

Acknowledgments

Tyler Barrett, Melissa Mehalick, and Sara Musetti Jenkins of Research Triangle Institute (RTI) Health Solutions provided medical writing support, which was funded by Pfizer Inc.

Data Availability

Data for this study were gathered from publicly available sources in accordance with their terms and conditions. Data sources used for this study can be found in Multimedia Appendix 1.

Authors' Contributions

RC, SS, RM, ARS, HC, and LD contributed to the design of the study. RC, RM, HC, and LD analyzed the data. All authors interpreted the data, contributed to drafting and critically revising the manuscript, and provided approval for publication.

Conflicts of Interest

RC, RM, HC, and LD are employees of Research Triangle Institute (RTI) Health Solutions, and this study was performed under a research contract between RTI Health Solutions and Pfizer Inc. SS, JCC, ARS, and RS are employees of Pfizer Inc.

Multimedia Appendix 1
Data sources.
[DOCX File , 23 KB - cancer_v9i1e39852_app1.docx]

Multimedia Appendix 2
Plain language summary.
[PDF File (Adobe PDF File), 263 KB - cancer_v9i1e39852_app2.pdf]

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Abbreviations

ALL: acute lymphoblastic leukemia
EORTC QLQ-C30: European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core Module
HRQOL: health-related quality of life
PRI: patient-reported information
RTI: Research Triangle Institute

Edited by A Mavragani; submitted 26.05.22; peer-reviewed by S Ofori, P te Boekhorst; comments to author 30.08.22; revised version received 27.10.22; accepted 14.11.22; published 01.05.23.

Please cite as:
Crawford R, Sikirica S, Morrison R, Cappelleri JC, Russell-Smith A, Shah R, Chadwick H, Doward L
The Patient Experience of Acute Lymphoblastic Leukemia and Its Treatment: Social Media Review
JMIR Cancer 2023;9:e39852
URL: https://cancer.jmir.org/2023/1/e39852
doi:10.2196/39852
PMID:37126376

Original Paper

Factors Associated With Online Patient-Provider Communications Among Cancer Survivors in the United States During COVID-19: Cross-sectional Study

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Abstract

Background: Online patient-provider communication (OPPC) is crucial in enhancing access to health information, self-care, and related health outcomes among cancer survivors. The necessity of OPPC increased during SARS-CoV-2/COVID-19, yet investigations in vulnerable subgroups have been limited.

Objective: This study aims to assess the prevalence of OPPC and sociodemographic and clinical characteristics associated with OPPC among cancer survivors and adults without a history of cancer during COVID-19 versus pre–COVID-19.

Methods: Nationally representative cross-sectional survey data (Health Information National Trends Survey 5, 2017-2020) were used among cancer survivors (N=1900) and adults without a history of cancer (N=13,292). COVID-19 data included data from February to June 2020. We calculated the prevalence of 3 types of OPPC, defined as using the email/internet, tablet/smartphone, or electronic health record (EHR) for patient-provider communication, in the past 12 months. To investigate the associations of sociodemographic and clinical factors with OPPC, multivariable-adjusted weighted logistic regression was performed to obtain odds ratios (ORs) and 95% CIs.

Results: The average prevalence of OPPC increased from pre-COVID to COVID among cancer survivors (39.7% vs 49.7%, email/internet; 32.2% vs 37.9%, tablet/smartphone; 19.0% vs 30.0%, EHR). Cancer survivors (OR 1.32, 95% CI 1.06-1.63) were slightly more likely to use email/internet communications than adults without a history of cancer prior to COVID-19. Among cancer survivors, the email/internet (OR 1.61, 95% CI 1.08-2.40) and EHRs (OR 1.92, 95% CI 1.22-3.02) were more likely to be used during COVID-19 than pre–COVID-19. During COVID-19, subgroups of cancer survivors, including Hispanics (OR 0.26, 95% CI 0.09-0.71 vs non-Hispanic Whites) or those with the lowest income (US $50,000-<US $75,000: OR 6.14, 95% CI 1.99-18.92; ≥US $75,000: OR 0.42, 95% CI 1.56-11.28 vs <US $20,000), with no usual source of care (OR 6.17, 95% CI 2.12-17.99), or reporting depression (OR 0.33, 95% CI 0.14-0.78) were less likely to use email/internet, and those who were the oldest (age 35-49 years: OR 9.33, 95% CI 2.18-40.01; age 50-64 years: OR 3.58, 95% CI 1.20-10.70; age 65-74 years: OR 3.09, 95% CI 1.09-8.76 vs age≥75 years), were unmarried (OR 2.26, 95% CI 1.06-4.86), or had public/no health insurance (Medicare, Medicaid, or other: ORs 0.19-0.21 vs private) were less likely to use a tablet/smartphone to communicate with providers. Cancer

survivors with a usual source of care (OR 6.23, 95% CI 1.66-23.39) or health care office visits in a year (ORs 7.55-8.25) were significantly more likely to use EHRs to communicate. Although it was not observed in cancer survivors, a lower education level was associated with lower OPPC among adults without a history of cancer during COVID-19.

Conclusions: Our findings identified vulnerable subgroups of cancer survivors who were left behind in OPPC, which is increasingly becoming part of health care. These vulnerable subgroups of cancer survivors with lower OPPC should be helped through multidimensional interventions to prevent further inequities.

(JMIR Cancer 2023;9:e44339) doi:10.2196/44339

KEYWORDS

online patient-provider communication; cancer survivor; COVID-19; telehealth; eHealth activities; telemedicine; eHealth; e-health; patient provider; online communication; patient-physician; national survey; sociodemographic; oncology; cancer

Introduction

Online patient-provider communication (OPPC) refers to using online tools, including email/internet, tablets/smartphones, and mobile apps, for patient-provider communication [1]. Patient-provider communication is an essential element of cancer care and is associated with improved disease management, treatment adherence and quality, better health outcomes (eg, reduced mortality and mental distress), and superior health-related quality of life among cancer survivors [2-6]. Optimal OPPC has been found to have comparable benefits to face-to-face patient-provider communications among cancer survivors [7]. In addition, further benefits of OPPC among cancer survivors include increased access to health information, enhanced self-care ability, and an increased chance to be involved in health-related decision-making [8-10].

During the SARS-CoV-2/COVID-19 pandemic, the prevalence of poor mental health increased among cancer survivors [11-14]. Cancer survivors may have experienced a higher level of stress, fear, and psychological distress (eg, nervousness, worrying) due to delayed cancer care, fear of COVID-19 infection and poor health outcomes, or worry for cancer progression during COVID-19 than those without cancer [11,15-17]. Their unique situations would have required timely care and active communications with health providers to address health concerns and discuss care plans. Online-based health care became widely available in various health sectors during the early pandemic when in-person clinic visits were extremely limited owing to the pandemic [18-26]. Moreover, online-based care and communications will likely remain postpandemic for those who have medical conditions, because it became a major part of health care during the pandemic [27].

However, we do not know much about the adoption of online-based communications among cancer survivors during the early COVID-19 pandemic, although internet or digital device use behaviors in general US populations were assessed [28]. Given that OPPC use could also be a proxy of online-based care (eg, telehealth), which is only starting to be reported in some populations (eg, Medicare beneficiaries) [29,30], it is important to investigate subgroups who had low OPPC practice.

Previously, few studies have identified subgroups of cancer survivors who were vulnerable to OPPC before COVID-19 [7,31,32] and none, to the best of our knowledge, during the pandemic.

Before the COVID-19 pandemic, the adoption of and access to technology-based communication with providers was found to differ by some socioeconomic characteristics among cancer survivors. In a study by Jiang et al [7] using the national survey data (Health Information National Trends Survey [HINTS] 2008-2017), income, education, age, and health status were associated with OPPC via email, mobile platforms, and electronic health records (EHRs) among cancer survivors, yet the associations were inconsistent by year [7]. Two other studies, using HINTS (2003-2008 [31] and 2003-2018 [32]), found that young, highly educated, and metropolitan cancer survivors were more likely to email health care professionals. However, knowledge gaps still exist in OPPC practice among cancer survivors during COVID-19 compared to pre–COVID-19. Moreover, no studies have compared OPPC use in cancer survivors to the general population in prevalence and associations. Therefore, this study aimed to evaluate whether OPPC was higher among cancer survivors during COVID-19 than pre–COVID-19 and identify subgroups of cancer survivors with lower adoption of OPPC compared to those without a history of cancer during COVID-19.

Methods

Data Source

This study used nationally representative survey data from HINTS [33]. HINTS contains publicly available, self-administered, cross-sectional data collected by the National Cancer Institute (NCI). HINTS 5 Cycles 1-4 data from 2017 to 2020 were used for this study. HINTS 5 Cycles 1, 2, and 4 are single-mode mailed surveys that used a 2-stage sampling design, while HINTS 5 Cycle 3 is a double-mode design with a pilot push-to web survey in addition to the mailed survey. Remediated HINTS 5 Cycle 3 data were released in March 2021, and this study used the updated data. The survey questionnaires were distributed to noninstitutionalized civilians aged 18 years and older in the United States. HINTS 5 applied 2 stratified geographic addresses with areas of a high concentration of minority populations or a low concentration of minority populations, except for HINTS 5 Cycle 1. Cycle 1 used 3 stratified geographic addresses, adding the counties of Central Appalachia. The study followed Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines [34]. The total number of survey respondents in HINTS 5 Cycles 1-4 was 16,092, and the 4-year average response rate was approximately 33.0% (n=3285, 32.4%, in Cycle 1; n=3504, 32.4%, in Cycle 2; n=5438, 30.3%, in Cycle 3; n=3865, 36.7%, in Cycle 4) [35]. Because we needed to combine the data from 4 survey cycles, we evaluated differences in variables across the cycles and the survey mode (mailed, push-to-web with paper return, push-to-web with web return) prior to merging the data. Because no critical discrepancies were identified in the variables of our interest by cycle, we merged the data from the 4 cycles, following the recommended analytic process provided by HINTS. We obtained 200 replicate weights, which were used to calculate SEs. Full sampling weights were applied for the sample to be nationally representative. The full sampling weight is intended to account for household-level base weight, nonresponse, person-level initial weight, and other biases [36]. Among the total respondents, excluding those who missed questions on a history of cancer (n=221, 1.4%), those who reported that they had ever been diagnosed with cancer were considered as cancer survivors after further excluding those with nonmelanoma skin cancer (N=1900) and the remaining (N=13,292) were considered as adults without a history of cancer.

Outcomes

OPPC was measured using 3 types of communication behaviors, including the email/internet, tablet/smartphone, and EHR, as described previously [7]. Although the 3 types of OPPC might not be mutually exclusive, we used the following questions to measure different types and levels of participants' behaviors in technology-based patient-provider communications: (1) "In the past 12 months, have you used email or the internet to communicate with a doctor or doctor's office?," which required a basic level of technology literacy (email) and a technology-enabling environment (internet connection); (2) "Has your tablet or smartphone helped you in discussions with your health care provider?," which demanded an advanced level of technology literacy (eg, live chatting, video visits) and digital device ownership (tablet, smartphone); and (3) "In the past 12 months, have you used your online medical record to securely message health care providers and staff?," which additionally required some degree of engagement with the health care system. The responses were either yes or no, and those who answered yes were considered as practicing OPPC. The tablet/smartphone and EHR questions were only asked to those who owned tablet computers/smartphones or had used EHRs at least once in the past 12 months. In this study, those who did not have a tablet/smartphone or did not use EHRs once in the past 12 months were included in the no-OPPC groups using a tablet/smartphone or EHRs, respectively.

Covariates

Sociodemographic Characteristics

We used the social determinants of the health conceptual framework from Healthy People 2030 [37] to choose sociodemographic factors as independent variables in this study: age (18-34, 35-49, 50-64, 65-74, ≥75 years), birth gender (male, female), race/ethnicity (non-Hispanic White, non-Hispanic Black/African American, Hispanic, non-Hispanic Asian, other), household income (<US $20,000, US $20,000-<US $35,000, US $35,000-<US $50,000, US $50,000-<US $75,000, ≥US $75,000), educational attainment (less than high school, high school graduate, some college, college graduate or more), marital status (married or living with a romantic partner as married vs not married, including divorced, widowed, separated, single/never been married), employment status (employed vs unemployed, including homemaker, student, retired, disabled), health insurance type (insured by employment, private insurance, Medicaid, Medicare, Tricare, Veterans Affairs [VA], Indian Health Services [IHS]), a usual source of care (yes, no), number of health care office visits (0, 1-4, 5-9), and rurality of residence (metropolitan, micropolitan, small town, rural). HINTS used the Urban-Rural Commuting Area (RUCA), which categorizes census tracts based on population density, urbanization, and commuting patterns developed by the United States Department of Agriculture to determine the rurality of residence of the respondents [38].

Clinical Characteristics

Clinical characteristics included general health status (excellent/very good/good, fair/poor), chronic medical conditions (diabetes, high blood pressure, heart disease, lung disease, depression), time since cancer diagnosis (<1 year, 2-5 years, 6-10 years, ≥11 years), psychological distress (little interest, hopelessness, nervousness, worrying), and cancer type the respondents were diagnosed with (breast, cervical, prostate, colon, lung, melanoma, bladder, bone, endometrial, head and neck, leukemia/blood, liver, lymphoma [Hodgkin and non-Hodgkin], oral, ovarian, pancreatic, pharyngeal, rectal, renal, stomach, multiple cancers). We recoded unknown and less prevalent cancer types, including bladder, bone, endometrial, head and neck, leukemia/blood, liver, lymphoma, oral, ovarian, pancreatic, pharyngeal, rectal, renal, and stomach cancer, as "other."

Statistical Analysis

We conducted survey-weighted descriptive analyses to demonstrate the sociodemographic and clinical characteristics of cancer survivors with frequency (n) and weighted percentage (%) during the COVID-19 (HINTS 5 Cycle 4, 2020) and pre–COVID-19 (HINTS 5 Cycles 1-3, 2017-2019) periods. Of note, the Cycle 4 questionnaires were collected from February to June 2020. Survey-weighted descriptive analyses were also performed to report the prevalence of 3 OPPC outcomes by sociodemographic and clinical factors among cancer survivors pre–COVID-19 and during COVID-19. We used multivariable-adjusted weighted logistic regression to obtain odds ratios (ORs) and associated 95% CIs to examine the associations of sociodemographic factors and clinical predictors with each OPPC outcome. The psychological distress measurements were converted to depression (little interest and hopelessness) or anxiety (nervousness and worrying) symptoms using the Patient Health Questionnaire-2 (PHQ-2) or General Anxiety Disorder-2 (GAD-2) scales, respectively, following their clinical cutoff (score≥3: symptom presents) [39]. Cancer survivors and adults without a history of cancer were analyzed in a model to compare the association of being a cancer survivor on each OPPC outcome after controlling for age, race/ethnicity, education, income, marital status, health insurance type, having a usual source of care, number of office visits, general health condition, chronic health condition (depression), and mental health (depression or anxiety symptoms). Because being a cancer survivor was associated with OPPC outcomes (email/internet use to communicate with providers, *P*=.035), we stratified cancer survivors and adults without a history of cancer to investigate the associations with sociodemographic and clinical factors. We developed 6 multivariable-adjusted weighted logistic regression models for 3 OPPC outcomes during COVID-19 and pre–COVID-19 among cancer survivors. Separately, 6 models were developed for adults without a history of cancer (Multimedia Appendix 1). Sociodemographic and clinical variables were included in a final model only if they were significantly associated with the outcome in univariable analyses (*P*<.05) or if they were considered a confounder for another covariate (eg, when the covariate effect estimate changed by more than 10%). Employment status was not reported in HINTS 5 Cycle 3, so it was not included in the models due to a huge portion of data unavailability (35.0%). For other covariates, the range of missingness varied from 0% to 13.3%, yet it was mostly less than 4.5%. To account for these missing data, which were considered suitable to impute, we applied a hot deck imputation method, which HINTS used to account for the nonresponse [36]. Adjustments for multiple testing were not performed, because this study was not confirmatory by design and we intended to avoid the potential risk of increasing type II errors [40,41]. Statistical significance was determined at *P*<.05 using SAS 9.4 (SAS Studio).

Ethical Considerations

This study used the publicly available national survey data (HINTS). The study was a secondary analysis of survey data; human subjects were not involved, and identifiable information was not included. Given that the data were deidentified, the study was deemed exempt from review by the Institutional Review Board of the University of California, Davis.

Results

Description of Cancer Survivors

Of 1900 cancer survivors, 1444 (76.0%) were surveyed pre–COVID-19 (2017-2019) and 456 (24.0%) were surveyed during the COVID-19 pandemic (2020). There were no significant differences between the characteristics of the cancer survivors during the pre–COVID-19 and COVID-19 periods (Tables 1 and 2). Nearly half (n=289, 48.0%) were aged 65 years or older, 59.0% (n=272) were female, 79.0% (n=329) were non-Hispanic White, 63.0% (n=313) had some college education or more, 63.0% (n=228) were married, 62.0% (n=338) had public/government-aided health insurance, 84.0% (n=392) had a usual source of care, and 91.0% (n=420) had health care office visits at least once in a year. Clinically, 73.0% (n=322) reported that their general health status was good, while 56.0% (n=283) reported high blood pressure, 28.0% (n=149) had diabetes, 24.0% (n=111) had depression, and 12.0% (n=62) and 13.0% (n=60) reported that they had depressive and anxiety symptoms in the past 2 weeks, respectively. Nearly half of the cancer survivors (n=211, 46.0%) were 11 years or more from cancer diagnosis (Tables 1 and 2).

Table 1. Sociodemographic characteristics of cancer survivors (N=1900) pre–COVID-19 (2017-2019; HINTS[a] 5 Cycles 1-3) and during COVID-19 (2020; HINTS 5 Cycle 4).

Characteristics	Pre–COVID-19[b] (n=1444)[c]		During COVID-19[b] (n=456)[c]	
	Frequency, n (%)	SE for weighted percentage	Frequency, n (%)	SE for weighted percentage
Age (years)				
18-34	22 (5.7)	2.0	9 (2.3)	0.8
35-49	99 (11.8)	1.6	31 (17.5)	3.7
50-64	412 (31.8)	1.9	127 (32.8)	4.0
65-74	477 (25.5)	1.6	155 (25.5)	2.6
≥75	434 (25.2)	1.6	134 (22.0)	2.3
Gender				
Female	875 (59.5)	2.0	272 (58.8)	4.0
Male	569 (40.5)	2.0	184 (41.2)	4.0
Race/ethnicity				
Non-Hispanic White	1057 (73.8)	2.0	329 (79.3)	2.6
Non-Hispanic Black/African American	179 (11.0)	1.7	53 (8.3)	1.5
Hispanic	120 (10.2)	1.5	53 (9.0)	2.2
Non-Hispanic Asian	33 (2.0)	0.5	10 (1.5)	0.6
Other	55 (3.1)	0.7	11 (1.8)	1.0
Education				
Less than high school	88 (7.5)	1.6	39 (7.0)	1.7
High school	315 (26.9)	2.0	104 (30.0)	3.1
Some college	481 (40.1)	2.0	137 (39.9)	3.3
College graduate or more	560 (25.6)	1.5	176 (23.1)	2.9
Household income (US $)				
<20,000	284 (16.9)	1.7	100 (21.9)	3.0
20,000-<35,000	242 (15.9)	1.4	73 (12.5)	2.2
35,000-<50,000	194 (14.9)	2.3	72 (16.3)	2.6
50,000-<75,000	285 (19.4)	1.7	78 (19.0)	3.1
≥75,000	439 (32.8)	2.0	133 (30.2)	2.9
Employment[d]				
Employed	228 (36.2)	2.5	126 (34.8)	3.7
Unemployed	535 (63.8)	2.5	328 (65.2)	3.7
Marital status				
Married	729 (59.6)	2.1	228 (63.3)	3.4
Not married	715 (40.4)	2.1	228 (36.7)	3.4
Rurality				
Metropolitan	1221 (83.6)	1.5	386 (78.7)	2.6
Micropolitan	127 (9.9)	1.2	33 (10.9)	2.6
Small town	56 (3.1)	0.6	18 (5.6)	2.1
Rural	40 (3.4)	0.7	19 (4.7)	1.5
Health insurance type				
Employment/private	359 (31.6)	2.1	118 (37.9)	3.7
Medicare	570 (31.9)	1.7	179 (32.4)	2.9

Characteristics	Pre–COVID-19[b] (n=1444)[c]		During COVID-19[b] (n=456)[c]	
	Frequency, n (%)	SE for weighted percentage	Frequency, n (%)	SE for weighted percentage
Medicaid	174 (16.6)	2.2	70 (16.7)	2.5
Tricare, VA[e], IHS[f]	173 (9.9)	1.2	40 (4.9)	1.1
Other	168 (10.1)	1.0	49 (8.0)	2.1
Usual source of care				
Yes	1205 (82.9)	1.4	392 (83.7)	3.2
No	239 (17.1)	1.4	64 (16.3)	3.2
Number of office visits in a year				
0	86 (7.4)	1.3	36 (9.5)	2.7
1-4	791 (56.9)	2.5	234 (50.6)	4.0
5-9	567 (35.8)	2.2	186 (39.9)	3.7

[a] HINTS: Health Information National Trends Survey.

[b] Missingness of covariates: pre–COVID-19 (age 2.1 %, gender 1.0%, race/ethnicity 11.9%, education 1.5%, income 13.0%, marital status 1.7%, health insurance type 4.4%, usual source of care 1.8%, general health status 1.5%, diabetes 2.8%, high blood pressure 2.4%, heart disease 1.6%, lung disease 1.7%, depression 2.6%, time since diagnosis 4.8%, cancer type 1.9%) and during COVID-19 (age 1.3 %, gender 0.7%, race/ethnicity 12.5%, education 3.9%, income 11.0%, marital status 2.9%, health insurance type 3.7%, usual source of care 3.3%, general health status 0.7%, diabetes 1.8%, high blood pressure 1.3%, heart disease 1.5%, lung disease 1.8%, depression 1.3, time since diagnosis 4.4%, cancer type 3.5%).

[c] Covariates with any missing values were imputed in the table.

[d] Employment data were not reported in Cycle 3; n=681 (35.8%) unavailable.

[e] VA: Veterans Affairs.

[f] IHS: Indian Health Services.

Table 2. Clinical characteristics of cancer survivors (N=1900) pre–COVID-19 (2017-2019; HINTS[a] 5 Cycles 1-3) and during COVID-19 (2020; HINTS 5 Cycle 4).

Characteristics	Pre–COVID-19[b] (n=1444)[c]		During COVID-19[b] (n=456)[c]	
	Frequency, n (%)	SE for weighted percentage	Frequency, n (%)	SE for weighted percentage
General health status				
Excellent/good	1073 (72.6)	1.9	322 (73.1)	3.0
Fair/poor	371 (27.4)	1.9	134 (26.9)	3.0
Chronic medical condition (ever told)				
Diabetes	415 (24.9)	1.8	149 (27.7)	3.0
High blood pressure	860 (54.5)	2.1	283 (55.5)	3.5
Heart disease	248 (15.6)	1.5	66 (11.6)	1.9
Lung disease	243 (16.1)	1.2	106 (20.2)	2.9
Depression	332 (22.7)	1.7	111 (24.0)	2.8
Mental health (past 2 weeks)				
Depression symptoms	203 (16.0)	1.9	62 (11.6)	2.0
Anxiety symptoms	168 (12.6)	1.4	60 (13.4)	2.2
Time since diagnosis (years)				
<1	177 (13.3)	1.5	67 (16.1)	3.1
2-5	313 (21.5)	1.8	87 (18.2)	2.9
6-10	268 (16.6)	1.4	91 (19.6)	2.4
≥11	686 (48.7)	2.0	211 (46.0)	3.7
Cancer type				
Breast	282 (17.0)	1.4	88 (19.2)	3.3
Cervical	96 (8.9)	1.4	36 (9.4)	2.5
Prostate	173 (8.6)	1.0	61 (8.8)	1.5
Colon	80 (5.4)	0.9	26 (4.6)	0.9
Lung	37 (2.8)	0.6	12 (1.3)	0.5
Melanoma	85 (5.1)	0.9	33 (10.9)	2.6
Multiple	348 (23.7)	1.6	90 (17.4)	2.4
Other	343 (28.5)	2.4	110 (28.4)	3.5

[a] HINTS: Health Information National Trends Survey.

[b] Missingness of covariates: pre–COVID-19 (age 2.1 %, gender 1.0%, race/ethnicity 11.9%, education 1.5%, income 13.0%, marital status 1.7%, health insurance type 4.4%, usual source of care 1.8%, general health status 1.5%, diabetes 2.8%, high blood pressure 2.4%, heart disease 1.6%, lung disease 1.7%, depression 2.6%, time since diagnosis 4.8%, cancer type 1.9%) and during COVID-19 (age 1.3 %, gender 0.7%, race/ethnicity 12.5%, education 3.9%, income 11.0%, marital status 2.9%, health insurance type 3.7%, usual source of care 3.3%, general health status 0.7%, diabetes 1.8%, high blood pressure 1.3%, heart disease 1.5%, lung disease 1.8%, depression 1.3, time since diagnosis 4.4%, cancer type 3.5%).

[c] Covariates with any missing values were imputed in the table.

Prevalence of OPPC Among Cancer Survivors Compared to Adults Without a History of Cancer

The average prevalence of OPPC increased pre–COVID-19 to COVID-19 among cancer survivors: from 39.7% to 49.7% for email/internet use for communications with the provider/office, from 32.2% to 37.9% for tablet/smartphone use for discussions with providers, and from 19.0% to 30.0% for EHR use for messaging providers pre–COVID-19; see Figure 1. The average prevalence of OPPC among cancer survivors was similar to that among adults without a history of cancer pre–COVID-19 (approximate percentage, averaging out 3 OPPCs=29.0%) but was higher among cancer survivors during COVID-19. In multivariable models, cancer survivors were approximately 1.3 times as likely to use email/internet pre–COVID-19 than adults without a history of cancer (Table 3).

Figure 1. Prevalence of OPPC use. Pre–COVID-19 (2017-2019) and during COVID-19 (2020). The prevalence of OPPC use was presented as a weighted percentage. Cancer survivors (N=1900) and US adults without a history of cancer (N=13,292). EHR: electronic health record; OPPC: online patient-provider communication; smartp: smartphone.

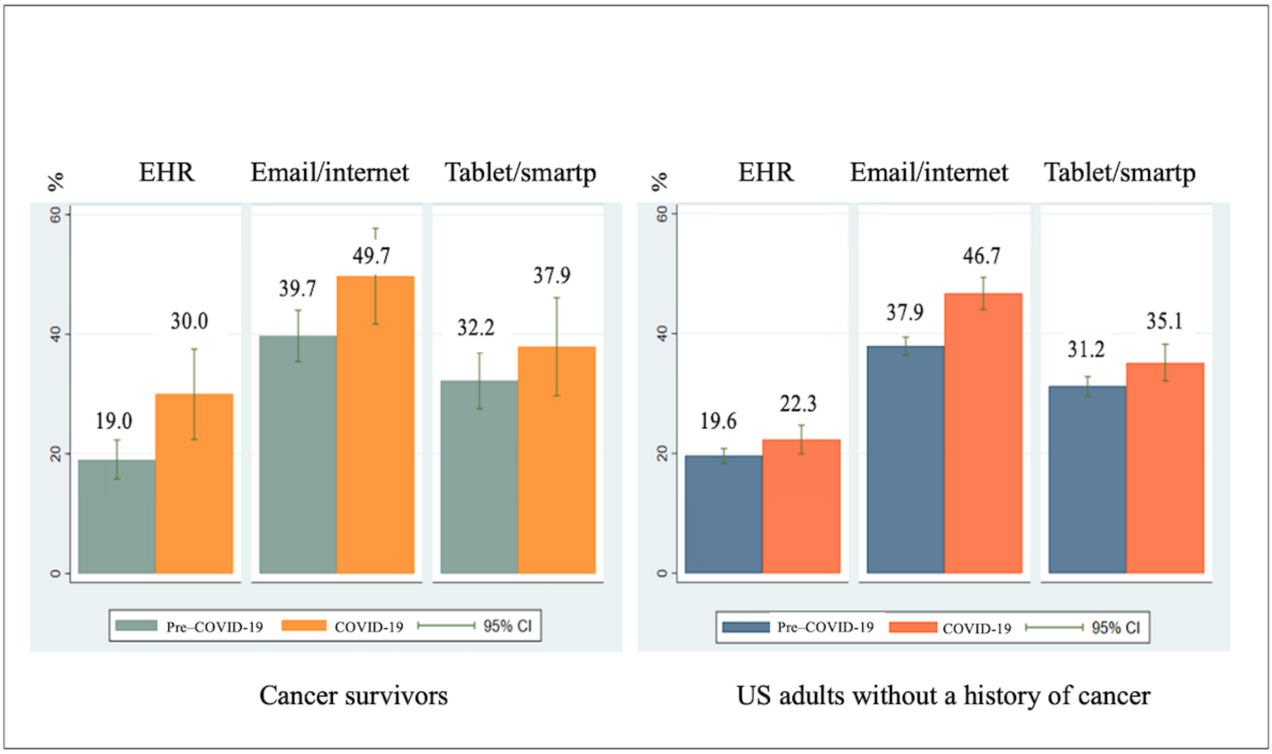

Table 3. Associations of a history of cancer with OPPC[a] outcomes.

History of cancer	Pre–COVID-19[b] (2017-2019; N=11,351), aOR[c,d] (95% CI)			During COVID-19[b] (2020), aOR[d] (95% CI)		
	Email/internet (n=11,351)	Tablet/smartphone (n=10,759)	EHR[e] (n=9751)	Email/internet (n=3568)	Tablet/smartphone (n=3554)	EHR (n=3541)
Yes	1.32 (1.06-1.63)[f]	1.21 (0.95-1.54)	0.98 (0.78-1.23)	1.28 (0.87-1.88)	1.20 (0.86-1.70)	1.39 (0.92-2.12)
No	Reference	Reference	Reference	Reference	Reference	Reference

[a] OPPC: online patient-provider communication.

[b] Total sample size: pre–COVID-19 (N=11,718) and during COVID-19 (N=3695).

[c] aOR: adjusted odds ratio.

[d] Adjusted by age, race/ethnicity, education, income, marital status, health insurance type, having a usual source of care, number of office visits, general health condition, chronic medical condition (depression), and mental health (depression or anxiety symptoms).

[e] EHR: electronic health record.

[f] *P*<.05.

Prevalence of OPPC by Sociodemographic and Clinical Factors Pre–COVID-19 and During COVID-19

Tables 4 and 5 show the prevalence of OPPC by sociodemographic and clinical factors among cancer survivors before and during COVID-19. In general, cancer survivors who were younger than 65 years, were more educated (some college or more education), had a high income (US $50,000 or more), were married, were employed, were metropolitan residents, had private/employment-based insurance, had a usual source of care or health care office visits, had good general health status and chronic medical conditions (eg, depression), were recently diagnosed (<6 years) or diagnosed with breast cancer showed a high prevalence of OPPC than the average in both time periods. Although the prevalence of OPPC was similar between pre–COVID-19 and COVID-19 for most sociodemographic and clinical subgroups, there were some noticeable differences during COVID-19. Non-Hispanic White cancer survivors had higher-than- average prevalence in all 3 types of OPPC during COVID-19, while non-Hispanic Asians had higher OPPC before COVID-19.

Table 4. Prevalence of OPPC[a] by sociodemographic factors among cancer survivors.

Characteristics	Pre–COVID-19 (2017-2019), weighted percentage (SE)			During COVID-19 (2020), weighted percentage (SE)		
	Email/internet	Tablet/smartphone	EHR[b]	Email/internet	Tablet/smartphone	EHR
Average prevalence (%)	39.7 (2.2)	32.2 (2.4)	19.0 (1.6)	49.7 (4.0)	37.9 (4.1)	30.0 (3.8)
Age (years)						
18-34	53.0 (21.8)[c]	56.8 (22.1)[c]	7.7 (5.2)	67.8 (23.9)[c]	40.6 (24.5)[c]	6.3 (7.0)
35-49	50.5 (6.4)[c]	36.4 (7.4)[c]	31.4 (6.1)[c]	58.8 (13.9)[c]	69.8 (13.2)[c]	21.5 (9.3)
50-64	46.4 (4.1)[c]	35.7 (3.9)[c]	19.9 (2.6)[c]	57.2 (7.1)[c]	50.0 (6.3)[c]	45.3 (7.5)[c]
65-74	39.1 (3.3)	35.0 (3.2)[c]	20.3 (2.8)[c]	40.8 (5.2)	23.7 (5.1)	25.0 (4.9)
≥75	23.2 (3.1)	15.6 (2.5)	12.9 (2.4)	39.0 (6.6)	9.9 (3.1)	21.0 (6.6)
Gender						
Female	37.1 (2.6)	29.7 (2.5)	19.5 (2.1)[c]	46.2 (6.0)	41.6 (5.5)[c]	27.2 (4.6)
Male	43.6 (4.0)[c]	35.8 (4.1)[c]	18.4 (2.8)	54.8 (4.5)[c]	33.0 (6.3)	34.0 (5.2)[c]
Race/ethnicity						
Non-Hispanic White	40.3 (2.2)[c]	29.0 (2.1)	20.6 (1.8)[c]	53.5 (4.4)[c]	38.3 (4.7)[c]	31.4 (4.3)[c]
Non-Hispanic Black/African American	44.5 (10.8)[c]	43.9 (11.9)[c]	10.7 (3.7)	30.6 (7.8)	27.8 (8.1)	26.6 (7.9)
Hispanic	28.7 (7.0)	36.8 (8.4)[c]	14.4 (6.7)	35.2 (11.8)	43.5 (10.8)[c]	24.4 (11.6)
Non-Hispanic Asian	50.2 (11.9)[c]	50.3 (12.3)[c]	36.5 (15.6)[c]	35.0 (18.3)	35.2 (18.7)	18.1 (14.2)
Other	38.8 (14.3)	43.7 (15.6)[c]	16.1 (7.8)	59.6 (30.0)[c]	47.8 (35.7)[c]	17.2 (13.9)
Education						
Less than high school	29.9 (18.5)	36.4 (20.0)[c]	3.8 (3.0)	30.2 (13.0)	11.2 (6.3)	20.9 (12.0)
High school	25.8 (3.7)	24.4 (4.0)	11.8 (2.7)	44.2 (7.9)	37.2 (8.5)	19.0 (6.6)
Some college	42.5 (3.7)[c]	33.8 (3.6)[c]	17.2 (2.8)	46.2 (6.6)	38.7 (6.6)[c]	28.8 (5.7)
College graduate or more	52.4 (3.1)[c]	36.2 (2.9)[c]	32.7 (3.2)[c]	69.8 (4.2)[c]	46.1 (7.0)[c]	50.0 (7.2)[c]
Household income (US $)						
<20,000	17.9 (3.2)	20.4 (4.2)	8.2 (2.1)	27.7 (6.7)	30.7 (8.8)	16.0 (5.5)
20,000-<35,000	29.4 (4.4)	26.3 (4.7)	15.2 (3.3)	30.2 (9.3)	21.5 (6.8)	15.7 (4.8)
35,000-<50,000	42.3 (7.2)[c]	35.4 (10.6)[c]	17.9 (5.0)	48.7 (8.9)	28.2 (6.6)	28.5 (7.7)
50,000-<75,000	44.6 (4.8)[c]	37.7 (4.7)[c]	20.8 (3.7)[c]	65.1 (8.8)[c]	45.9 (10.4)[c]	29.3 (7.9)
≥75,000	51.8 (3.5)[c]	35.8 (3.7)[c]	25.4 (3.0)[c]	63.5 (7.1)[c]	48.7 (7.4)[c]	47.3 (8.5)[c]
Marital status						
Married	44.1 (2.4)[c]	34.0 (2.7)[c]	20.9 (2.1)[c]	54.1 (5.2)[c]	44.8 (5.5)[c]	34.7 (5.5)[c]
Not married	33.3 (4.0)	29.5 (4.2)	16.2 (2.4)	42.0 (6.4)	24.8 (4.2)	21.6 (4.9)
Employment						
Employed	49.4 (4.8)[c]	33.8 (4.8)[c]	21.8 (4.0)[c]	65.6 (7.4)[c]	59.7 (6.8)[c]	39.3 (8.0)[c]
Unemployed	31.0 (3.3)	31.0 (3.7)	16.1 (2.7)	41.1 (4.1)	26.3 (4.6)	24.9 (2.9)
Rurality						
Metropolitan	42.5 (2.4)[c]	34.0 (2.6)[c]	19.7 (1.9)[c]	51.2 (4.5)[c]	38.6 (4.5)[c]	30.7 (4.0)[c]
Micropolitan	28.0 (5.2)	20.4 (5.5)	16.9 (4.8)	51.1 (14.7)	35.2 (17.3)	43.5 (16.4)
Small town	26.6 (7.2)	30.4 (8.7)	14.7 (6.8)	10.7 (10.9)	34.5 (33.4)	10.5 (11.8)

Characteristics	Pre–COVID-19 (2017-2019), weighted percentage (SE)			During COVID-19 (2020), weighted percentage (SE)		
	Email/internet	Tablet/smartphone	EHR[b]	Email/internet	Tablet/smartphone	EHR
Rural	16.2 (7.8)	23.8 (9.7)	12.7 (7.0)	68.2 (18.0)[c]	36.9 (19.5)	8.5 (5.6)
Health insurance						
Employment/private	55.9 (4.2)[c]	36.8 (4.2)[c]	23.8 (3.1)[c]	64.9 (7.3)[c]	65.6 (6.0)[c]	43.6 (8.0)[c]
Medicare	34.2 (2.8)	27.0 (2.7)	20.5 (2.5)[c]	39.2 (5.3)	17.2 (3.7)	22.6 (4.2)
Medicaid	31.4 (8.9)	37.5 (9.5)[c]	13.4 (4.3)	40.8 (10.7)	26.0 (7.7)	17.0 (6.8)
Tricare, VA[d], IHS[e]	29.0 (5.3)	30.3 (5.2)	13.4 (4.4)	60.1 (12.9)[c]	29.8 (9.3)	32.0 (11.0)[c]
Other	30.3 (4.5)	26.7 (5.0)	14.7 (3.9)	35.1 (7.8)	18.9 (4.9)	23.2 (6.1)
Usual source of care						
Yes	42.3 (2.5)[c]	34.8 (2.7)[c]	20.9 (2.0)[c]	53.6 (4.1)[c]	37.8 (4.7)	34.2 (4.0)[c]
No	27.5 (4.5)	20.0 (4.0)	8.9 (2.4)	26.6 (11.8)	38.6 (14.9)[c]	5.7 (2.9)
Number of office visits in a year						
0	20.6 (6.6)	10.7 (4.9)	7.9 (6.3)	43.9 (16.3)	30.3 (19.5)	3.9 (2.7)
1-4	39.8 (2.9)[c]	30.5 (3.3)	16.0 (2.0)	47.7 (5.2)	37.6 (6.1)	31.9 (4.7)[c]
5-9	43.6 (3.4)[c]	39.7 (3.7)[c]	25.7 (3.1)[c]	53.7 (6.7)[c]	39.9 (6.8)[c]	33.5 (5.6)[c]

[a] OPPC: online patient-provider communication.

[b] EHR: electronic health record.

[c] Prevalence is higher than the average.

[d] VA: Veterans Affairs.

[e] IHS: Indian Health Services.

Table 5. Prevalence of OPPC[a] by clinical factors among cancer survivors.

Characteristics	Pre–COVID-19 (2017-2019), weighted percentage (SE)			During COVID-19 (2020), weighted percentage (SE)		
	Email/internet	Tablet/smartphone	EHR[b]	Email/internet	Tablet/smartphone	EHR
General health status						
Excellent/good	42.6 (2.5)[c]	30.9 (2.8)	19.5 (2.0)[c]	54.9 (4.5)[c]	43.5 (4.5)[c]	32.0 (4.4)[c]
Fair/poor	31.9 (3.8)	35.9 (4.4)[c]	17.9 (3.0)	35.4 (6.4)	23.0 (5.4)	24.7 (5.9)
Chronic condition (ever diagnosed)						
Diabetes	35.5 (4.0)	29.1 (4.1)	18.4 (3.3)	47.7 (7.3)	32.6 (6.9)	32.5 (7.7)[c]
High blood pressure	37.2 (2.6)	30.7 (2.4)	19.5 (2.2)[c]	51.6 (4.4)[c]	33.2 (5.7)	33.1 (5.1)[c]
Heart disease	36.7 (4.9)	33.2 (5.1)[c]	20.1 (4.3)[c]	37.5 (8.4)	27.6 (7.4)	23.1 (6.3)
Lung disease	32.9 (4.6)	30.2 (4.9)	18.2 (4.0)	43.6 (6.2)	33.6 (7.6)	30.0 (5.6)
Depression	44.4 (3.9)[c]	38.1 (4.6)[c]	23.9 (4.0)[c]	38.4 (7.3)	38.9 (7.5)[c]	26.3 (5.9)
Mental health (past 2 weeks)						
Depression symptoms	41.2 (8.1)[c]	38.3 (8.9)[c]	15.7 (4.4)	40.1 (9.3)	27.3 (10.0)	21.1 (7.8)
Anxiety symptoms	42.3 (5.8)[c]	36.0 (5.8)[c]	20.4 (5.1)[c]	46.0 (9.5)	36.0 (9.7)	28.4 (8.4)
Time since diagnosis (years)						
<1	43.9 (6.2)[c]	36.4 (6.6)[c]	19.4 (4.9)[c]	63.8 (10.2)[c]	54.8 (12.1)[c]	32.7 (10.1)[c]
2-5	49.5 (5.5)[c]	43.7 (6.2)[c]	25.0 (4.3)[c]	47.2 (8.8)	35.0 (8.6)	30.2 (8.2)[c]
6-10	39.4 (4.2)	29.0 (3.9)	22.5 (4.1)[c]	38.9 (9.3)	32.4 (9.4)	19.0 (5.3)
≥11	34.3 (3.1)	27.0 (2.7)	14.9 (2.1)	50.3 (5.7)[c]	35.3 (5.4)	33.2 (5.9)[c]
Cancer type						
Breast	39.9 (4.0)[c]	36.8 (4.5)[c]	23.6 (3.9)[c]	55.8 (9.1)[c]	52.2 (9.1)[c]	32.3 (8.1)[c]
Cervical	41.7 (7.9)[c]	31.1 (7.8)	22.9 (7.0)[c]	49.7 (16.4)	39.4 (15.1)[c]	27.2 (13.8)
Prostate	34.1 (5.2)	29.3 (4.9)	12.6 (3.5)	48.4 (11.3)	18.9 (7.1)	35.2 (10.3)[c]
Colon	42.2 (10.9)[c]	50.2 (11.2)[c]	10.6 (8.1)	45.0 (12.9)	26.8 (10.7)	24.6 (10.0)
Lung	19.8 (8.5)	11.2 (6.8)	7.0 (3.6)	38.2 (22.2)	41.4 (21.5)[c]	7.6 (6.3)
Melanoma	45.5 (8.9)[c]	20.8 (5.9)	23.6 (7.9)[c]	52.8 (14.1)[c]	40.0 (17.0)[c]	31.3 (14.0)[c]
Multiple	43.0 (4.5)[c]	31.5 (3.7)	22.0 (3.5)[c]	49.3 (9.7)	20.8 (5.6)	29.6 (7.8)
Other	38.6 (5.2)	32.4 (5.6)[c]	16.5 (2.8)	46.2 (8.2)	45.0 (9.3)[c]	29.3 (7.3)

[a] OPPC: online patient-provider communication.

[b] EHR: electronic health record.

[c] Prevalence is higher than the average.

Sociodemographic and Clinical Factors Associated With OPPC Among Cancer Survivors Pre–COVID-19 vs COVID-19

Email/internet and EHR-based communications were 1.5-2 times as likely to be used during COVID-19 than pre–COVID-19 (email/internet: OR 1.61, 95% CI 1.08-2.40; EHR: OR 1.92, 95% CI 1.22-3.02).

Pre–COVID-19, younger age groups (18-74 years old) had nearly 2-9 times the odds of using the email/internet, tablet/smartphone, or EHR to communicate with providers compared to those 75 years or older (Tables 6-8). Cancer survivors with a higher annual income (US $20,000 or more) were 2-3.5 times as likely to communicate electronically with providers via the email/internet, tablet/smartphone, or EHR than those with less than US $20,000 of income. Those insured by private or employment-based plans had 2 times the odds of using email/internet for communications than those with public/government-supported insurance (Medicaid, Tricare/VA/IHS, other: ORs 0.41-0.49). Those who were recently diagnosed with cancer (2-5 years) were nearly 2 times as likely to use the email/internet, tablet/smartphone, or EHR for communications with providers/offices as those diagnosed more than 10 years ago (OR 2.02, 95% CI 1.23-3.33; OR 1.86, 95% CI 1.14-3.03; and OR 2.30, 95% CI 1.29-4.11, respectively). Those with a usual source of health care had 2.5 times (OR 2.55, 95% CI 1.21-5.38) the odds of using EHRs, and those who had health care office visits at least once had 4-6 times (ORs 4.46-5.91) the odds of using a tablet/smartphone to communicate with providers compared to those without a usual source of care or office visits. Breast cancer survivors were more likely to use a tablet/smartphone and EHRs than lung cancer survivors to communicate with providers.

During COVID-19, cancer survivors with a usual source of care had 6 times the odds of using email/internet (OR 6.17, 95% CI 2.12-17.99) or EHRs (OR 6.23, 95% CI 1.66-23.39) to communicate with providers/offices (Tables 6-8). Moreover, those who had health care office visits at least once in a year were 8 times as likely to use EHRs to send messages to the provider (1-4 times: OR 8.25, 95% CI 1.61-42.18; 5-9 times: OR 7.55, 95% CI 1.56-36.60) than those without any office visits. Hispanic cancer survivors (OR 0.26, 95% CI 0.09-0.71) were significantly less likely to use email/internet to communicate with providers/offices than their non-Hispanic White counterparts. Cancer survivors with more income (≥US $50,000 vs <US $20,000) had 4-6 times the odds of using email/internet for communications with providers/offices. Cancer survivors reporting a history of depression diagnosis were less likely to use email/internet to communicate with providers/offices (OR 0.33, 95% CI 0.14-0.78). The oldest individuals (≥75 years) were significantly less likely to use a tablet/smartphone to discuss with providers than their younger counterparts (35-74 years: ORs 3.09-9.33). Married cancer survivors were 2 times as likely to use a tablet/smartphone for communications (OR 2.26, 95% CI 1.06-4.86). Cancer survivors insured by Medicare (OR 0.21, 95% CI 0.08-0.54), Medicaid (OR 0.19, 95% CI 0.06-0.61), or other types of health plans (OR 0.20, 95% CI 0.07-0.58) were significantly less likely to discuss with providers via a tablet/smartphone than those with private or employment-based insurance.

Table 6. Associations of time period with OPPC[a] among cancer survivors.

Time period	Email/internet, aOR[b,c] (95% CI)	Tablet/smartphone, aOR[c] (95% CI)	EHR[d], aOR[c] (95% CI)
During COVID-19 (2000)	1.61 (1.08-2.40)[e]	1.40 (0.90-2.20)	1.92 (1.22-3.02)[e]
Pre–COVID-19 (2017-2019)	Reference	Reference	Reference

[a] OPPC: online patient-provider communication.

[b] aOR: adjusted odds ratio.

[c] Adjusted for all the variables in the table.

[d] EHR: electronic health record.

[e] *P*<.05.

Table 7. Associations of sociodemographic factors with OPPC[a] among cancer survivors pre–COVID-19 (2017-2019) and during COVID-19 (2020).

Factors	Pre–COVID-19 (N=1444), aOR[b,c] (95% CI)			During COVID-19 (N=456), aOR[c] (95% CI)		
	Email/internet (n=1411)	Tablet/smartphone (n=1307)	EHR[d] (n=1229)	Email/internet (n=446)	Tablet/smartphone (n=441)	EHR (n=444)
Age (years)						
18-34	7.43 (2.47-22.29)[e]	9.59 (3.03-30.35)[e]	0.87 (0.21-3.65)	5.38 (0.65-44.88)	1.04 (0.03-39.71)	0.40 (0.01-11.97)
35-49	2.52 (1.18-5.39)[e]	2.85 (1.26-6.46)[e]	2.52 (1.03-6.19)[e]	3.53 (0.55-22.47)	9.33 (2.18-40.01)[e]	1.13 (0.18-7.14)
50-64	2.30 (1.30-4.06)[e]	2.85 (1.62-5.01)[e]	1.47 (0.69-3.11)	1.74 (0.43-7.10)	3.58 (1.20-10.70)[e]	1.94 (0.38-9.82)
65-74	2.16 (1.36-3.43)[e]	2.91 (1.81-4.66)[e]	1.53 (0.86-2.73)	1.25 (0.45-3.43)	3.09 (1.09-8.76)[e]	1.31 (0.42-4.13)
≥75	Reference	Reference	Reference	Reference	Reference	Reference
Race/ethnicity						
Non-Hispanic White	Reference	Reference	Reference	Reference	Reference	Reference
Non-Hispanic Black/African American	1.37 (0.72-2.63)	1.87 (0.98-3.57)	0.58 (0.25-1.33)	0.64 (0.24-1.69)	1.16 (0.46-2.92)	1.04 (0.32-3.38)
Hispanic	0.60 (0.29-1.27)	2.67 (0.49-2.79)	0.83 (0.28-2.43)	0.26 (0.09-0.71)[e]	1.14 (0.32-4.05)	0.47 (0.16-1.39)
Non-Hispanic Asian	1.27 (0.51-3.13)	2.67 (0.93-7.64)	2.11 (0.66-6.70)	0.32 (0.07-1.40)	1.33 (0.17-10.78)	0.47 (0.07-3.31)
Other	0.78 (0.34-1.82)	1.09 (0.38-3.11)	0.98 (0.30-3.23)	1.62 (0.30-8.89)	1.39 (0.17-11.41)	0.47 (0.08-2.62)
Education						
Less than high school	Reference	Reference	Reference	Reference	Reference	Reference
High school	0.99 (0.41-2.38)	0.65 (0.25-1.74)	2.37 (0.45-12.57)	0.67 (0.13-3.61)	2.54 (0.35-18.35)	0.48 (0.07-3.46)
Some college	1.64 (0.71-3.78)	0.96 (0.41-2.24)	2.93 (0.59-14.65)	0.90 (0.18-4.60)	2.61 (0.33-20.58)	0.80 (0.12-5.37)
College graduate or more	1.94 (0.78-4.81)	1.00 (0.41-2.47)	6.24 (1.22-32.05)[e]	1.75 (0.40-7.62)	2.88 (0.34-24.23)	1.76 (0.27-11.38)
Household income (US $)						
<20,000	Reference	Reference	Reference	Reference	Reference	Reference
20,000-<35,000	2.03 (1.00-4.11)[e]	2.41 (1.07-5.40)[e]	1.79 (0.76-4.23)	2.08 (0.61-7.07)	1.04 (0.31-3.55)	0.79 (0.21-2.91)
35,000-<50,000	3.40 (1.70-6.82)[e]	2.88 (1.22-6.80)[e]	2.14 (0.94-4.91)	2.69 (0.77-9.38)	0.66 (0.20-2.16)	1.51 (0.38-6.03)
50,000-<75,000	3.26 (1.69-6.29)[e]	3.22 (1.56-6.66)[e]	2.20 (1.06-4.56)[e]	6.14 (1.99-18.92)[e]	2.07 (0.34-3.33)	1.67 (0.53-5.23)
≥75,000	3.55 (1.82-6.90)[e]	3.03 (1.46-6.28)[e]	2.36 (1.05-5.31)[e]	4.20 (1.56-11.28)[e]	0.99 (0.32-3.09)	1.59 (0.52-4.85)
Marital status						
Married	1.10 (0.72-1.69)	1.20 (0.80-1.81)	0.83 (0.52-1.32)	0.88 (0.46-1.67)	2.26 (1.06-4.86)[e]	1.09 (0.54-2.20)
Not married	Reference	Reference	Reference	Reference	Reference	Reference
Health insurance type						
Employment/private	Reference	Reference	Reference	Reference	Reference	Reference
Medicare	0.65 (0.38-1.10)	0.99 (0.54-1.83)	1.19 (0.58-2.43)	0.47 (0.16-1.35)	0.21 (0.08-0.54)[e]	0.41 (0.13-1.35)
Medicaid	0.48 (0.25-0.91)[e]	1.01 (0.49-2.11)	0.88 (0.37-2.11)	0.83 (0.24-2.90)	0.19 (0.06-0.61)[e]	0.36 (0.11-1.21)
Tricare, VA[f], IHS[g]	0.41 (0.21-0.80)[e]	1.05 (0.53-2.09)	0.61 (0.26-1.44)	1.42 (0.39-5.26)	0.69 (0.21-2.29)	0.89 (0.21-3.78)
Other	0.49 (0.27-0.89)[e]	0.88 (0.43-1.79)	0.71 (0.29-1.75)	0.34 (0.09-1.37)	0.20 (0.07-0.58)[e]	0.34 (0.010-1.21)
Usual source of care						

Factors	Pre–COVID-19 (N=1444), aOR[b,c] (95% CI)			During COVID-19 (N=456), aOR[c] (95% CI)		
	Email/internet (n=1411)	Tablet/smartphone (n=1307)	EHR[d] (n=1229)	Email/internet (n=446)	Tablet/smartphone (n=441)	EHR (n=444)
Yes	1.58 (0.88-2.84)	1.58 (0.91-2.76)	2.55 (1.21-5.38)[e]	6.17 (2.12-17.99)[e]	0.98 (0.26-3.69)	6.23 (1.66-23.39)[e]
No	Reference	Reference	Reference	Reference	Reference	Reference
Number of office visits in a year						
0	Reference	Reference	Reference	Reference	Reference	Reference
1-4	2.05 (0.73-5.77)	4.46 (1.49-13.37)[e]	1.98 (0.51-7.60)	0.83 (0.26-2.63)	2.15 (0.50-9.25)	8.25 (1.61-42.18)[e]
5-9	2.55 (0.90-7.22)	5.91 (1.94-17.97)[e]	2.85 (0.67-12.02)	1.18 (0.35-3.97)	2.32 (0.52-10.34)	7.55 (1.56-36.60)[e]

[a] OPPC: online patient-provider communication.

[b] aOR: adjusted odds ratio.

[c] Adjusted for all the variables in the table.

[d] EHR: electronic health record.

[e] *P*<.05.

[f] VA: Veterans Affairs.

[g] IHS: Indian Health Services.

Table 8. Associations of clinical factors with OPPC[a] among cancer survivors pre–COVID-19 (2017-2019) and during COVID-19 (2020).

Factors	Pre–COVID-19 (N=1444), aOR[b,c] (95% CI)			During COVID-19 (N=456), aOR[c] (95% CI)		
	Email/internet (n=1411)	Tablet/smartphone (n=1307)	EHR[d] (n=1229)	Email/internet (n=446)	Tablet/smartphone (n=441)	EHR (n=444)
General health status						
Excellent/good	1.36 (0.87-2.12)	0.79 (0.49-1.28)	0.81 (0.45-1.48)	1.52 (0.64-3.63)	1.94 (0.82-4.60)	0.84 (0.35-2.00)
Fair/poor	Reference	Reference	Reference	Reference	Reference	Reference
Chronic condition						
Depression	1.46 (0.93-2.29)	1.43 (0.88-2.32)	1.43 (0.80-2.57)	0.33 (0.14-0.78)[e]	1.59 (0.55-4.55)	0.73 (0.32-1.70)
No depression	Reference	Reference	Reference	Reference	Reference	Reference
Mental health (past 2 weeks)						
Depression symptoms	1.35 (0.69-2.66)	1.10 (0.56-2.17)	0.87 (0.39-1.92)	0.99 (0.24-4.10)	0.52 (0.14-2.00)	0.41 (0.07-2.29)
No symptoms	Reference	Reference	Reference	Reference	Reference	Reference
Anxiety symptoms	1.23 (0.61-2.48)	1.10 (0.54-2.23)	1.24 (0.53-2.88)	2.21 (0.51-9.61)	1.52 (0.29-7.93)	2.14 (0.53-8.62)
No symptoms	Reference	Reference	Reference	Reference	Reference	Reference
Time since diagnosis (years)						
<1	1.56 (0.88-2.77)	1.49 (0.81-2.74)	1.36 (0.65-2.84)	1.26 (0.47-3.40)	2.15 (0.69-6.69)	0.88 (0.24-3.15)
2-5	2.02 (1.23-3.33)[e]	1.86 (1.14-3.03)[e]	2.30 (1.29-4.11)[e]	0.97 (0.40-2.39)	0.54 (0.18-1.63)	1.17 (0.50-2.70)
6-10	1.21 (0.76-1.92)	0.99 (0.60-1.61)	1.83 (0.97-3.43)	0.47 (0.20-1.09)	0.59 (0.26-1.35)	0.42 (0.15-1.18)
≥11	Reference	Reference	Reference	Reference	Reference	Reference
Cancer type						
Breast	Reference	Reference	Reference	Reference	Reference	Reference
Cervical	0.94 (0.40-2.21)	0.61 (0.26-1.43)	1.28 (0.51-3.22)	0.90 (0.26-3.10)	0.41 (0.13-1.30)	1.58 (0.31-8.22)
Prostate	1.01 (0.51-1.97)	0.79 (0.41-1.53)	0.43 (0.17-1.09)	1.17 (0.38-3.57)	0.26 (0.09-0.77)[e]	1.65 (0.48-5.69)
Colon	1.08 (0.45-2.57)	1.47 (0.60-3.59)	0.40 (0.10-1.66)	1.74 (0.42-7.21)	0.87 (0.22-3.45)	1.60 (0.36-7.01)
Lung	0.41 (0.14-1.20)	0.14 (0.04-0.47)[e]	0.26 (0.08-0.86)[e]	1.68 (0.25-11.27)	3.21 (0.59-17.42)	0.26 (0.02-2.92)
Melanoma	0.99 (0.39-2.49)	0.41 (0.17-1.00)	0.85 (0.31-2.33)	0.97 (0.24-3.92)	0.39 (0.08-1.98)	0.82 (0.18-3.71)
Multiple	1.81 (0.97-3.36)	0.99 (0.56-1.78)	1.18 (0.63-2.22)	1.07 (0.32-3.65)	0.42 (0.14-1.28)	1.14 (0.31-4.20)
Other	0.88 (0.48-1.59)	0.62 (0.35-1.07)	0.72 (0.38-1.36)	0.90 (0.32-2.53)	0.61 (0.24-1.58)	1.26 (0.38-4.18)

[a] OPPC: online patient-provider communication.

[b] aOR: adjusted odds ratio.

[c] Adjusted for all the variables in the table.

[d] EHR: electronic health record.

[e] *P*<.05.

Cancer Survivors vs Adults Without a History of Cancer

Among cancer survivors (Tables 6-8) and adults without a history of cancer (Multimedia Appendix 1), those with a usual source of care were 2-6 times as likely to use OPPC than those without a source pre–COVID-19 and during COVID-19. Among those without a history of cancer in both time periods, those who were more educated were 2-6 times and those who reported depression were 1.5-2 times as likely to use OPPC (Multimedia Appendix 1). However, among cancer survivors, we did not observe associations with education and found that depression was inversely associated with OPPC.

Discussion

Principal Findings

Using nationally representative survey data in the United States from 2017 to 2020, we identified that having a usual source of care or health care office visits is strongly associated with 3 types of OPPC, and different sociodemographic and clinical characteristics were associated with OPPC among cancer survivors and adults without a history of cancer during the pre–COVID-19 and COVID-19 periods. Cancer survivors were more likely to use email/internet to communicate with providers than those without a history of cancer prior to the COVID-19 pandemic, yet no difference was found during the early pandemic. However, OPPC use was higher during COVID-19 than pre–COVID-19 among cancer survivors. During COVID-19, subgroups of cancer survivors were less likely to use OPPC, including the oldest cancer survivors (≥75 years), who were Hispanic, had the lowest income, were unmarried, had no usual source of care or no visits to health providers, had public/no health insurance, or reported having depression. However, a lower education level was associated with lower OPPC among adults without a history of cancer during COVID-19. Our findings identified vulnerable subgroups of cancer survivors who were left behind in OPPC, which is increasingly becoming part of health care [19-21,24].

During COVID-19, but not prior to the pandemic, cancer survivors who were not married or had Medicare, Medicaid, or other health plans, including no insurance, were significantly less likely to use a tablet/smartphone to communicate with providers. Our marital status findings are consistent with prior studies that have found that individuals living with a spouse or partner are more likely to perform healthy behaviors (eg, a higher success rate of quitting tobacco [42,43]). Differences by health insurance could be related to the surge in telehealth use among those with private/employment-based insurance when major insurance companies started reimbursement for telehealth services in early 2020 [44]. The Centers for Medicare and Medicaid Services (CMS) also expanded health care professionals' role to provide telemedicine to increase telehealth access and its use, including telephone/audio-only or e-visits [45-47]. However, the CMS's effort to create an enabling environment for telehealth use might not have been enough for cancer survivors with Medicare or Medicaid to increase their use of mobile devices (eg, tablets/smartphones) for communication with providers compared to those with private/employment-based insurance.

Although racial/ethnic differences were not observed among cancer survivors prior to COVID-19 in this study and previously [7,31,32], we observed that Hispanic cancer survivors were significantly less likely to have online communications with providers/offices via email/internet than their non-Hispanic White counterparts during COVID-19. Early in the pandemic, Hispanic populations had higher rates of COVID-19–related hospitalization, intensive care unit admission, or in-hospital death [48,49], which could have been related to a higher prevalence of chronic diseases [50] or having more unmet health care needs [51]. In our study, chronic disease prevalence was not significantly different between racial/ethnic groups, but we were unable to account for unmet health care needs, other than lacking a usual source of care, that could have resulted in less use of online tools to communicate with providers.

Before COVID-19, cancer survivors aged ≥75 years were least likely to practice OPPC via email, the internet, a tablet, or a smartphone. This was also observed among adults without a history of cancer in this study, which aligns with the previous literature [28]. Prior studies suggest that adults aged 65 years and older had less interest in exchanging medical information online with providers [52], less frequently used social media for health communication [53], and less frequently used the internet to search for health information [54] compared to younger generations. This could be potentially due to lower eHealth literacy or higher computer stress among the oldest (≥70 years) compared with younger individuals [55-57]. Older individuals have poorer COVID-19 outcomes [58] and a higher level of fear of COVID-19 [59]; hence, their demands for OPPC might have been high to avoid possible exposure during our study period, yet the barriers noted before could have limited their use of OPPC. In addition, low income was significantly associated with lower OPPC among cancer survivors before COVID-19, consistent with low income being strongly associated with low health technology use in the general population [52,55]. Specifically, low-income older adults designated a lack of financial resources as a barrier to technology access and ownership [60]. However, these strong associations with low income in OPPC were less evident among cancer survivors during COVID-19, suggesting that lacking financial resources was less of a barrier to OPPC use in the early COVID-19 period. Because older age and low income have been associated with eHealth activities, including OPPC, further investigations are warranted to confirm whether they remain in the extended COVID-19 period.

Notably, we observed different associations between depression and education with the use of OPPC among cancer survivors compared to adults without a cancer history. In our study, cancer survivors reporting depression as a chronic condition were less likely to use email/internet to communicate with providers than their counterparts during COVID-19. Prior studies either have not found associations [31] or have not assessed the associations of depression with OPPC [7,32]. However, depression was associated with the use of all 3 types of OPPC among adults without a history of cancer pre–COVID-19 and during COVID-19. The differing associations with OPPC among cancer survivors will need to be further investigated to determine whether our findings were specific to conditions in the early COVID-19 period that generated extreme mental distress. In addition, even though less educated adults without a history of cancer were less likely to use OPPC during COVID-19 and pre–COVID-19, these associations were not observed among cancer survivors in our study. In contrast to our findings, 2 prior studies (2003-2008 [31] and 2003-2018 [32]) have reported that highly educated cancer survivors are more likely to email providers [7]. Given the widespread use of email/internet, the education level may impact OPPC use less compared to other factors, such as access or eHealth literacy, that have been found to impact use more recently [55]. Therefore, our findings suggest that education level might not be a barrier to cancer survivors' use of OPPC.

In this study, 16% of cancer survivors and 36% of US adults without a history of cancer reported no usual source of care, which was consistently associated with lower OPPC use among both cancer survivors and adults without a history of cancer before and during COVID-19. The likelihood of OPPC use among cancer survivors with a usual source of care appeared to be stronger during COVID-19. In addition, visiting the health provider's office was strongly associated with EHR-based communications during the pandemic. One potential explanation could be that it would have been easier for those who had a usual source of care or recent office visits to connect with providers online than those without, particularly when in-person office visits were extremely limited under the stay-at-home order in 2020. Previous studies have not considered the usual source of care when assessing OPPC among cancer survivors [7,31,32]. However, it has been associated with OPPC in the general population [61]. To increase the usual source of care among cancer survivors, enhancing insurance coverage (eg, Medicaid expansion [51]) will need to be prioritized to improve health care access in underserved populations [62]. In addition, improving the perceived quality of care and physician trust [63,64] could improve health care–seeking behaviors [65,66].

Given that OPPC is a combination of health technology use and health care–seeking behavior, it requires a multifaceted approach to support it among cancer survivors. Prior studies have identified that health technology use is impacted by low digital device ownership, poor internet access, and lack of technical assistance [29,67,68] and health care seeking is lower among racial/ethnic minority populations and those with a poor patient-provider relationship [63,69]. Our study adds to this knowledge base by identifying vulnerable subgroups in OPPC. Interventions to improve OPPC should incorporate comprehensive and consistent health policies to cover diverse televisits (eg, audio-only calls, videoconferences), enhancing eHealth literacy, and increasing access to digital devices. Given that OPPC is technology-based communication, an effort to improve eHealth literacy among the targeted groups (eg, low socioeconomic status) is recommended, along with creating a technology-enabling environment [54]. One example of improving health literacy is the nationwide collaboration of the Adult Basic Education (ABE) network with community health organizations [70,71] by raising awareness of health literacy among ABE-registered low-literate individuals and implementing pilot projects into the targeted population via peers (eg, peer language navigators [72]). In addition, qualitative studies are suggested for a deeper understanding of barriers to and facilitators of OPPC in the vulnerable subgroups identified in this study.

Limitations

This study has some limitations. First, because we used cross-sectional survey data, we could not determine the prospective and longitudinal associations with OPPC. Second, although the data used in this study were high-quality national survey data, they carry inevitable weaknesses originating from self-reporting and the possibilities of reporting bias (eg, communicated with providers via EHRs more than 12 months ago but reported it as within 12 months, intentionally or unintentionally). Third, due to the questionnaire time frame (in the past 12 months), it is possible that our outcome measurements during COVID-19 could have captured respondents' behaviors before COVID-19. Fourth, the overall response rate of an average 33.0% during the study period could result in selection bias. However, HINTS applied full sampling weights and conducted imputation to minimize nonresponse. Fifth, the COVID-19 sample size was smaller than the pre–COVID-19 sample size (2017-2019) since the year 2020 was the only available data for COVID-19. Further, the HINTS 5 Cycle 4 questionnaires were administered and collected in the first half year of 2020 (February-June). Hence, we need to interpret the findings of this study from the context of the early COVID-19 period.

Conclusion

Our findings suggest that cancer survivors who were older, had no usual source of care or health care office visits, had a low income, had public or no health insurance, were Hispanic, were unmarried, or reported depression were less likely to use OPPC during COVID-19, findings that differed from associations in adults without a history of cancer. As OPPC is increasingly becoming part of health care, we need to continue to evaluate disparities in its use in the extended COVID-19 period. Strategies to increase the use of OPPC include improvement in health policies to cover virtual visits, interventions to enhance eHealth literacy, and community-based or nationwide efforts to expand health technology access. Our findings identify vulnerable subgroups of cancer survivors with lower OPPC who can be targeted through multidimensional interventions to prevent further inequities.

Data Availability

The data for this study are publicly available [73].

Conflicts of Interest

None declared.

Multimedia Appendix 1

Associations of sociodemographic and clinical factors with OPPC among noncancer populations pre–COVID-19 (2017-2019) and during COVID-19 (2020). OPPC: online patient-provider communication.

[DOCX File , 32 KB - cancer_v9i1e44339_app1.docx]

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Abbreviations

ABE: Adult Basic Education
CMS: Centers for Medicare and Medicaid Services
EHR: electronic health record
HINTS: Health Information National Trends Survey
IHS: Indian Health Services
OPPC: Online Patient-Provider Communication
OR: odds ratio
VA: Veterans Affairs

Edited by A Mavragani; submitted 18.11.22; peer-reviewed by YR Hong, R Jensen, S Han; comments to author 16.03.23; revised version received 05.04.23; accepted 17.04.23; published 22.05.23.

Please cite as:
Kim J, Linos E, Fishman DA, Dove MS, Hoch JS, Keegan TH
Factors Associated With Online Patient-Provider Communications Among Cancer Survivors in the United States During COVID-19: Cross-sectional Study
JMIR Cancer 2023;9:e44339
URL: https://cancer.jmir.org/2023/1/e44339
doi:10.2196/44339
PMID:37074951

Original Paper

Smartphone-Based Psychotherapeutic Interventions in Blended Care of Cancer Survivors: Nested Randomized Clinical Trial

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Abstract

Background: Cancer is related to not only physical but also mental suffering. Notably, body image disturbances are highly relevant to cancer-related changes often persisting beyond recovery from cancer. Scalable and low-barrier interventions that can be blended with face-to-face psychotherapy for cancer survivors are highly warranted.

Objective: The aim of the study is to investigate whether smartphone-based bodily interventions are more effective to improve the mood of patients with cancer than smartphone-based fairy tale interventions (control intervention).

Methods: We recruited patients with cancer in 2 Swiss hospitals and conducted daily, fully automated smartphone-based interventions 6 times a week for 5 consecutive weeks, blended with weekly face-to-face group body psychotherapy. We applied 2 types of smartphone-based interventions using a within-subject design, randomly assigning patients daily to either bodily interventions or fairy tales. Each intervention type was presented 3 times a week. For this secondary analysis, 3-level mixed models were estimated with mood assessed by the 3 Multidimensional Mood Questionnaire subscales for good-bad mood, wakefulness, and calmness as key indicators. In addition, the effects on experience of presence, vitality, and burden assessed with visual analog scales were investigated.

Results: Based on the data from *s*=732 interventions performed by 36 participants, good-bad mood improved (β=.27; 95% CI 0.062-0.483), and participants became calmer (β=.98; 95% CI 0.740-1.211) following smartphone-based interventions. Wakefulness did not significantly change from pre- to postsmartphone–based intervention (β=.17; 95% CI –0.081 to 0.412). This was true for both intervention types. There was no interaction effect of intervention type with change in good-bad mood (β=–.01; 95% CI –0.439 to 0.417), calmness (β=.22; 95% CI –0.228 to 0.728), or wakefulness (β=.14; 95% CI –0.354 to 0.644). Experience of presence (β=.34; 95% CI 0.271-0.417) and vitality (β=.35; 95% CI 0.268-0.426) increased from pre- to postsmartphone–based intervention, while experience of burden decreased (β=–0.40; 95% CI –0.481 to 0.311). Again, these effects were present for both intervention types. There were no significant interaction effects of intervention type with pre- to postintervention changes in experience of presence (β=.14; 95% CI –0.104 to 0.384), experience of vitality (β=.06; 95% CI –0.152 to 0.265), and experience of burden (β=–.16; 95% CI –0.358 to 0.017).

Conclusions: Our results suggest that both smartphone-based audio-guided bodily interventions and fairy tales have the potential to improve the mood of cancer survivors.

Trial Registration: ClinicalTrials.gov NCT03707548; https://clinicaltrials.gov/study/NCT03707548

International Registered Report Identifier (IRRID): RR2-10.1186/s40359-019-0357-1

(JMIR Cancer 2023;9:e38515) doi:10.2196/38515

KEYWORDS

digital therapeutics; ecological momentary assessment (EMA); ecological momentary intervention (EMI); internet- and mobile-based intervention; microintervention; neoplasm; smartphone-based intervention; postcancer treatment; body psychotherapy; mobile phone

Introduction

Cancer is an often life-threatening disease, posing multiple challenges. Although cancer is increasingly curable and the number of survivors has grown, it still remains one of the most feared diseases [1]. Patients living with cancer suffer from symptoms of their illness as well as from side effects of cancer therapies [2]. Both have physical but also mental implications, preventing patients from returning to their normal lives. Notably, body image disturbances are among the physically, mentally, and interpersonally most relevant cancer-related changes often persisting beyond initial recovery from cancer [3]. Key aspects of body image disturbances include (1) the self-perception of change in appearance and displeasure with this change, (2) a decline concerning various aspects of physical functioning, and (3) the psychological distress caused by these changes [4], highlighting the interrelatedness of body image disturbances with mood and affect. Considering these issues, developing interventions that target mental burden in posttreatment cancer survivors with bodily disturbances is highly warranted. Hence, we developed and applied a group body psychotherapy (BPT) for patients with cancer who are in posttreatment [5], which was based on an experience-oriented holistic approach [6,7].

Mobile mental health has become a topic of considerable interest for patients with cancer to promote self-management of their chronic disease [8]. Previous studies indicated that smartphone-based interventions have the potential to reduce symptoms of mental disorders, such as anxiety and depression [9,10]. Notably, smartphone-based interventions may be used as a specific type of ecological momentary intervention (EMI) and allow supporting patients in their daily lives, thereby reducing the personal and economic costs of mental health problems [11]. In addition, in the field of cancer treatment, there is an increasing focus on the development of technological at-home interventions that aim to improve health outcomes [12]. Furthermore, there is evidence that web-based interventions can be successfully blended with face-to-face psychotherapy [13] and that the use of mobile technology can increase the effectiveness of psychotherapeutic interventions [14]. Yet, the effects of smartphone-based interventions embedded in a psychotherapeutic context as blended psychotherapy for cancer survivors remain to be elucidated. Hence, we set out to complement group BPT by daily smartphone-based digital interventions, with the aim to investigate whether these had short-term effects on patients' moods. We provided digital interventions based on daily randomization: either providing an intervention specifically addressing bodily perceptions consisting of bodily interventions or providing an unspecific intervention consisting of fairy tales as a comparator.

The goal of this randomized clinical trial component nested in a convergent parallel design was to explore changes in mood after smartphone-based bodily intervention compared to fairy tale intervention (comparator). It was hypothesized that the mood of cancer survivors improves from pre- to postsmartphone–based bodily interventions. Furthermore, we expected that mood improvement was greater following bodily interventions as compared to fairy tales (comparator). Due to a small study sample, we have performed exploratory analyses of our hypotheses.

Methods

Study Design and Setting

Presented data originated from a nested randomized controlled trial, embedded in a nonrandomized study registered in ClinicalTrials.gov (NCT03707548). The aim of this larger nonrandomized study was to evaluate the treatment effects of a BPT group intervention.

We recruited patients between September 3, 2018, and May 12, 2019, in 2 Swiss hospitals (University Hospital Basel and Cantonal Hospital Winterthur). All participants signed an informed consent before study participation. We kindly refer to a previous publication [15] for more information regarding the larger nonrandomized trial.

Ethics Approval

The entire nonrandomized study, including the present nested randomized controlled trial component, is designed according to the Declaration of Helsinki, the Human Research Act, and the Human Research Ordinance. The Ethikkommission Zentral- und Nordwestschweiz (EKNZ; vote: EKNZ 2018-01115, dated August 28, 2018, and amendment dated March 14, 2019) has approved the study. In addition, we obtained ethical approval from the Kantonale Ethikkommission Zu¨rich. Consistent with good clinical practice, we informed patients about participation in the larger nonrandomized study, the planned secondary analysis of data, and the implications of participation. All participants signed an informed consent form before study participation. Informed consent from the original, larger nonrandomized study allows the present analysis of secondary outcomes without additional consent. Participation was voluntary and could be withdrawn at any time during the entire study. Participants did not receive any compensation. Data were treated confidentially and were strictly analyzed in deidentified form.

Inclusion Criteria and Recruitment

Inclusion criteria for the entire nonrandomized study were (1) age≥18 years, (2) sufficient knowledge of spoken German, (3) having received curatively intended treatment for any malignant neoplasm, (4) suffering from bodily disturbances, (5) primary treatment being completed at least 3 months prior to recruitment, (6) an Eastern Cooperative Oncology Group performance score of 0-1 [16], (7) an anticipated life expectancy of ≥12 months, and (8) the anticipated capacity to participate in the baseline assessment, the preintervention assessment, 6 group BPT sessions, the postintervention assessment, and the smartphone-based interventions and daily assessments. In addition, for participation in the smartphone-based component of the study, patients were required to own a smartphone and to be able to access their email accounts through it. Exclusion criteria for the entire nonrandomized study were (1) sign of progress or recurrence of malignancy at study inclusion, (2) having a severe current mental disorder, (3) risk of current suicidality, (4) participation in any other clinical trial with a psychosocial intervention, (5) receiving other current psychotherapeutic treatment for less than 6 months (with the exception of already existing therapies lasting ≥6 months), and (6) inability to understand and speak German. All eligibility criteria are described in detail in the study protocol [15]. Patients were recruited at the study centers; additionally, they were approached via public advertisements.

Intervention

The smartphone-based digital intervention was embedded in a nonrandomized study with face-to-face psychotherapy, consisting of 6 group BPT sessions, 90 minutes each. As part of the nested randomized controlled trial component, participants received either an audio instruction of bodily interventions (3 times a week) or audio recordings of fairy tales as unspecific intervention and comparator (3 times a week) via smartphone between sessions, over a period of 5 consecutive weeks. There was no smartphone-based intervention on the day of the group BPT session. The smartphone-based bodily intervention offered audio clips consisting of BPT tools, experiences, and strategies that reflected the content of the face-to-face sessions. For more details on the contents of these bodily interventions, please refer to Multimedia Appendix 1 [7,15,17-19] or the entire study protocol [15]. The unspecific comparator interventions consisted of 15 selected Grimms' fairy tales. Both types of interventions lasted about 10 minutes each. They were provided at random, with randomization taking place daily.

The Clinical Trial Unit of the University Hospital Basel independently generated the random sequences using R software (R Foundation for Statistical Computing), applying a block design to ensure that each patient received both interventions 3 times a week. This allowed individual daily randomization of each participant to either the bodily or the fairy tale intervention (within-subject randomization). Trial participants were blinded to randomization up until the moment at which the intervention was provided; body psychotherapists were also blinded to randomization.

To familiarize participants with the smartphone-based interventions, all patients received an invitational email with a link to an introductory audio file and the request to complete the questionnaire at the end of the first group BPT session. Data collected during this training were not included in the analyses.

Patients could freely choose the time of day they participated in the digital intervention. The time window started each day at 7 AM with the invitational email including the day-specific hyperlink giving access to the intervention. This hyperlink expired at midnight of the same day. We used on the web Questback software (Questback Ltd) [20] to conduct the smartphone-based interventions, including instructions, presentation of the audio clips, collection of the questionnaire data, and sending the invitational emails.

The detailed procedure of each smartphone-based intervention was as follows: (1) participants used their own smartphones to get connected via internet browser to the Questback server, using a day-specific personalized hyperlink provided in the daily invitational email. We instructed patients to log into their email once a day. (2) We asked patients to enter their individual self-generated personal code, which allowed for verifying subject identity. (3) Participants replied to a short questionnaire ("pre") described in more detail below. (4) To start the session, patients were asked to click on the "play" button of the audio player. (5) Participants listened to the audio clip using either headphones or the smartphone speaker and eventually performed the bodily intervention. (6) Participants again replied to the short questionnaire ("post"). (7) The session finished by thanking the patients for their participation in that day's session.

Assessment

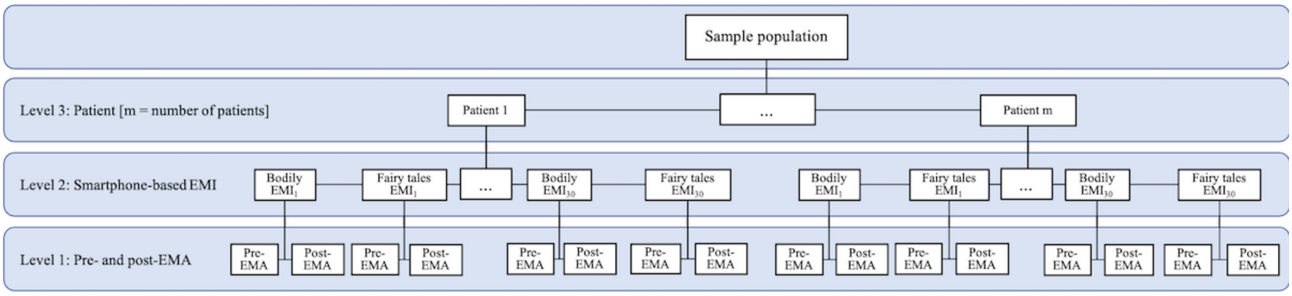
We assessed mood pre- and postsmartphone–based interventions via web-based questionnaires. We applied the German version of the "Multidimensional Mood Questionnaire" Short-Form A (MDMQ) [21,22]. The MDMQ Short-Form A comprises 12 adjectives, with three subscales: (1) good-bad mood, (2) awake-tired, and (3) calm-nervous. Each item is rated on a 5-point Likert scale ranging from 1="not at all" to 5="very." For every subscale, we added up the values of the corresponding items, resulting in scale values potentially ranging between 4 and 20. High scores suggest positive affectivity, wakefulness, and calmness, respectively [21]. The MDMQ is a well-established tool for the self-assessment of current mood, especially suited for repeated measures with short intervals, which has previously been successfully applied within the context of smartphone-based microinterventions [23]. Additionally, we applied 3 single-item visual analog scales (VAS) to self-assess the experience of presence, vitality, and burden (eg, How present do you feel right now? VAS ranging from 0=”not at all” to 10=”extremely strong”).

We screened patients for eligibility at baseline assessment (T0), including standardized questionnaires and a semistructured interview. Included patients with cancer who are in posttreatment underwent a waiting period of approximately 6 weeks followed by a pre-face-to-face psychotherapy questionnaire assessment (T1). After the face-to-face group session, a postpsychotherapy assessment (T2) with standardized questionnaires and a second semistructured interview took place. The smartphone-based part of the study applied ecological momentary assessments taking place daily along the face-to-face psychotherapy sessions (ie, between T1 and T2).

Statistical Analyses

We conducted a secondary analysis of data collected in the larger nonrandomized study. The primary outcome analysis of the entire study is reported elsewhere [24]. According to Monsalves et al [25], calculating mixed models in a nested study design is indicated if the dependent variables are at a lower level than the independent variables. Hence, as we were interested in the effect of 2 different smartphone-based interventions (level 2) on mood changes in cancer survivors from pre- to postsmartphone–based intervention, we applied mixed models as indicated in Figure 1. To estimate changes in mood, experience of presence, experience of vitality, and experience of burden, mixed model analyses were conducted using restricted maximum likelihood (REML) estimation. Separate mixed models were calculated with the three MDMQ subscales: (1) good-bad mood, (2) awake-tired, and (3) calm-nervous as dependent variables. Similarly, separate mixed models were estimated with the single-item VAS experience of presence, experience of vitality, and experience of burden as dependent variables. Further, the main effect models included assessment time (pre- vs postsmartphone–based intervention) as an independent variable and interventions nested within individual participants as random intercepts. Interaction models included an interaction effect between assessment time (pre- vs postsmartphone–based intervention) and intervention type (fairy tales vs bodily interventions) as independent variables. Moreover, these cross-level interaction models included the lowest-level variable (pre- vs postsmartphone–based intervention) as random slopes, following suggestions by Heisig and Schaeffer [26]. Additionally, separate models were calculated for both smartphone-based intervention types (fairy tales and bodily interventions) with MDMQ subscales and the VAS for the experience of presence, vitality, and burden. We excluded subjects that did not participate in the smartphone-based component of the study and handled further missing data by applying mixed models with maximum likelihood estimation. For calculating and reporting mixed models, the Logical Explanations & Visualizations of Estimates in Linear mixed model checklist by Monsalves et al [25] was followed.

Figure 1. Mixed model diagram. Mixed model diagram for a 3-level hierarchical study with 2 types of smartphone-based interventions (bodily and fairy tales) nested in patients and pre- and postintervention assessments (based on the Logical Explanations & Visualizations of Estimates in Linear checklist by Monsalves et al [25]). EMA: ecological momentary assessment; EMI: ecological momentary intervention.



We compared the subsample of patients who participated in the smartphone-based intervention with the sample only participating in the larger nonrandomized study based on the variables age, gender, and distress at baseline (assessed by the National Comprehensive Cancer Network Distress Thermometer) using chi-square tests and *t* tests for independent samples. To investigate the association between age and frequency of participation in digital interventions, the Pearson correlation coefficient was calculated. We estimated gender-specific differences in participation in the digital interventions by using *t* tests for independent samples. The data for normal distribution by histograms and qq-plots were visually inspected. We summarized sample characteristics using descriptive statistics. We followed the CONSORT (Consolidated Standards of Reporting Trials) guidelines to report results (Multimedia Appendix 2).

We used R Studio (version 1.2.5033; R Foundation for Statistical Computing) [27] for all statistical analyses and visualization, importing the data into R Studio using the R package *haven* [28]. For data preparation and descriptive statistics, we used the R package *tidyverse* [29] in addition to basic R. The R package *lme4* [30] was used to conduct mixed model analyses, and the R package *effects* [31] was used to plot the models.

Results

Participant Characteristics

We screened 171 patients, of whom 40 were scheduled to take part in the face-to-face group BPT (see the flowchart in Figure 2). In total, 39 of these patients met the inclusion criteria; 1 patient was included incorrectly. We formed 7 face-to-face psychotherapy groups, consisting of 5 to 7 patients each. Of the 40 patients scheduled to take part in the face-to-face group psychotherapy interventions of the larger nonrandomized study, 4 did not participate in the smartphone-based interventions and were thus excluded from this nested randomized controlled trial. One of the nonparticipants was the patient who had been included by mistake, 2 were dropout patients, and 1 patient took part in the group sessions but did not participate in the digital smartphone interventions. Another patient could not participate in the group sessions but agreed to take part in the smartphone-based intervention. Therefore, the results of the smartphone-based interventions are based on data from 36 participants. Participants and nonparticipants in the smartphone-based interventions did not differ significantly in terms of age (*P*=.70), gender (*P*=.43), and baseline distress (*P*=.44). Table 1 presents the sociodemographic and cancer-related characteristics of all patients participating in the nested randomized controlled trial, receiving the smartphone-based interventions.

Figure 2. Study flow. *The digital smartphone-based bodily and fairy tale (comparator) interventions were provided over a period of 5 consecutive weeks on 6 days per week in parallel to the face-to-face group BPT phase. Thus, each patient underwent 15 bodily and 15 fairy tale interventions. BPT: body psychotherapy; RCT: randomized controlled trial.

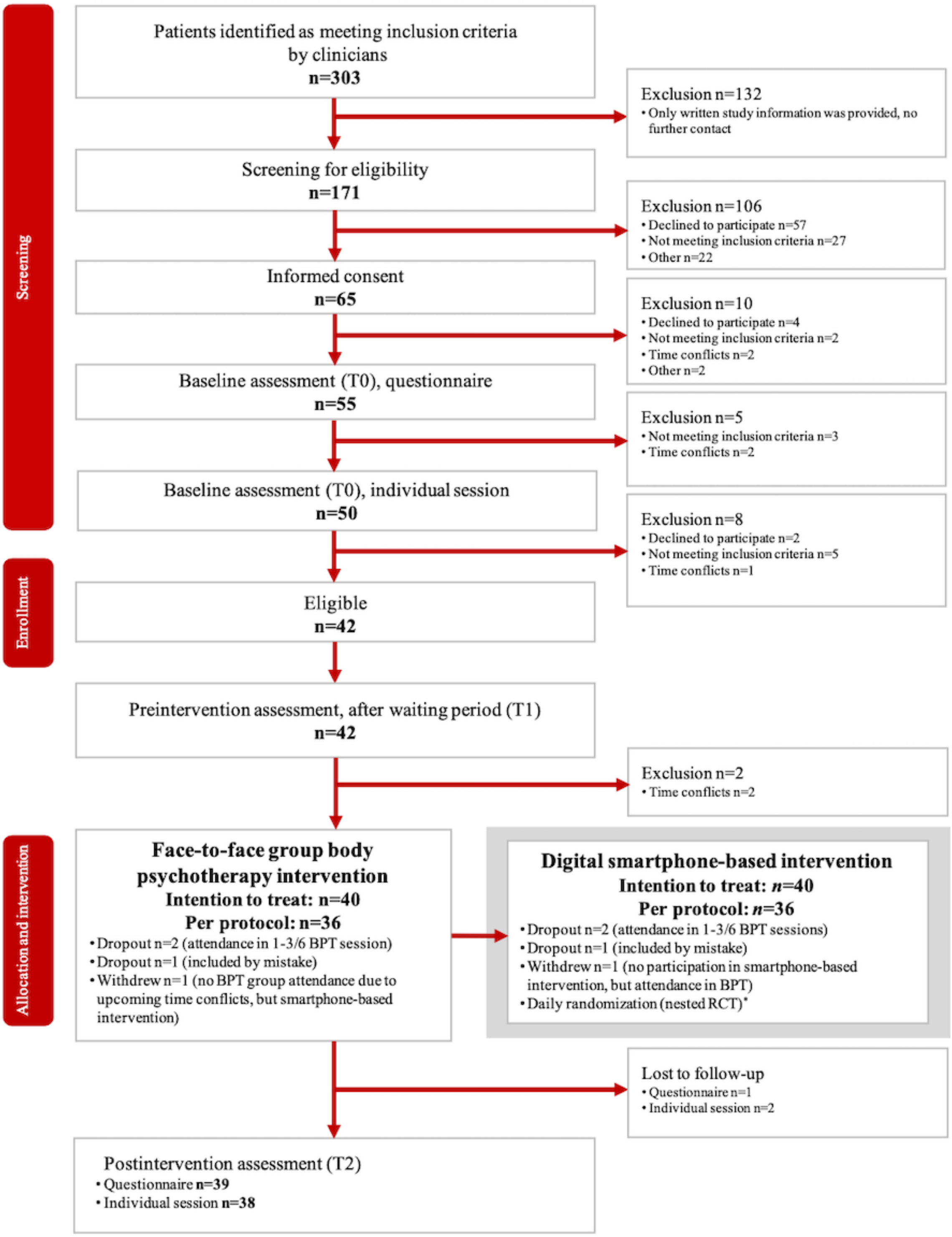


Table 1. Sample characteristics.[a]

	Intention to treat (N=40)	Per protocol (N=36)
Sex, n (%)		
Female	35 (87.5)	32 (88.9)
Male	5 (12.5)	4 (11.1)
Level of education, n (%)		
Elementary school	8 (20.5)	7 (22.9)
Secondary school	12 (30.8)	12 (31.4)
Technical college entrance qualification	8 (20.5)	5 (14.3)
High school graduation	8 (20.5)	8 (22.9)
Other certificates	3 (7.7)	3 (8.6)
Main diagnosis, n (%)		
MN[b] of breast	23 (57.5)	22 (61.1)
Hodgkin lymphoma	4 (10.0)	4 (10.9)
Non-Hodgkin lymphoma	3 (7.5)	2 (5.6)
MN of lung	2 (5.0)	2 (5.6)
MN of ovary	1 (2.5)	1 (2.8)
MN of testis	1 (2.5)	1 (2.8)
MN of rectum	1 (2.5)	1 (2.8)
MN of small intestine	1 (2.5)	—[c]
MN of tongue	1 (2.5)	1 (2.8)
MN of kidney cell	1 (2.5)	—
MN of stomach	1 (2.5)	1 (2.8)
MN of peritoneum	1 (2.5)	1 (2.8)
Age (range 22 to 77 years), mean (SD)	51.7 (13.8)	51.8 (14.4)

[a] Totals that do not add up to N=40 or N=36 are the result of missing values.

[b] MN: malignant neoplasm.

[c] Not available.

Evaluation Outcomes

Results of our key secondary outcome variables assessed using the MDMQ scales indicate that postsmartphone–based intervention's positive affectivity improved significantly (β=.27; 95% CI 0.062-0.483) and that patients became significantly calmer (β=.98; 95% CI 0.740-1.211; Table 2). However, participants did not experience significant changes in wakefulness pre- compared to postsmartphone–based intervention (β=.17; 95% CI –0.081 to 0.412). This was irrespective of the type of smartphone-based intervention. As depicted in Table 3, we did not find any interaction effect between the type of smartphone-based intervention and the change from pre- to postassessment for positive affectivity (β=–.01; 95% CI –0.439 to 0.417), calmness (β=.22; 95% CI –0.228 to 0.728), or wakefulness (β=.14; 95% CI –0.354 to 0.644). Similarly, the experience of presence (β=.34; 95% CI 0.271-0.417) and vitality (β=.35; 95% CI 0.268-0.426) increased significantly from pre- to postsmartphone–based intervention, while the experience of burden significantly decreased (β=–.40; 95% CI –0.481 to –0.311; Table 4). Again, these effects were independent of the type of smartphone-based intervention. As indicated in Table 5, there were no significant interaction effects between the type of smartphone-based intervention (bodily intervention vs fairy tale intervention) and the comparison of pre- and postassessment for the experience of presence (β=.14; 95% CI –0.104 to 0.384), the experience of vitality (β=.06; 95% CI –0.152 to 0.265), and the experience of burden (β=–0.16; 95% CI –0.358 to 0.017).

Furthermore, by calculating separate models for the 2 intervention types (Table 6), we found evidence that there was a significant increase in wakefulness in the bodily intervention (β=.25; 95% CI 0.050-0.442) but not in the comparator, fairy tales intervention (β=.09; 95% CI –0.109 to 0.290). In contrast, we found no significant pre- to postchanges of experience of presence, vitality, and burden when calculating separate models for the 2 smartphone-based intervention types (Table 7). The results of the effects related to the face-to-face BPT intervention will be reported elsewhere (personal communication by Grossert and colleagues, 2022).

Table 2. MDMQ[a] random-intercept linear mixed models: main effects of pre- and postsmartphone–based intervention (N=36; models account for nested data [patient per intervention]).

Value of category	MDMQ good[b] (*s*[c]=732)	MDMQ awake[d] (*s*=732)	MDMQ calm[e] (*s*=732)
Pre- and postassessment level variables			
Preintervention	Reference	Reference	Reference
Postintervention, β (95% CI)	.27 (0.062 to 0.483)[f]	.17 (–0.081 to 0.412)	.98 (0.740 to 1.211)[f]
$ICC_{patient}$[g]	0.534	0.500	0.479
$ICC_{intervention}$	0.032	0.043	0.041
AIC[h]	6436.23	6904.00	6756.88

[a] MDMQ: Multidimensional Mood Questionnaire.

[b] Intercept only model: intralevel correlation coefficient $(ICC)_{patient}$=0.534; $ICC_{intervention}$=0.032; Akaike information criterion (AIC)=6438.03.

[c] *s* is the number of successfully conducted interventions over all participants.

[d] Intercept only model: $ICC_{patient}$=0.500; $ICC_{intervention}$=0.043; AIC=6901.43.

[e] Intercept only model: $ICC_{patient}$=0.470; $ICC_{intervention}$=0.038; AIC=6817.11.

[f] Significant results.

[g] ICC: intralevel correlation coefficient.

[h] AIC: Akaike information criterion.

Table 3. MDMQ[a] random-intercept and random-slope linear mixed models: interaction of intervention type and pre- and postsmartphone–based intervention (N=36; models account for nested data [patient per intervention]).

Value of category	MDMQ good[b] (*s*[c]=732)	MDMQ awake[d] (*s*=732)	MDMQ calm[e] (*s*=732)
Intervention-level variables			
Fairy tale (comparator)	Reference	Reference	Reference
Bodily intervention, β (95% CI)	.35 (–0.049 to 0.689)	.47 (–0.022 to 0.855)	.12 (–0.357 to 0.596)
Pre-and postlevel variables			
Preintervention	Reference	Reference	Reference
Postintervention, β (95% CI)	.28 (–0.021 to 0.577)	.09 (–0.257 to 0.441)	.86 (0.522 to 1.187)[f]
Cross-level interaction			
Intervention and pre-post, β (95% CI)	–.01 (–0.439 to 0.417)	.14 (–0.354 to 0.644)	.22 (–0.228 to 0.728)
$ICC_{patient}$[g]	0.568	0.537	0.550
$ICC_{intervention}$	0.009	0.016	0.066
AIC[h]	6446.87	6923.23	6754.74

[a] MDMQ: Multidimensional Mood Questionnaire.

[b] Main effect model of intervention and pre-post: intralevel correlation coefficient $(ICC)_{patient}$=0.569; $ICC_{intervention}$=0.009; Akaike information criterion (AIC)=6450.40.

[c] *s* is the number of successfully conducted interventions over all participants.

[d] Main effect model of intervention and pre-post: $ICC_{patient}$=0.537; $ICC_{intervention}$=0.016; AIC=6920.78.

[e] Main effect model of intervention and pre-post: $ICC_{patient}$=0.550; $ICC_{intervention}$=0.066; AIC=6752.78.

[f] Significant results.

[g] ICC: intralevel correlation coefficient.

[h] AIC: Akaike information criterion.

Table 4. Visual analog scale random-intercept linear mixed models: main effects of pre- and postintervention (N=36; models account for nested data [patient per intervention]).

Value of category	Experience of presence[a] (*s*[b]=732)	Experience of vitality[c] (*s*=732)	Experience of burden[d] (*s*=732)
Pre- and postassessment level variables			
Preintervention	Reference	Reference	Reference
Postintervention, β (95% CI)	.34 (0.271 to 0.417)[e]	.35 (0.268 to 0.426)[e]	–.40 (–0.481 to –0.311)[e]
$ICC_{patient}$[f]	0.607	0.538	0.665
$ICC_{intervention}$	0.039	0.060	0.030
AIC[g]	14,567.56	15,330.08	15,920.78

[a] Intercept only model: intralevel correlation coefficient $(ICC)_{patient}$=0.603; $ICC_{intervention}$=0.039; Akaike information criterion (AIC)=14,645.75.

[b] *s* is the number of successfully conducted interventions over all participants.

[c] Intercept only model: $ICC_{patient}$=0.535; $ICC_{intervention}$=0.060; AIC=15,396.17.

[d] Intercept only model: $ICC_{patient}$=0.662; $ICC_{intervention}$=0.029; AIC=15,997.08.

[e] Significant results.

[f] ICC: intralevel correlation coefficient.

[g] AIC: Akaike information criterion.

Table 5. Visual analog scale random-intercept and random-slope linear mixed models: interaction of intervention type and pre- and postintervention (N=36; models account for nested data [patient per intervention]).

Value of category	Experience of presence[a] (*s*[b]=732)	Experience of vitality[c] (*s*=732)	Experience of burden[d] (*s*=732)
Intervention-level variables			
Fairy tale (comparator)	Reference	Reference	Reference
Bodily interventions, β (95% CI)	.05 (–0.161 to 0.254)	.08 (–0.168 to 0.319)	.02 (–0.244 to 0.276)
Pre- and postlevel variables			
Preintervention	Reference	Reference	Reference
Postintervention, β (95% CI)	.32 (0.120 to 0.515)[e]	.31 (0.151 to 0.478)[e]	–.34 (–0.522 to –0.159)[e]
Cross-level interaction			
Intervention and pre-post, β (95% CI)	.14 (–0.104 to 0.384)	0.06 (–0.152 to 0.265)	–.16 (–0.358 to 0.017)
$ICC_{patient}$[f]	0.570	0.551	0.655
$ICC_{intervention}$	0.036	0.043	0.033
AIC[g]	14,479.56	15,316.24	15,902.87

[a] Main effect model of intervention and pre-post: intralevel correlation coefficient $(ICC)_{patient}$=0.570; $ICC_{intervention}$=0.036; Akaike information criterion (AIC)=14,476.51.

[b] *s* is the number of successfully conducted interventions over all participants.

[c] Main effect model of intervention and pre-post: $ICC_{patient}$=0.551; $ICC_{intervention}$=0.042; AIC=15,311.86.

[d] Main effect model of intervention and pre-post: $ICC_{patient}$=0.654; $ICC_{intervention}$=0.033; AIC=15,901.09.

[e] Significant results.

[f] ICC: intralevel correlation coefficient.

[g] AIC: Akaike information criterion.

Table 6. MDMQ[a] random-intercept linear mixed models main effects of pre- and postintervention separately for bodily interventions and fairy tales interventions (comparator; N=36).

Value of category	MDMQ good[b] (s[c]=732)	MDMQ awake[d] (s=732)	MDMQ calm[e] (s=732)
Fairy tales (comparator)			
Preintervention	Reference	Reference	Reference
Postintervention, β (95% CI)	.27 (0.097 to 0.452)[f]	.09 (–0.109 to 0.290)	.85 (0.669 to 1.039)[f]
$ICC_{patient}$[g]	0.479	0.531	0.004
$ICC_{intervention}$	0.030	0.003	0.526
AIC[h]	10,063.42	10,593.79	10,260.67
Bodily interventions			
Preintervention	Reference	Reference	Reference
Postintervention, β (95% CI)	.27 (0.111 to 0.426)[f]	.25 (0.050 to 0.442)[f]	1.11 (0.914 to 1.300)[f]
$ICC_{patient}$	0.367	0.121	0.013
$ICC_{intervention}$	0.307	0.470	0.561
AIC	8812.84	9740.26	9622.30

[a] MDMQ: Multidimensional Mood Questionnaire.

[b] Intercept only model of bodily interventions: intralevel correlation coefficient $(ICC)_{patient}$=0.366; $ICC_{intervention}$=0.307; Akaike information criterion (AIC)=8818.81; intercept only model of fairy tales: $ICC_{patient}$=0.474; $ICC_{intervention}$=0.034; AIC=10,067.62.

[c] s is the number of successfully conducted interventions over all participants.

[d] Intercept only model of bodily interventions: ICC patient=0.097; $ICC_{intervention}$=0.494; AIC=9741.52; intercept only model of fairy tales: $ICC_{patient}$=0.531; $ICC_{intervention}$=0.003; AIC=10,589.84.

[e] Intercept only model of bodily interventions: $ICC_{patient}$=0.038; $ICC_{intervention}$=0.520; AIC=9742.46; intercept only model of fairy tales: $ICC_{patient}$=0.002; $ICC_{intervention}$=0.519; AIC=10,335.96.

[f] Significant results.

[g] ICC: intralevel correlation coefficient.

[h] AIC: Akaike information criterion.

Table 7. Visual analog scale random-intercept linear mixed models main effects of pre- and postintervention separately for bodily interventions and fairy tales interventions (comparator; N=36; models account for nested data [patient per intervention]).

Value of category	Experience of presence[a] (s[b]=732)	Experience of vitality[c] (s=732)	Experience of burden[d] (s=732)
Fairy tales (comparator)			
Preintervention	Reference	Reference	Reference
Postintervention, β (95% CI)	.27 (0.177 to 0.368)[e]	.30 (0.194 to 0.415)[e]	–.32 (–0.440 to –0.200)[e]
$ICC_{patient}$[f]	0.406	0.220	0.335
$ICC_{intervention}$	0.285	0.402	0.332
AIC[g]	7282.42	7946.26	8315.11
Bodily interventions			
Preintervention	Reference	Reference	Reference
Postintervention, β (95% CI)	.42 (0.310 to 0.532)[e]	.39 (0.278 to 0.507)[e]	–.48 (–0.598 to –0.357)[e]
$ICC_{patient}$	0.137	0.577	0.319
$ICC_{intervention}$	0.464	0.00003	0.405
AIC	7331.91	7447.89	7691.17

[a] Intercept only model of bodily interventions: intralevel correlation coefficient $(ICC)_{patient}$=0.139; $ICC_{intervention}$=0.456; Akaike information criterion (AIC)=7380.44; intercept only model of fairy tales: $ICC_{patient}$=0.387; $ICC_{intervention}$=0.301; AIC=7307.48.

[b] s is the number of successfully conducted interventions over all participants.

[c] Intercept only model of bodily interventions: $ICC_{patient}$=0.535; $ICC_{intervention}$=0.037; AIC=7486.92; intercept only model of fairy tales: $ICC_{patient}$=0.215; $ICC_{intervention}$=0.405; AIC=7969.31.

[d] Intercept only model of bodily interventions: $ICC_{patient}$=0.425; $ICC_{intervention}$=0.294; AIC=7745.00; intercept only model of fairy tales: $ICC_{patient}$=0.330; $ICC_{intervention}$=0.334; AIC=8336.69.

[e] Significant results.

[f] ICC: intralevel correlation coefficient.

[g] AIC: Akaike information criterion.

Results of this secondary analysis were based on a total of s=732 interventions of 36 patients. These patients participated in 65.5% (354/540) of the smartphone-based bodily interventions and in 70% (378/540) of the smartphone-based control interventions (fairy tales). The frequency distribution of interventions per category over all patients is depicted in Multimedia Appendix 3. There were no statistically significant associations of the frequency of participation in the smartphone interventions with the age of the participants (r_{34}=0.08; P=.64) and with gender (r_{34}=–0.11; P=.23). Pre- and postsmartphone–based intervention, mean and SD of the MDMQ subscales and the 3 VAS items are depicted in Multimedia Appendix 4.

Discussion

Principal Results

The aim of this exploratory secondary analysis was to evaluate the potential of smartphone-based bodily interventions focusing on related mood changes from pre- to post-EMI in cancer survivors with body image disturbances. We compared smartphone-based bodily interventions with smartphone-based fairy tale interventions (comparator) using a within-subject design. Over the course of 5 consecutive weeks, participants were randomly assigned daily to either the bodily or fairy tale intervention (comparator). We blended face-to-face psychotherapy with this smartphone-based intervention. It was hypothesized that the mood of cancer survivors improves from pre- to postsmartphone–based bodily interventions. Furthermore, we expected that mood improvement was greater following bodily interventions as compared to fairy tales (comparator). Results indicate that the mood of patients with cancer who are in posttreatment improved following smartphone-based interventions, irrespective of the intervention type. Accordingly, results support the first part of our hypotheses but not the second. Hence, listening to fairy tales might have equally soothing and calming effects on people's moods as bodily interventions [32]. Notably, the mere action of pausing daily life and listening to an audio clip might have positive effects on the general population and on cancer survivors' moods. This phenomenon may in part also explain our findings that suggest the "active ingredients" of bodily interventions in the form of smartphone-based EMIs cannot fully explain mood improvements in cancer survivors. Further, in the context of the design of blended therapies, our study does not support the notion that the digital intervention component requires to be conceptually in line with the face-to-face intervention component [13].

In addition, we found no indication of an association between the patients' age and the frequency of applying the smartphone-based intervention. Hence, there was no indication that younger patients were more skilled or motivated to use smartphone-based interventions as compared to older patients. Notably, the identified participation rates of between 65.5% and 70.0% can be seen as largely satisfactory, yet still indicate relevant potential for improvement, for example, by extending the time window in which patients were granted access to the daily digital interventions or by applying daily smartphone push notifications to remind patients to take part in the digital interventions. Importantly, mood differences from pre- to postsmartphone–based interventions were statistically significant but rather small in magnitude, indicating that a sequence of digital interventions with accumulating treatment effects [23] may be required to obtain clinically significant changes.

Overall, the findings of this study indicate that blending face-to-face BPT for cancer survivors with smartphone-based interventions is not only feasible—in line with previous reports on group therapy for depression [33], but is also likely to at least temporarily improve patients' mood.

Strengths and Limitations

Our study has several strengths. First, we used common technology (ie, no installation of special apps required) to provide daily and easily available body psychotherapeutic interventions, facilitating the uptake and translation of the interventions into routine clinical practice. Second, patients were free with regard to the timing of the smartphone-based interventions during everyday life, allowing a rather flexible integration of the smartphone-based intervention into daily routines. Third, smartphone-based interventions were designed to be very intuitive and straightforward to use, not requiring high internet or smartphone literacy of patients, further facilitating the uptake of the technology. Notably, the application of this kind of smartphone-based intervention could be particularly interesting for older patient populations and people with little smartphone or internet-related knowledge. Limitations of this study include a rather small number of included patients, which was only partially compensated by the up to 30 smartphone-based intervention sessions per patient. Our study was also limited by the fact that women with breast cancer were overrepresented. Although our group BPT was open to all patients with cancer who are in posttreatment with any malignant neoplasm, only 4 men participated. This should be taken into consideration when generalizing our findings. Furthermore, we could not blind participants with regard to the intervention. Hence, it is possible that patients were aware of what was the intervention of interest (bodily intervention) and what was the comparator (fairy tales). This may have resulted in biased mood assessments pre- and postsmartphone–based interventions. Nevertheless, we did not inform patients that the overall goal of the smartphone-based interventions was to compare the effects of bodily interventions with that of fairy tales on mood. Importantly, we measured changes in mood but not in bodily disturbances in relation to the smartphone-based interventions. Changes in bodily well-being were merely assessed at baseline (T0) and pre- (T1) and post- (T2) group face-to-face BPT intervention [15]. Thus, it remains unclear whether there were differences in effectiveness between the 2 smartphone-based interventions in terms of changing bodily disturbances or body mindfulness. Notably, fairy tales as an active comparator may have been a too powerful intervention strategy to detect significant differences. Furthermore, it was not possible to verify whether patients actually performed the smartphone-based bodily interventions or whether they just listened to the audio instructions. Thus, we could not distinguish between potential effects on mood, which resulted from merely listening to audio-guided bodily interventions and potential effects from performing the exercises. Finally, it is yet to be determined for how long the observed mood improvements following smartphone-based intervention persist in cancer survivors.

Conclusions and Implications

The number of patients surviving cancer continues to rise. For example, there were 16.9 million cancer survivors in the United States on January 1, 2019 [34]. Many of them must cope with the physical effects of cancer and its treatment, potentially leading to functional, cognitive, and psychological impairments. Beyond that, in recent years, psychosocial interventions have gained increasing importance [35]. To further improve health-related quality of life in patients with cancer, innovative and scalable approaches are highly warranted.

The results of this study suggest that smartphone-based bodily interventions, which can be combined with face-to-face psychotherapy in terms of blended therapy may represent such an innovative intervention. This study underlines the feasibility and acceptance of smartphone-based interventions in postcancer survivors with bodily disturbances. These represent a new, promising treatment model that can be offered as a low-threshold supplement to face-to-face psychotherapy.

Acknowledgments

The authors are grateful to their participants for their commitment to this research project. Furthermore, the authors would like to thank the participating departments in Basel and Winterthur and their staff. This study was funded by the Swiss Cancer League (grant KLS-4304-08-2017). The funding source was not involved in the design or conduct of the study; in the collection, management, analysis, or interpretation of the data; or in the preparation, review, or approval of the paper. GM and RS received funding from the Stanley Thomas Johnson Stiftung & Gottfried und Julia Bangerter-Rhyner-Stiftung under projects PC 28/17 and PC 05/18 and from Gesundheitsförderung Schweiz (project 18.191/K50001). GM received funding from the Research Foundation of the International Psychoanalytic University Berlin and from the Swiss National Science Foundation (project 100014_135328). RS received funding from the Köhler Stiftung (project SO112/10209/16).

Data Availability

Due to the nature of this research, participants of this study did not agree for their data to be shared publicly; hence, supporting data are not available.

Authors' Contributions

GM conceptualized the interventions and the study design. He participated in obtaining funding, supervision of the study, data assembly, analysis, and interpretation, and in the writing of the paper. AG (coordinating investigator) conceptualized the interventions and study design, obtained funding, and provided study materials. Further, AG was one of the 2 body psychotherapy therapists and took part in patients' recruitment, study coordination, collection, and assembly of data and its interpretation, as well as in the writing of the paper. CM participated in the entire coordination of the study, its design, collection, and assembly of data. NR conducted the data analysis and interpretation and contributed to the writing of the paper. BW, UG, VH, CR, and SH contributed to the study design and participated in obtaining funding. MP was responsible for the conduct of the study in Winterthur. RS (sponsor investigator) conceptualized the interventions and the study design. He participated in obtaining funding, supervision of the study and its coordination, data interpretation, and in the writing of the paper. All authors read and approved the final paper.

Conflicts of Interest

RS received funding from the Stanley Thomas Johnson Stiftung & Gottfried und Julia Bangerter-Rhyner-Stiftung under projects number PC 28/17 and PC 05/18, from the Swiss Cancer League (Krebsliga Schweiz) under project number KLS-4304-08-2017, from Promotion Santé Suisse (Gesundheitsförderung Schweiz) under contract number 18.191/ K50001, from the Health Departement Basel-City, in the context of a Horizon Europe project from the Swiss State Secretariat for Education, Research and lnnovation (SERI) under contract number 22.00094, and from Wings Healths in the context of a proof of concept study. RS received a speaker honorarium from Novartis. He is chairman of the Basel Institute for Psychosomatic Medicine (BIPM) and founder and managing director of the Psychosomatic and Psychosocial Services GmbH, that develops and implements psychosomatic and psychosocial training and continuing education programs. RS is member of the Swiss Academy of Psychosomatic and Psychosocial Medicine (SAPPM), of the Société Médicale Suisse d'Hypnose (SMSH), of the Dt. Kollegium für Psychosomatische Medizin (DKPM), of the Dt. Gesellschaft für Psychosomatische Medizin und Ärztliche Psychotherapie (DGPM), and of the German Balint Society. He is member of the board of trustees of the Foundation Psychosomatic and Social Medicine (Ascona Foundation).

Multimedia Appendix 1
Content of interventions: group body psychotherapy with patients with cancer and smartphone-based bodily interventions (published in Grossert et al [15]).
[DOCX File , 23 KB - cancer_v9i1e38515_app1.docx]

Multimedia Appendix 2
CONSORT-eHEALTH checklist (V 1.6.1).
[PDF File (Adobe PDF File), 401 KB - cancer_v9i1e38515_app2.pdf]

Multimedia Appendix 3
Distribution of intervention frequency (number of interventions).
[PNG File , 21 KB - cancer_v9i1e38515_app3.png]

Multimedia Appendix 4
Descriptive values of pre- and postsmartphone–based intervention assessments.
[DOCX File , 19 KB - cancer_v9i1e38515_app4.docx]

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Abbreviations

BPT: body psychotherapy
CONSORT: Consolidated Standards of Reporting Trials
EKNZ: Ethikkommission Nord und Zentralschweiz
EMI: ecological momentary intervention
MDMQ: Multidimensional Mood Questionnaire
REML: restricted maximum likelihood
VAS: visual analog scale

Edited by A Mavragani; submitted 11.05.22; peer-reviewed by A Mpillis, S Schlaepfer; comments to author 01.02.23; revised version received 23.03.23; accepted 27.04.23; published 28.08.23.

Please cite as:
Meinlschmidt G, Grossert A, Meffert C, Roemmel N, Hess V, Rochlitz C, Pless M, Hunziker S, Wössmer B, Geuter U, Schaefert R
Smartphone-Based Psychotherapeutic Interventions in Blended Care of Cancer Survivors: Nested Randomized Clinical Trial
JMIR Cancer 2023;9:e38515
URL: https://cancer.jmir.org/2023/1/e38515
doi:10.2196/38515
PMID:37639296

Original Paper

Effects of Web-Based and Mobile Self-Care Support in Addition to Standard Care in Patients After Radical Prostatectomy: Randomized Controlled Trial

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Abstract

Background: Prostate cancer is a common form of cancer that is often treated with radical prostatectomy, which can leave patients with urinary incontinence and sexual dysfunction. Self-care (pelvic floor muscle exercises and physical activity) is recommended to reduce the side effects. As more and more men are living in the aftermath of treatment, effective rehabilitation support is warranted. Digital self-care support has the potential to improve patient outcomes, but it has rarely been evaluated longitudinally in randomized controlled trials. Therefore, we developed and evaluated the effects of digital self-care support (electronic Patient Activation in Treatment at Home [ePATH]) on prostate-specific symptoms.

Objective: This study aimed to investigate the effects of web-based and mobile self-care support on urinary continence, sexual function, and self-care, compared with standard care, at 1, 3, 6, and 12 months after radical prostatectomy.

Methods: A multicenter randomized controlled trial with 2 study arms was conducted, with the longitudinal effects of additional digital self-care support (ePATH) compared with those of standard care alone. ePATH was designed based on the self-determination theory to strengthen patients' activation in self-care through nurse-assisted individualized modules. Men planned for radical prostatectomy at 3 county hospitals in southern Sweden were included offline and randomly assigned to the intervention or control group. The effects of ePATH were evaluated for 1 year after surgery using self-assessed questionnaires. Linear mixed models and ordinal regression analyses were performed.

Results: This study included 170 men (85 in each group) from January 2018 to December 2019. The participants in the intervention and control groups did not differ in their demographic characteristics. In the intervention group, 64% (53/83) of the participants used ePATH, but the use declined over time. The linear mixed model showed no substantial differences between the groups in urinary continence ($\beta=-5.60$; *P*=.09; 95% CI −12.15 to −0.96) or sexual function ($\beta=-.12$; *P*=.97; 95% CI −7.05 to −6.81). Participants in the intervention and control groups did not differ in physical activity (odds ratio 1.16, 95% CI 0.71-1.89; *P*=.57) or pelvic floor muscle exercises (odds ratio 1.51, 95% CI 0.86-2.66; *P*=.15).

Conclusions: ePATH did not affect postoperative side effects or self-care but reflected how this support may work in typical clinical conditions. To complement standard rehabilitation, digital self-care support must be adapted to the context and individual preferences for use and effect.

Trial Registration: ISRCTN Registry ISRCTN18055968; https://www.isrctn.com/ISRCTN18055968

International Registered Report Identifier (IRRID): RR2-10.2196/11625

(JMIR Cancer 2023;9:e44320) doi:10.2196/44320

KEYWORDS

eHealth; linear mixed model; prostatic neoplasms; radical prostatectomy; randomized controlled trial; self-care; telemedicine; mobile health; mHealth; prostate cancer; sexual dysfunction; urinary incontinence; web-based; pelvic exercise; physical activity

Introduction

Background

Prostate cancer is one of the most common forms of cancer worldwide. The survival rate is >93% thanks to improved care [1], meaning that a growing number of men are living with the consequences of treatment. One of the most common treatments is radical prostatectomy, which can have side effects that decrease the quality of life [2]. The most commonly reported side effects of radical prostatectomy are urinary incontinence and sexual dysfunction [3]. The psychological impact of a prostate cancer diagnosis and its treatment, with uncertainty and worries about the future [4,5], may impact recovery and engagement in self-care. Participation and engagement in self-care increase the likelihood of living life as desired [6].

Self-care recommendations for patients with prostate cancer focus on pelvic floor muscle exercises and physical activity but also include recommendations on tobacco cessation, penile rehabilitation, and limited alcohol consumption [7]. Sexual function can benefit from pelvic floor muscle exercises [8] and physical activity, which can increase feelings of masculinity [9]. Sexual rehabilitation includes pharmacological treatments for erectile function, partner engagement, and processing of psychological aspects, making self-care recommendations multifaceted [10]. Physical activity has been found to reduce incontinence [11] and cancer-specific fatigue while increasing cancer-specific quality of life, fitness, and body strength [12]. Pelvic floor muscle exercises are recommended, as they have been shown to shorten the time of recovery from urinary incontinence postoperatively [13]. Although research indicates that adherence is crucial for the efficacy of pelvic floor muscle exercises [14], it may be difficult to mobilize and maintain motivation and self-care behaviors over a long time, resulting in increased symptoms. Men with prostate cancer describe that they need to change and adapt their lifestyle so that self-care can fit into everyday life [15] and they need easily accessible and individual support for self-care throughout rehabilitation [16]. A recent review and meta-analysis showed that the most significant benefits of pelvic floor muscle exercises seemed to be achieved under the guidance and supervision of a therapist, compared with when using only verbal instructions. The availability of therapists may vary, and alternative routes to access support could benefit patients [17].

Systematic reviews show that interventions to increase physical activity in prostate cancer rehabilitation can have positive effects; however, more research on optimal delivery methods to reach patients throughout their rehabilitation has been suggested [18,19]. Furthermore, internet-based programs for psychosocial support show positive effects on psychological aspects but not on health-related quality of life [20,21]. Programs often reveal low engagement in the interventions [22], and there is a scarcity of research on long-term effects [23]. Achieving behavior change requires programs that go beyond providing information and instruct on why a change is needed and how it can be made [19]. Web-based interventions to support patients with prostate cancer differ in design, and no consensus has been reached on the best way to engage patients in long-term self-care for symptom relief [24]. Furthermore, the interventions currently offered tend not to be adaptable to the differing needs of men with prostate cancer across the recovery trajectory [22,25]. Although some interventions show improved symptom burden in patients with prostate cancer in the first months after surgery [18-21], to our knowledge, the long-term effects have only been sparsely evaluated in randomized controlled trials.

Providing web-based support for a range of problems in cancer rehabilitation could be a way to meet the increasing number of patients where they usually go for information and support [26], thereby increasing accessibility. Digital self-care support called electronic Patient Activation in Treatment at Home (ePATH) is a web-based and mobile app [27,28] accessible to patients for 1 year after radical prostatectomy. It offers cohesive support for self-care, focusing on self-care to reduce the most common problems after surgery (urinary incontinence and sexual dysfunction).

Objective

In this study, we compared the effect of additional ePATH support with the effect of standard care alone on postoperative complications and adherence to self-care after radical prostatectomy over a 1-year period. The specific aims were to investigate the effects of the ePATH intervention on (1) urinary continence and (2) sexual function and adherence to self-care recommendations in (3) pelvic floor muscle exercises and (4) physical activity.

Methods

Study Design

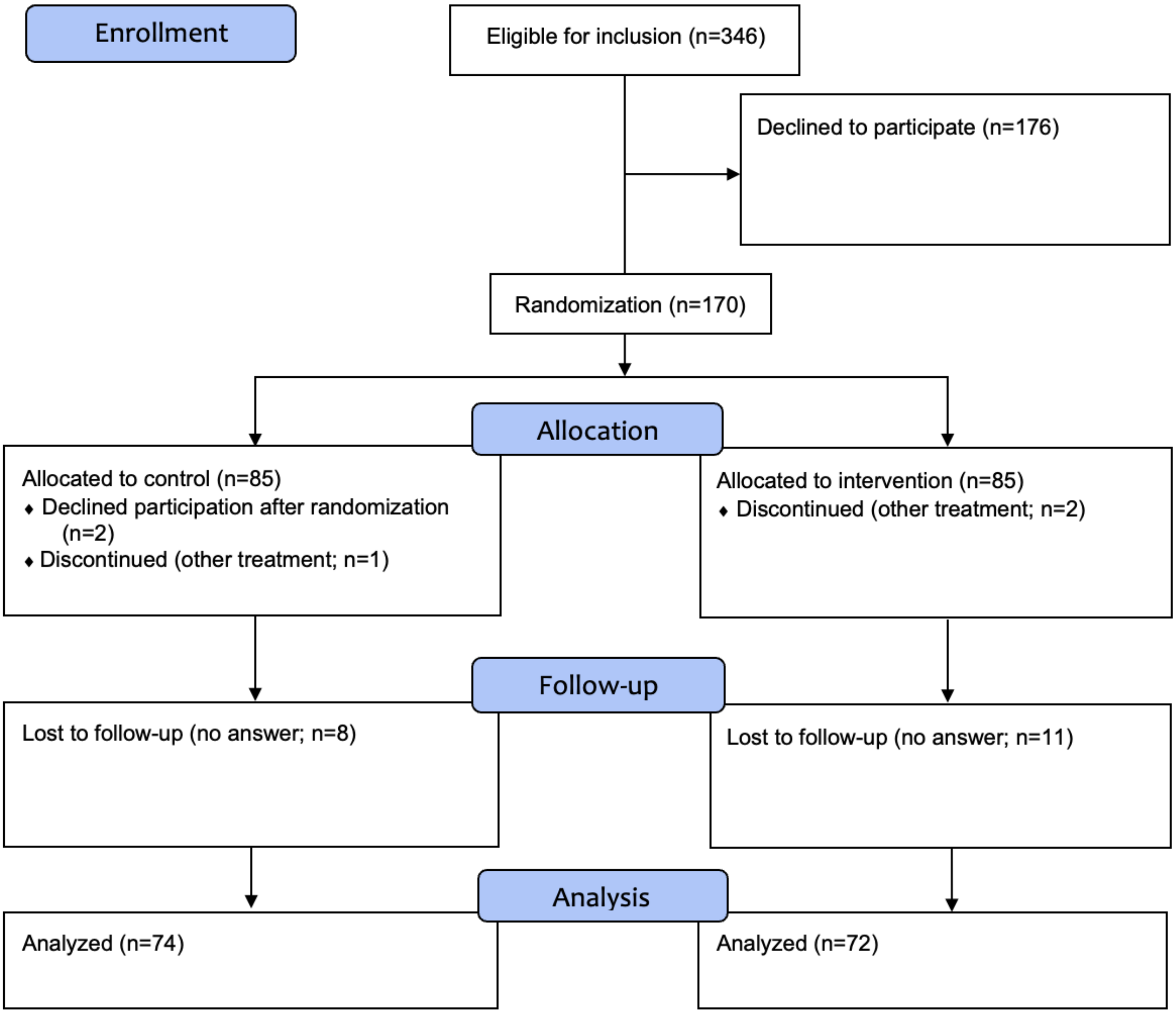
This multicenter block-randomized controlled trial with 2 study arms had a longitudinal design with follow-up measures at 1, 3, 6, and 12 months after surgery. The study was conducted in routine clinical practice to strengthen external validity and increase the possibility of implementation at a larger scale [29]. The study was designed in accordance with the Medical Research Council’s framework for the evaluation of complex interventions [30,31], and a study protocol has previously been published [32]. The study followed the CONSORT-EHEALTH (Consolidated Standards of Reporting Trials of Electronic and Mobile Health Applications and Online Telehealth; version 1.6) [33]. The trial was registered in the International Standard Randomized Controlled Trial registry (ClinicalTrials.gov NCT18055968) and International Registered Report Identifier (10.2196/11625).

Participants and Setting

A total of 170 men (Figure 1) from 3 urology departments at county hospitals in southern Sweden participated in this study. The 3 hospitals were situated in regions with approximately

94,000 to 360,000 citizens. Each of the 3 sites performed 45 to 125 radical prostatectomies annually (2020). The care organizations at the 3 sites differed somewhat, meaning that the inclusion process varied slightly, but all the included clinics used the national standardized care trajectory. One site provided preoperative information in groups and regular postoperative appointments with a clinical sexologist. Another site provided individual preoperative information, postoperative sexual medicine counseling by a urotherapist, and a series of group seminars after treatment. The third site offered preoperative individual information and postoperative counseling by a sexual medicine counselor. All patients could contact their cancer nurse specialist or urotherapist when needed.

Figure 1. CONSORT (Consolidated Standards of Reporting Trials) flow diagram. The intervention group and control group allocated 85 men each. Five men withdrew from participation because of other treatment or without giving a reason. No answers were received from 19 men, who were considered lost to follow-up.



Sample Size

The sample size was calculated with a 2-sided 5% significance level and power of 80% based on the sample size table and suggested end point provided by developers of the Expanded Prostate Cancer Index Composite (EPIC) [34]. As recommended by the developers of the EPIC, to show clinical importance, the effect size was set at 0.5 [35], and a medium effect [36,37] and 4 domains of EPIC were used. This required a sample size of 114 patients per group, given a dropout rate of 25% [28].

Recruitment

Recruitment began in January 2018 and was completed in December 2019. Data collection was completed in January 2021. All men scheduled for radical prostatectomy who met the inclusion criteria at the 3 hospitals were eligible for inclusion. They received preoperative written information about the study and a manual for ePATH from their cancer nurse specialist in conjunction with the treatment decision. Approximately a week after receiving written information, the men were asked verbally by the cancer nurse specialist about participation; if they chose to participate, a signed consent form was sent by post to the researchers. Inclusion took place every alternate week, during which new participants received the baseline survey by one of the researchers (AH).

The inclusion criteria were having intermediate- or high-risk localized prostate cancer, being treated with radical prostatectomy, being aged >18 years, being able to speak Swedish, having a facility for secure mobile log-in, being computer literate (assessed by each man himself), and having an active email address. The exclusion criterion was having a cognitive impairment, to the extent that the patient would not be able to participate in the intervention fully (assessed by the cancer nurse specialist from medical records and personal communication).

Intervention

The ePATH Intervention

The intervention group received access to ePATH through the web or mobile app in addition to standard care [7]. The ePATH intervention was developed by the research group to address the need for self-care support that has been identified during rehabilitation after radical prostatectomy [32,38]. ePATH was tested for quality and usability in a collaborative approach with end-user groups to address various needs for self-care support [27,28]. Minor bugs in the system were fixed during the evaluation process, but no changes were made to the content. The ePATH intervention is theory driven (self-determination theory) and based on the assumption that autonomy, competence, and relatedness foster intrinsic motivation and enhance engagement in self-care [39,40]. ePATH serves to increase the patient's activation by improving the knowledge, skills, and confidence to manage self-care as well as creating the necessary support for adopting the desired self-care behavior into daily life and maintaining it over time.

The cancer nurse specialists at the 3 sites received information and instructions on how to administer and introduce ePATH through meetings with the research group at the beginning of the study. One researcher (CW) was the primary contact person for the cancer nurse specialists during the inclusion of patients if questions arose or if technical support was needed.

The cancer nurse specialists tailored the information and support in ePATH into interactive self-care modules based on each patient's needs. For example, if a patient used tobacco, a module concerning tobacco cessation was added, and other modules could be adjusted depending on whether a patient was physically active or not preoperatively, to fit the patient's goals. Self-care in ePATH focuses primarily on pelvic floor muscle exercises (Kegel: contractions and relaxations of the pelvic floor muscles), which are recommended 3 times per day, and physical activity, including endurance and resistance training. To further support sexual rehabilitation, patients were provided with supplementary information on changes that could occur in sexual function after radical prostatectomy and on available pharmacological treatments for erectile dysfunction. The participants could use and personalize their account to fit individual circumstances and preferences in whatever way they preferred, including times of day or days of the week to perform exercises. The participants were free to use the ePATH account as they felt appropriate [28].

One module provided individualized information about the diagnosis, treatment, and rehabilitation. Another module explained why self-care was warranted. Patients had the possibility to register self-care completed, rate self-care efforts (eg, intensity of physical activities), and set goals for self-care. Patients could also receive reminders on self-care as notifications through the mobile app if they chose to activate that feature. One module provided information on how to assess health and evaluate self-care. Patients could see graphs of performed self-care in relation to symptoms experienced (eg, pelvic floor muscle exercises in relation to urinary continence over time). ePATH also included a function for messaging the cancer nurse specialists for support and guidance through a secure pathway. The cancer nurse specialists read and answered patient messages daily (asynchronously) but did not check patient engagement in ePATH.

Control Condition

The control group received care in accordance with the standardized cancer care trajectory in Sweden (standard care). The national strategy states that each patient with cancer should be offered a personal cancer nurse specialist for psychosocial support and coordinating care. All men scheduled for radical prostatectomy received written information on self-care as well as verbal information about rehabilitation, pre- and postoperatively, in conjunction with regular contact with health care. In accordance with the standardized care trajectory, the cancer nurse specialists contacted men in conjunction with the regular prostate-specific antigen checkups, usually performed at 3- or 6-month intervals, asking about overall well-being and side effects of treatment [7].

Randomization and Blinding

Three block randomization lists (1 list per site) were created by an independent statistician using Microsoft Excel to ensure an even distribution in the intervention and control groups between sites. The predetermined randomization lists were kept in sealed, sequentially numbered envelopes, consecutively opened by CW to reveal the allocation to the intervention or control group. CW created ePATH accounts for the men in the intervention group, and the cancer nurse specialists individualized the information and functions. All men were notified via email (from CW) regarding their randomization into either the intervention or control group, approximately 1 week after completing the baseline questionnaire. Those in the intervention group also received a message in ePATH from their cancer nurse specialist, informing them when their account was ready to use.

Both groups answered web questionnaires (paper was not an option) at baseline and at 1, 3, 6, and 12 months after radical prostatectomy. For each follow-up, 2 reminders were sent by email (within 10 days). Questionnaire responses were processed by CW. The nature of the intervention meant that there was no possibility of blinding the intervention researcher (CW), cancer nurse specialists, or participating men.

Measures

Characteristics of the Participants

Self-reported demographic data (age, education, household income, and marital status) were obtained at baseline. Data on the Gleason score (used to evaluate cancer severity), length of hospital stay, complications, and nerve-sparing surgery [7] were retrieved from the medical records by the cancer nurse specialist once the patient provided informed consent.

Primary Outcomes

Two domains of the EPIC were used to study the primary outcomes (urinary continence and sexual function). This is a validated comprehensive questionnaire for examining patient function and bother after prostate cancer treatment, including surgery, radiotherapy, and hormonal therapy. The questionnaire contains 26 questions encompassing the domains *Urinary Incontinence*, *Urinary Irritative*, *Bowel*, *Sexual*, and *Hormonal*. Here, the *Urinary Incontinence* and *Sexual* domains were chosen because they were relevant for patients after radical prostatectomy. The other domains mainly focus on function and bother after radiotherapy and hormonal treatment [41].

The *Urinary Incontinence* domain contains 4 questions measuring urinary continence. The *Sexual* domain includes 6 questions concerning sexual function after prostate cancer treatment. For both these domains, answers are given on a Likert scale with 4 or 5 levels and then converted to a 0 to 100 score. The total score for each domain was calculated by adding the scores for each question and dividing it by the number of questions. Higher scores represent better urinary continence (less urinary incontinence) and better sexual function (better erectile and orgasmic function and overall satisfaction). The scores on these 2 domains were calculated 1, 3, 6, and 12 months after surgery. At baseline, single questions measuring urinary continence and sexual function from the respective domains of the EPIC were used.

Secondary Outcomes

Physical activity was assessed using the Saltin-Grimby Physical Activity Level Scale [42,43] at all time points. Participants rated their level and frequency of physical activity per week on a 4-point scale: 1=sedentary, 2=some physical activity, 3=regular physical activity and training, and 4=regular hard physical training.

Pelvic floor muscle exercises were assessed using a single item on the frequency of postoperative pelvic floor muscle exercises. Participants rated their performance on pelvic floor muscle exercises as 0=never, 1=once a day, 2=2 times a day, 3=3 times a day, or 4=>3 times a day.

Use of ePATH

Log data were retrieved from the ePATH server to investigate use. Men in the intervention group were categorized as ePATH users if they had logged into ePATH more than once or registered self-care in ePATH. Those who had logged in once or not at all were categorized as nonusers.

Statistical Analyses

Data were analyzed using SPSS software (version 26; IBM Corp) for Windows [44]. Analysis of the missing data showed that 19 participants had not provided data on any of the outcome measures. Not all individuals need to be included in an intention-to-treat analysis, as the accuracy of the analysis is based on whether its assumptions are valid [45]. The analysis used here can be referred to as a modified intention-to-treat analysis [46]. We excluded participants without any data, resulting in 146 participants (74 in the control group and 72 in the intervention group) being included in the final analysis (Figure 1). An analysis of the missing data patterns for the remaining participants showed missing values at the individual level over time for approximately 15% of the outcome measures. Therefore, we imputed the data using multiple imputations with predictive mean matching [47]. Five imputation rounds were performed, and the pooled values of these imputations are presented. An analysis of sensitivity was performed, comparing the final models with unimputed data [45,48].

Descriptive statistics, such as percentage distributions, were used to describe the participant characteristics and baseline data. Means and SDs were used to describe the normally distributed continuous variables. To identify differences between groups (intervention or control), Pearson chi-square test was used for nominal variables, the Mann-Whitney *U* test for ordinal variables, and the independent 2-tailed Student *t* test for continuous variables. A 2-sided significance level of <.05 was used for all statistical tests. Normal distribution was assessed based on visual evaluations of histograms and plots. Individual trajectories were plotted on a simple line graph for the sample to obtain an overview of the variation at baseline and the development over time.

We conducted 2 different multivariate analyses to investigate the longitudinal effects of treatment on primary and secondary outcome variables.

Linear mixed models were used to investigate the difference between the intervention and control groups in primary outcome measures, in a sequence of 4 models, and to assess the mean score differences over time for continuous variables [49]. We applied fixed effects of time and group using an unstructured correlation structure with 4 repeated measures (1, 3, 6, and 12 months postoperatively).

To investigate the longitudinal effects of the ePATH intervention on the secondary outcomes (physical activity and pelvic floor muscle exercises), ordinal regression with generalized estimating equations was used, with 4 repeated measures (1, 3, 6, and 12 months postoperatively).

Interactions between time and group were tested in all models (both linear mixed models and generalized estimating equations). Interactions indicated differing trajectories of outcome variables between groups over time. The models were tested for the impact of participant characteristics (age, education, household income, marital status, and nerve-sparing surgery) and, in linear mixed models, secondary outcomes as well (physical activity and pelvic floor muscle exercises). This was done by including them in the models consecutively.

Ethics Approval

The study received ethics approval from the Regional Ethics Committee (reference 2016/484-31; 2017/512-32; and 2018/147-32) in Sweden.

Informed Consent and Participation

All men provided written informed consent at inclusion and were informed that they could terminate their participation at any time without giving a reason and that this would not affect their health care. No compensation was provided for participation in the study. All data were processed confidentially.

Results

Characteristics of Participants at Inclusion and Baseline Analysis

The characteristics of the participants (Table 1) were similar across the groups at inclusion. In brief, participants were aged 48 to 78 (mean 64, SD 6.23) years. The largest proportion of participants (79/165, 47.9%) was treated with bilateral nerve-sparing surgery, whereas 32.1% (53/165) were treated with unilateral surgery and 20% (33/165) without nerve-sparing surgery. For the majority (101/165, 61.2%), the hospital stay was 1 day, with a range of up to 19 days. Five men stayed in the hospital for >4 days because of complications (eg, hemorrhage, hernia, or infection).

The intervention and control groups were similar in terms of outcome variables at baseline, that is, urinary continence, sexual function, and physical activity (pelvic floor muscle exercises were not measured; Table 1).

Table 1. Characteristics of the participants and baseline data (n=165).

Characteristic	Intervention group (n=83)	Control group (n=82)	*P* value
Age (years), mean (SD)	64 (6.2)	64 (6.3)	.68[a]
Marital status, n (%)			.82[b]
Single	22 (27)	23 (28)	
Married or partner	36 (43)	44 (54)	
Education, n (%)			.74[c]
Primary school (9 years)	10 (12)	11 (13)	
Upper secondary school	22 (27)	20 (24)	
Folk high school or vocational school	4 (5)	11 (13)	
University	22 (27)	24 (29)	
Household monthly income (SEK[d]), n (%)			.51[c]
0 to 14,999	3 (4)	1 (1)	
15,000 to 29,999	10 (12)	14 (17)	
30,000 to 44,999	12 (14)	20 (24)	
≥45,000	33 (40)	32 (39)	
Nerve-sparing surgery, n (%)			.82[c]
No	17 (20)	16 (20)	
Unilateral	25 (30)	28 (34)	
Bilateral	41 (49)	38 (46)	
Gleason score, mean (SD)	6.9 (0.5)	7.1 (0.6)	.05[a]
Sexual function, n (%)			.55[c]
Very poor	8 (10)	8 (10)	
Poor	14 (17)	6 (7)	
Moderate	8 (10)	22 (27)	
Good	21 (25)	20 (24)	
Very good	6 (7)	8 (10)	
Urinary continence, n (%)			.65[c]
Leakage more than once a day	4 (5)	2 (2)	
Leakage about once a day	0 (0)	1 (1)	
Leakage more than once a week	3 (4)	6 (7)	
Leakage about once a week	3 (4)	5 (6)	
Seldom or no leakage	48 (58)	52 (63)	
Physical activity, n (%)			.35[c]
Sedentary	3 (4)	1 (1)	
Some physical activity for at least 4 hours per week	25 (30)	29 (35)	
Regular moderate physical exercise at least 2 to 3 hours per week	27 (33)	27 (33)	
Regular hard training and competitive sports	2 (2)	8 (10)	

[a] Independent sample *t* test.

[b] Chi-square test.

[c] Mann-Whitney *U* test.

[d] SEK: Swedish Crown (SEK 1=US $0.12).

Effects on Primary Outcome Measures: Urinary Continence and Sexual Function

Linear Mixed Models for Urinary Continence and Sexual Function

Four linear mixed models were used to determine whether ePATH improved the primary outcomes urinary continence (Table 2) and sexual function (Table 3).

Model 1 provided results for urinary continence (Table 2). No statistically significant differences in the changes over time were found between the intervention and control groups (interaction). Therefore, the interaction term is excluded from the model. Urinary continence did not significantly differ between the intervention and control groups (*P*=.09). There was a statistically significant effect showing increasing levels of urinary continence over time in both the groups (all *P*<.001). Investigations of the impact of participant characteristics (age, education, household income, marital status, and nerve-sparing surgery) and secondary outcomes (physical activity and pelvic floor muscle exercises) were performed by adding these variables, one by one, to model 1. Model 2 included nerve-sparing surgery, as it statistically significantly affected urinary continence in a positive direction (*P*<.001 and *P*=.01).

Sexual function was assessed using the same procedure (Table 3). The interaction term was omitted from the model, as the analysis revealed no statistically significant differences in changes over time between the intervention and control groups. No statistically significant difference in sexual function was observed between the intervention and control groups (*P*=.97), but time had a statistically significant effect and showed increasing levels of sexual function (*P*<.001 and *P*=.002). Investigations of the impact of participant characteristics (age, education, household income, marital status, and nerve-sparing surgery) and secondary outcomes (physical activity and pelvic floor muscle exercises) were then performed by adding these variables, one by one, to model 3. Model 4 included age (*P*=.01) and nerve-sparing surgery (*P*<.001 and *P*=.003), as they had significant effects. Younger age and bilateral nerve-sparing surgery affected sexual function positively.

Table 2. Results from 2 linear mixed model analyses on urinary continence (Expanded Prostate Cancer Index Composite) with fixed effects.

Variable	Model 1[a]		Model 2[a,b]	
	β (95% CI)	*P* value	β (95% CI)	*P* value
Intercept	73.62 (68.33 to 78.92)	<.001	80.75 (74.73 to 86.77)	<.001
Intervention group[c]	−5.60 (−12.15 to 0.96)	.09	−5.82 (−11.99 to 0.35)	.06
1 month[d]	−34.36 (−38.25 to −30.48)	<.001	−34.36 (−38.25 to −30.48)	<.001
3 months[d]	−21.23 (−24.49 to −17.98)	<.001	−21.23 (−24.49 to −17.98)	<.001
6 months[d]	−7.60 (−10.53 to −4.66)	<.001	−7.60 (−10.53 to −4.66)	<.001
No nerve-sparing surgery	N/A[e]	N/A	−18.78 (−26.99 to −10.57)	<.001
Unilateral nerve-sparing surgery	N/A	N/A	−10.00 (−17.03 to 2.99)	.01

[a] The characteristics of the participants (age, education, household income, marital status, and nerve-sparing surgery) and secondary outcomes were investigated as potential confounders and models controlled for interactions between time and group.

[b] Including nerve-sparing surgery; reference=bilateral nerve-sparing surgery.

[c] Reference=control group.

[d] Reference=12 months postoperatively.

[e] N/A: not applicable (not included in model 1).

Table 3. Results from 2 linear mixed model analyses on sexual function (Expanded Prostate Cancer Index Composite) with fixed effects.

Variable	Model 3[a]		Model 4[a,b]	
	β (95% CI)	*P* value	β (95% CI)	*P* value
Intercept	30.32 (24.86 to 35.79)	<.001	88.51 (53.47 to 123.56)	<.001
Intervention group[c]	−.12 (−7.05 to 6.81)	.97	−1.24 (−7.49 to 5.02)	.70
1 month[d]	−9.84 (−13.71 to −5.96)	<.001	−9.84 (−13.71 to −5.96)	<.001
3 months[d]	−5.74 (−9.30 to −2.19)	.002	−5.74 (−9.30 to −2.19)	.002
6 months[d]	−1.37 (−4.15 to −1.42)	.34	−1.37 (−4.15 to −1.42)	.34
Age	N/A[e]	N/A	−.78 (−1.32 to −.24)	.01
No nerve-sparing surgery	N/A	N/A	−18.20 (−26.78 to −9.63)	<.001
Unilateral nerve-sparing surgery	N/A	N/A	−10.85 (−18.03 to −3.66)	.003

[a] The characteristics of the participants (age, education, household income, marital status, and nerve-sparing surgery) and secondary outcomes were investigated as potential confounders and models controlled for interactions between time and group.

[b] Controlled for age and nerve-sparing surgery; reference=bilateral nerve-sparing surgery.

[c] Reference=control group.

[d] Reference=12 months postoperatively.

[e] N/A: not applicable (not included in model 3).

Longitudinal Changes in Urinary Continence and Sexual Function in Comparison With Baseline

To illustrate changes over time in urinary continence and sexual function in comparison with baseline, the means of the responses to the single questions (obtained preoperatively) in both groups were plotted (Figure 2), showing decreasing values of urinary continence and sexual function 1 month after surgery, which then increased up to 12 months (in line with linear mixed models; Table 4) without returning to the preoperative levels at baseline.

Figure 2. Urinary continence and sexual function (mean) over time in the intervention and control groups. BL: baseline; MO: month.

Table 4. Estimated mean values (Expanded Prostate Cancer Index Composite—urinary continence and sexual function) between groups over time (linear mixed model).

Characteristic	1 month, mean (SE; 95% CI)	3 months, mean (SE; 95% CI)	6 months, mean (SE; 95% CI)	12 months, mean (SE; 95% CI)
Urinary continence				
Intervention group	33.66 (2.48; 28.81-38.52)	46.79 (2.66; 41.59-52.00)	60.43 (2.72; 55.10-65.77)	68.03 (2.74; 62.67-73.39)
Control group	39.26 (2.46; 34.44-44.08)	52.39 (2.63; 47.24-57.54)	66.03 (2.68; 60.77-71.29)	73.62 (2.70; 68.33-78.92)
Sexual function				
Intervention group	20.37 (2.63; 15.21-25.53)	24.46 (2.82; 18.94-29.99)	28.84 (2.72; 23.52-34.16)	30.21 (2.79; 24.73-35.68)
Control group	20.49 (2.57; 15.45-25.52)	24.58 (2.75; 19.20-29.96)	28.96 (2.72; 23.62-34.30)	30.32 (2.79; 24.86-35.79)

Effects on Secondary Outcomes: Physical Activity and Pelvic Floor Muscle Exercises

To study whether ePATH affected the secondary outcomes (physical activity and pelvic floor muscle exercises) over time, ordinal regression analyses were performed (Table 5). No statistically significant interaction effect was found, indicating that there were no differences in the changes over time between the intervention and control groups. Therefore, the interaction term was excluded. ePATH did not show any significant effect on physical activity (*P*=.57), but physical activity increased after 1 month in both groups (model 1). There was no statistically significant difference in pelvic floor muscle exercises between the intervention and control groups (*P*=.15). Pelvic floor muscle exercises decreased over time in both groups (model 2). Participant characteristics (age, education, household income, marital status, and nerve-sparing surgery) were added to the models investigating the effects; no statistically significant impacts were found.

Table 5. Results from ordinal regression analyses (generalized estimating equations) on self-care activities: physical activity and pelvic floor muscle exercises.

Variable	Model 1: physical activity[a]		Model 2: pelvic floor muscle exercises[a]	
	Odds ratio (95% CI)	*P* value	Odds ratio (95% CI)	*P* value
Intervention group[b]	1.16 (0.71-1.89)	.57	1.51 (0.86-2.66)	.15
1 month[c]	0.41 (0.23-0.73)	.004	14.45 (9.50-22.00)	<.001
3 months[c]	0.97 (0.62-1.52)	.91	4.15 (2.85-6.03)	<.001
6 months[c]	0.99 (0.69-1.42)	.97	1.20 (1.63-3.35)	<.001

[a] The characteristics of the participants (age, education, household income, marital status, and nerve-sparing surgery) were investigated as potential confounders and models controlled for interactions between time and group.

[b] Reference=control group.

[c] Reference=12 months postoperatively.

Use

In the intervention group, 64% (53/83) of the participants were defined as users. Use ranged between 1 and 28,214 activities (log-ins or registrations of self-care) over 12 months and declined over time. The median for use was 70 (IQR 6-2330). Nonusers of ePATH accounted for 36% (30/83) of the sample. Of the 53 users, 36 (68%) used ePATH during the first month postoperatively. In total, 32% (17/53) of the participants still used ePATH after 3 months, and the number of users had declined to 21% (11/53) at 6 months. One year after surgery, 11% (6/53) of the men were still using ePATH.

Discussion

Principal Findings

The main findings of this randomized controlled trial in cancer rehabilitation were that digital self-care support showed no statistically significant effects on urinary continence or sexual function but increasing levels of urinary continence and sexual function in both the intervention and control groups over time. Previous research shows increasing functioning and decreasing side effects after prostate cancer surgery over time [1], in line with what was shown in both the intervention and control groups in our study. However, estimates and definitions of urinary continence vary among studies, making evaluations difficult to assess and compare. The mechanisms for increasing urinary continence are multifactorial, depending on, for example, surgical technique, anatomical conditions, and self-care technique [3], which may not have been fully captured in this study (ie, body weight or BMI, measurements of obesity, were not included in the study). Individual variations and preferences might impact self-care results, although adherence is crucial to achieve any effect [14]. Therefore, recommendations and support must be customized based on these aspects. This study highlights the need to explore self-care interventions that improve well-being and minimize postoperative complications and to further investigate when support is needed during rehabilitation. The declining use of ePATH over time indicates that this type of support may be appropriate when new behaviors are to be learned and less useful in the long term. It is possible that the need for support in ePATH declined in parallel with the side effects. Previous research shows that patients progress through phases in self-care management, which correspond to differing support needs. When a patient finds routines for self-care and functions gradually return, the patient's need for support changes [15]. Although the study did not yield the anticipated outcomes, it contributes to the current body of knowledge by emphasizing the significance of providing continuous support to men during their postcancer recovery phase [50]. The maintenance of self-care practices within the home environment is particularly crucial, considering the growing population of patients undergoing rehabilitation owing to improved survival rates [1].

No differences were observed in the effectiveness of ePATH in relation to sexual function between the intervention and control groups. The support delivered through ePATH regarding sexual function entailed physical activity, pelvic floor muscle exercises, and supplementary information regarding sexual rehabilitation. However, sexual rehabilitation is a multifaceted matter that may require multiple different approaches over a longer period and extend to any partner [51-54]. Support and follow-up during the first year after surgery might not encompass all relevant aspects (eg, psychological impact, relationship status, and possibility of using pharmacological agents). It should be noted that our results were not controlled for pharmacological agents in penile rehabilitation. Future research should prioritize the development and assessment of comprehensive web-based sexual rehabilitation support that is adaptable to various contexts.

Self-care regarding physical activity and pelvic floor muscle exercises was not affected by ePATH; however, physical activity increased postoperatively. This is in line with previous research [55], which shows a gradual return to physical activity after surgery. Exercise is increasingly seen as being significant in prostate cancer rehabilitation as a strategy to enhance sexual function, improve feelings of masculinity, and reduce the distress that men experience after prostate cancer [51]. However, urinary incontinence after radical prostatectomy may hinder physical activities [15]. As urinary continence increased, physical activity also increased, thus supporting this notion. Therefore, support from health care might be needed to emphasize the importance of modified physical activity in the early phases of rehabilitation. In our study, pelvic floor muscle exercise decreased over time. Pelvic floor muscle exercises should preferably be guided by a therapist [17,56] or biofeedback [57] to ensure correct technique and achieve an effect on urinary continence. However, such guidance is not standard [7]. Our results highlight the need for additional support for patients to stay adherent to recommendations on pelvic floor muscle exercises in the long term, and a digital app with reminders was not sufficient. Expanded gamification elements and automatic responses incorporated into digital self-care support may encourage adherence to recommendations [58]. For gamification to be relevant for users, established theories on user experiences and the psychological effects of gaming mechanics would need to be applied in the design of eHealth solutions [59].

Although several studies provide evidence of improved health outcomes when using eHealth services [60,61], the evidence remains inconclusive [62]. Reinhardt et al [63] showed that both user-related barriers and intervention-related barriers were common when eHealth tools were used, and digital support does not suit everyone [64,65]. Although there are challenges in evaluating technologically complex interventions in health care, knowledge can be drawn from programs where predicted outcomes do not occur [66]. We explored user needs [16] and based the digital self-care support on theory and evidence [38]. Our pilot study showed promising usability and feasibility [27]. Although people living in the aftermath of cancer treatment often search for information and accessible and effective support tools on the web [26], 36% (30/83) of the participants in the intervention group did not use ePATH. The study design limits the possibility of drawing conclusions regarding nonusers. Qualitative research in the same patient group reported that some men do not feel any need for support [15] or did not have the energy to engage in digital self-care support, as their overall health was poor [27]. Changing behavior is generally difficult, and managing a cancer diagnosis adds another layer to this. There is evidence that different user characteristics are associated with different use patterns; for example, patients with low levels of social support and a high illness burden may find eHealth tools particularly useful [67,68]. In our study, it was unclear whether differences in use could be attributed to comorbidity, symptom distress, support from cancer nurse specialists, need for support, or ePATH per se. Further investigations should explore when, why, and for whom digital self-care support is useful and for whom it is less suitable, so as to adapt digital support to different patient groups.

Although digitization is a top priority in the global health and development sectors, the implementation of innovative interventions and new practices in standard care shows slow progress [69]. Before implementation, a thorough investigation of cost efficiency should be performed to evaluate the clinical relevance of the intervention for patients and in the organization. However, digital interventions have proven to be cost-effective, but further focus is needed on their implementation [70]. The success of an intervention relies on the complex interplay between barriers and enablers, which can determine its effectiveness [71]. Barriers to implementation can take various forms, including poor contextual alignment and systemic factors such as organizational culture and ineffective communication. However, the readiness for change among staff members is particularly crucial, as it affects their willingness and preparedness to adopt behavioral changes and adapt to new care processes [72]. ePATH was added as a complement to standard care to mimic the clinical reality in which implementation could be possible and strengthen the external validity [29]. However, the nurses' overall workload might have affected their likelihood of engaging in the ePATH intervention. For successful integration of digital interventions, technology needs to be aligned with the organization structure and with the daily processes and user goals [73]. Thus, nurses' limited time to follow-up on rehabilitation activities might have impacted the outcomes and use. The effectiveness of digital behavioral change interventions in cancer rehabilitation is also dependent on users' digital and health literacy, attitudes, and engagement and how well the patient needs and contents of the intervention align [36].

Strengths and Limitations

Multiple strengths and limitations must be considered when evaluating a complex intervention in a randomized controlled trial, in particular external validity and applicability. External factors could have affected the outcomes, as not all influencing factors can be controlled for in a complex trial. The outcome measures used were validated patient-reported outcome measures, which have shown good reliability and validity [41-43]. Using objective measures for physical activity or incontinence (eg, accelerometers or weighing pads) could have increased reliability, but this would risk adding to the burden on participants. As ePATH necessitated an internet connection and a secure mobile log-in facility, the study did not reach certain populations [64,65]. However, eHealth trials that require internet connection, particularly self-help applications, generally have high dropout rates [74]. We applied broad inclusion criteria to reach more participants and did not assess eHealth literacy, technological acceptance, or attitude toward technology [68], which might have had an impact on heterogeneity with regard to patient attrition. The possibility exists that the men who chose not to participate differed from those who were enrolled in the study, potentially impacting the generalizability of the findings. Therefore, it is important to consider the potential impact of self-selection bias when interpreting the results and drawing conclusions about their generalizability to a broader population.

The use and functionality of the application must also be considered. Reminders sent to participants from the research group may have increased use and adherence to the intervention. However, because the study design focused on investigating the intervention in real-world clinical settings rather than ideal circumstances, it was not possible to make such interferences. Consequently, the results of this study are valuable for enhancing our understanding of the nuances and complexities of real-world scenarios, thereby improving the relevance and applicability of research findings [29]. A process evaluation of contextual factors in parallel with the study period would have uncovered barriers and potential improvements of the intervention that may have been useful for implementation in routine care [31,69-72]. However, a lesson learned is that there is probably a need for specific efforts to change work routines and enhance patients' adherence to prostate cancer rehabilitation.

The planned sample size of 228 randomly assigned participants would have provided at least 80% power to show differences between the groups in this modified intention-to-treat analysis [34]. As the recruitment of participants was slower than expected, enrollment ended at a sample size of 170 for the timeline of the study to be reasonable. The study participants were followed up according to the protocol. Two domains of the EPIC were not included in the analysis despite the power calculations being based on all 4 domains.

A strength is that the repeated measures with 4 assessment points and the use of linear mixed models enabled the inclusion of participants with at least 1 assessment point, which improved the representativeness of the sample [49]. The imputation of missing values should be considered. However, to enhance validity, a widely accepted imputation method was used, and a sensitivity analysis was conducted. To ensure the validity of the results, patients without outcome measures were excluded from imputations (modified intention-to-treat analysis) [45,46]. Imputation and analysis models that are compatible have been shown to result in consistent estimates of both regression parameters and variance components [75]. It is important to consider the dynamic nature of the repeated variables and control effects in the ordinal regression models when interpreting the results.

Conclusions

Digital solutions have been launched as cancer rehabilitation support in clinical practice, often without sufficient evidence of their benefits. This study adds to the body of knowledge by conducting an effectiveness test of digital self-care support as an adjunct to standard care in real-world conditions. Although this study did not reveal any benefits of rehabilitation after prostatectomy, it provides evidence that comprehensively reflects how this support may function in its clinical context. To optimize support for prostate cancer rehabilitation, further efforts for continued motivation and the use of digital support need to be considered. Future research should focus on user requirements and timing of support in the population with prostate cancer as well as structural preconditions for implementing effective digital support in existing work processes.

Acknowledgments

The authors thank the participating men, the urological clinics, and the nurses who made this study possible. The authors also thank the statisticians Magnus Backheden and Hans Högberg for their statistical expertise.

The Kamprad Family Foundation for Entrepreneurship, Research & Charity (no 20150067); the Swedish Cancer Society (CAN 2017/748); the Research Council of Southeast Sweden (FORSS-657211, 760131); the Cancer Foundation in Kalmar; and Region Kalmar County, provided funding for this study. The funding body played no role in the design of the study, interpretation of data, or writing the manuscript.

Data Availability

The data sets generated and analyzed during this study are not publicly available because of ethics approval concerning the handling of the gathered data. However, they are available from the corresponding author upon reasonable request.

Authors' Contributions

CW, AH, KS, and ME contributed to study design and conceptualization of the study. CW was responsible for the recruitment of participants and administered the data collection together with AH. CW conducted the formal analysis with support and supervision from AH, ME, and statisticians. CW drafted the original manuscript as the first author. All authors contributed to the interpretation and visualization of data, writing, reviewing, and editing the original draft. ME was the primary investigator and was responsible for funding acquisition.

Conflicts of Interest

None declared.

Multimedia Appendix 1
CONSORT-eHEALTH checklist (V 1.6.1).
[PDF File (Adobe PDF File), 12799 KB - cancer_v9i1e44320_app1.pdf]

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Abbreviations

CONSORT-EHEALTH: Consolidated Standards of Reporting Trials of Electronic and Mobile Health Applications and Online Telehealth
ePATH: electronic Patient Activation in Treatment at Home
EPIC: Expanded Prostate Cancer Index Composite

Edited by G Eysenbach, T de Azevedo Cardoso; submitted 16.11.22; peer-reviewed by H Sievanen, K Sundberg; comments to author 20.04.23; revised version received 09.06.23; accepted 21.07.23; published 06.09.23.

Please cite as:
Wennerberg C, Hellström A, Schildmeijer K, Ekstedt M
Effects of Web-Based and Mobile Self-Care Support in Addition to Standard Care in Patients After Radical Prostatectomy: Randomized Controlled Trial
JMIR Cancer 2023;9:e44320
URL: https://cancer.jmir.org/2023/1/e44320
doi:10.2196/44320
PMID:37672332

Original Paper

Predictors of the Use of a Mental Health–Focused eHealth System in Patients With Breast and Prostate Cancer: Bayesian Structural Equation Modeling Analysis of a Prospective Study

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Abstract

Background: eHealth systems have been increasingly used to manage depressive symptoms in patients with somatic illnesses. However, understanding the factors that drive their use, particularly among patients with breast and prostate cancer, remains a critical area of research.

Objective: This study aimed to determine the factors influencing use of the NEVERMIND eHealth system among patients with breast and prostate cancer over 12 weeks, with a focus on the Technology Acceptance Model.

Methods: Data from the NEVERMIND trial, which included 129 patients with breast and prostate cancer, were retrieved. At baseline, participants completed questionnaires detailing demographic data and measuring depressive and stress symptoms using the Beck Depression Inventory–II and the Depression, Anxiety, and Stress Scale–21, respectively. Over a 12-week period, patients engaged with the NEVERMIND system, with follow-up questionnaires administered at 4 weeks and after 12 weeks assessing the system's perceived ease of use and usefulness. Use log data were collected at the 2- and 12-week marks. The relationships among sex, education, baseline depressive and stress symptoms, perceived ease of use, perceived usefulness (PU), and system use at various stages were examined using Bayesian structural equation modeling in a path analysis, a technique that differs from traditional frequentist methods.

Results: The path analysis was conducted among 100 patients with breast and prostate cancer, with 66% (n=66) being female and 81% (n=81) having a college education. Patients reported good mental health scores, with low levels of depression and stress at baseline. System use was approximately 6 days in the initial 2 weeks and 45 days over the 12-week study period. The results revealed that PU was the strongest predictor of system use at 12 weeks ($\beta_{\text{use at 12 weeks is predicted by PU at 12 weeks}}$=.384), whereas system use at 2 weeks moderately predicted system use at 12 weeks ($\beta_{\text{use at 12 weeks is predicted by use at 2 weeks}}$=.239). Notably, there were uncertain associations between baseline variables (education, sex, and mental health symptoms) and system use at 2 weeks, indicating a need for better predictors for early system use.

Conclusions: This study underscores the importance of PU and early engagement in patient engagement with eHealth systems such as NEVERMIND. This suggests that, in general eHealth implementations, caregivers should educate patients about the benefits and functionalities of such systems, thus enhancing their understanding of potential health impacts. Concentrating resources on promoting early engagement is also essential given its influence on sustained use. Further research is necessary to clarify the remaining uncertainties, enabling us to refine our strategies and maximize the benefits of eHealth systems in health care settings.

(JMIR Cancer 2023;9:e49775) doi:10.2196/49775

KEYWORDS

mental health; eHealth system; perceived usefulness; structural equation modeling; cancer; NEVERMIND system; usability; digital health; Technology Acceptance Model

Introduction

Background

Technological advancements have led to the emergence of eHealth systems as potential tools to enhance the delivery of health care services. The concept of eHealth systems refers to health services and information delivered or enhanced through the internet and related technologies. These self-management tools provide patients with the ability and skills to improve their health by self-monitoring and receiving personalized feedback [1,2]. An area in which eHealth tools have shown promise is the treatment of depression, a prevalent comorbidity in patients with cancer [3,4].

Patients with breast and prostate cancer in particular face unique challenges associated with their diagnoses, such as body image concerns, sexual dysfunction, and hormonal imbalances, which can contribute to an increased risk of developing depression and stress and significantly affect an individual’s well-being and daily functioning [5,6]. Over the past 2 decades, a growing body of research has demonstrated the efficacy of eHealth interventions for the treatment of depression and stress [7-9].

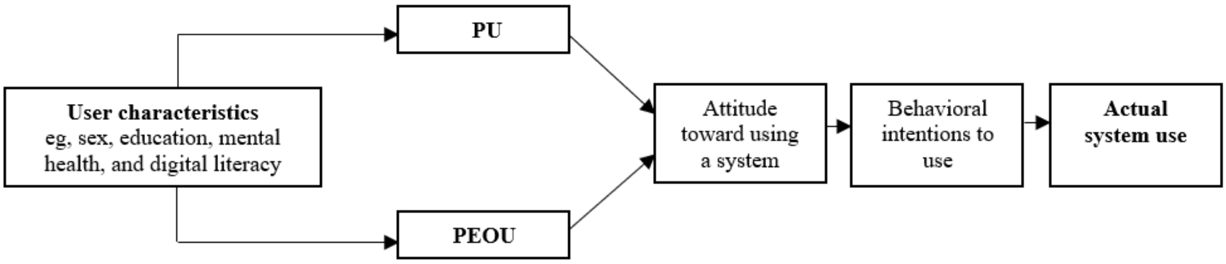
However, the adoption and use of eHealth interventions for depression treatment in patients with cancer remains suboptimal. This is due to several factors, including limited awareness of eHealth interventions’ effectiveness, complex user interfaces or designs, and a lack of integration into health care systems, which necessitates a better understanding of the factors that drive their use [10,11]. As such, the role of usability and acceptability becomes an essential focal point in the use of eHealth interventions, with adequate attention paid to what influences the ease of use and acceptance by patients.

Prior Work and Theoretical Frameworks

Research highlights the importance of considering user-centered design and user experience, such as user engagement and user satisfaction, to ensure accessibility and effectiveness for a wide range of users, including those with mental health issues [2]. Similarly, a recent pilot study by Chow et al [12] identified the need to improve the usefulness and satisfaction of mental health apps in patients with breast cancer to increase user engagement. Worse mental conditions such as high depressive and stress symptoms also pose challenges such as reduced motivation and engagement and skepticism about digital interventions [13]. Similarly, a study by Lally et al [14] also found that the total time users spent on the CaringGuidance program—an autonomous web-based platform providing psychoeducation and facilitating self-management of distress—after a breast cancer diagnosis, the number of log-ins, and the number of program components viewed did not correlate with distress levels. Instead, the depth of engagement and the users’ ability to find the support they need from the program appear to be the more crucial factors.

A common and relatively easy-to-understand theoretical framework to comprehend and investigate user acceptance of new technologies is the Technology Acceptance Model (TAM), focusing on perceived ease of use (PEOU) and perceived usefulness (PU) [15]. According to the TAM, an individual’s likelihood of adopting and using technology is influenced by their perception of its ease of use and usefulness in achieving desired outcomes. For patients already grappling with health challenges, any perceived complexity or lack of immediate value can severely limit their engagement with eHealth solutions. Although the TAM has been validated empirically, incorporating more external user characteristics such as age, socioeconomic status, and mental health factors (eg, depression and stress) can improve the specificity and exploratory utility of this model (Figure 1).The TAM is an apt model for our study, which seeks to understand the adoption and use of the NEVERMIND system among patients with breast and prostate cancer with varying levels of depressive and stress symptoms.

Figure 1. The Technology Acceptance Model (adopted and modified from Davis [15]). PEOU: perceived ease of use; PU: perceived usefulness.



The NEVERMIND System

The NEVERMIND system was developed to reduce depressive symptoms in patients diagnosed with 5 somatic illnesses. The system comprises a mobile app and a sensorized T-shirt. The T-shirt collects physiological data, whereas the app gathers mental health questionnaires, both working together to predict depressive symptom levels. The system facilitates self-management of mental health symptoms in patients with somatic illnesses by allowing them to monitor their mental health and providing personalized feedback [16]. The effectiveness of the NEVERMIND system has been demonstrated in a randomized controlled trial (RCT) [9], and its acceptability and usability have been evaluated through usability questionnaires, with a higher favorability of the mobile app among female individuals and a higher use among male individuals [17].

Goal of This Study

Although previous studies have provided valuable insights into the factors influencing the adoption and use of eHealth systems in general, few have specifically explored the role of baseline mental health symptoms, early engagement, PEOU, and PU within the context of the TAM, particularly in patients with breast and prostate cancer. In addition, most of the existing literature relies on traditional frequentist methods, which cannot fully investigate the relationship between theory and data collected from the system.

To address these gaps, our study uses Bayesian structural equation modeling (SEM), or more specifically, a path analysis, also called structural regression. This method offers several advantages over traditional frequentist methods. Bayesian methods allow for the incorporation of knowledge from previous research, enhancing the robustness and reliability of the drawn inferences. Moreover, Bayesian SEM excels in handling complex modeling assumptions more effectively than classic SEM, which typically uses maximum likelihood estimation [18]. These assumptions include the ability to manage complex distributions and nonlinear relationships and tackle challenges such as nonnormality, interactions, and measurement errors. This comprehensive approach enables a more nuanced interpretation of the interplay among variables.

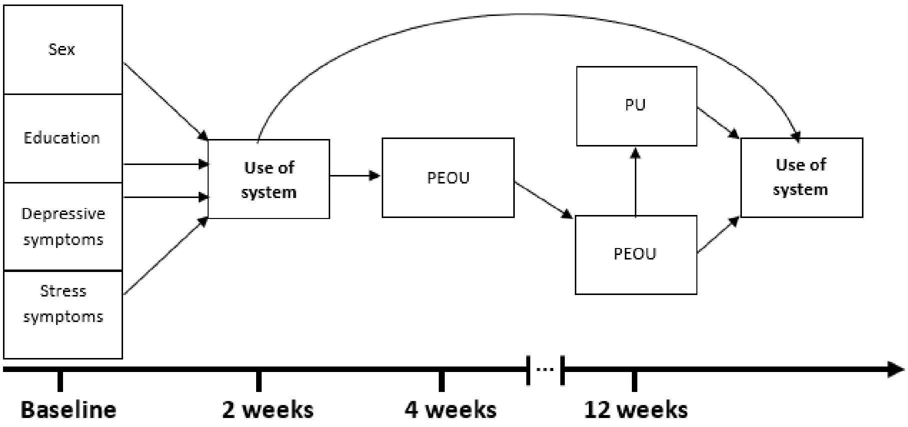
This study, based on the TAM, aimed to explore the relationships among sex, education, baseline depressive and stress symptoms, initial use, PEOU, PU, and the use of the NEVERMIND eHealth system among patients with breast and prostate cancer.

To investigate the uncertainties in predicting the actual use of the NEVERMIND eHealth system within the TAM, the following hypotheses were formulated:

1. Male individuals, individuals with a higher educational level, and those exhibiting more depressive and stress symptoms are likely to use the system at 2 weeks.
2. Higher system use at 2 weeks is likely to lead to a higher PEOU at 4 weeks.
3. Higher system use at 2 weeks will lead to higher system use at 12 weeks.
4. Higher PEOU at 4 weeks will lead to a higher PEOU at 12 weeks.
5. Higher PEOU at 12 weeks will lead to higher system use at 12 weeks.
6. Higher PU at 12 weeks will lead to higher system use at 12 weeks.

These hypotheses are summarized in the study's model (Figure 2). The model incorporates the TAM, but some components (attitudes toward using the system and behavioral intentions to use the system) were not measured in the main study; thus, they were not included in the model of this study.

Figure 2. Model of the study. PEOU: perceived ease of use; PU: perceived usefulness.



Methods

Study Design

This study used a longitudinal design to explore the relationships among sex, educational level, baseline depressive and stress symptoms, PEOU, PU, and the use of the NEVERMIND eHealth system among patients with breast and prostate cancer. Participants were recruited from 2 large oncology centers, one specializing in breast cancer and the other in prostate cancer, in Pisa and Turin, Italy. Comprehensive details regarding the design, content, and functionality of the NEVERMIND system have been described in previous publications [9,17] (German Clinical Trials Register RKS00013391).

Recruitment

Overview

Patients with prostate cancer were at an advanced stage (stage IV) at the time of recruitment. All treatments, with the exception of adjuvant androgen deprivation therapy, had been completed at least a month before their inclusion in the study. Similarly, patients with breast cancer were at stage III or IV at the time of recruitment. All treatments, barring hormonal or trastuzumab therapy, had been completed at least one month before their participation in the study. More extended inclusion and exclusion criteria for the NEVERMIND RCT have been described in detail in the protocol of the study [16]. As this is a secondary data analysis, the inclusion and exclusion criteria only refer to the subsample for this study.

Inclusion

Eligible participants were patients diagnosed with either breast or prostate cancer who were part of the NEVERMIND RCT study who were allocated to the NEVERMIND eHealth system.

Exclusion

Patients with breast and prostate cancer allocated to treatment as usual were excluded. Patients who belonged to the NEVERMIND intervention group but who dropped out of the study before receiving the NEVERMIND system were also excluded. Patients were also excluded if they had missing data on any of the variables of interest.

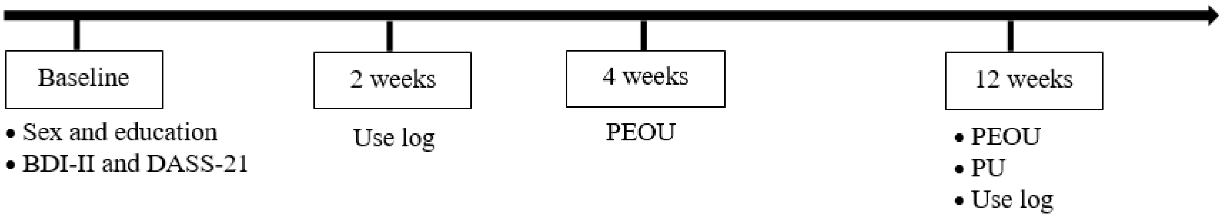
Data Collection

Overview

Participants were asked to complete a set of questionnaires at baseline assessing their demographic information, depressive symptoms, and stress symptoms. Following the completion of the baseline questionnaires, participants were introduced to the NEVERMIND eHealth system and given a brief overview of its use. They were instructed to use the system for a period of 12 weeks, engaging daily with the app and at least twice a week with the sensorized T-shirt. Participants completed an interim follow-up questionnaire at 4 weeks and another questionnaire after the 12-week use period. The questionnaire included items assessing PEOU and PU using validated scales adapted to the eHealth context. The timeline of data collection is summarized in Figure 3.

A description of each variable is provided in the following sections.

Figure 3. Timeline of data collection. BDI-II: Beck Depression Inventory–II; DASS-21: Depression, Anxiety, and Stress Scale–21; PEOU: perceived ease of use; PU: perceived usefulness.



Demographic Variables

Baseline sociodemographic data were collected for all patients recruited to the study. These data included sex and educational level. Educational level was dichotomized into low (below college or diploma) and high (college or above).

Mental Health Variables

Depressive symptoms were measured using the Beck Depression Inventory–II (BDI-II) [19], and stress symptoms were measured using the Depression, Anxiety, and Stress Scale (DASS-21) [20]. The BDI-II is a widely used 21-item self-report inventory that measures the severity of depressive symptoms in adults and adolescents, with each item rated on a scale from 0 to 3 based on the intensity of the symptom. The BDI-II score is calculated by adding the scores of its 21 items, with total scores ranging from 0 to 63, where higher scores signify more severe depressive symptoms. The Stress Scale of the DASS-21 is a 7-item subscale that assesses the respondent's experience of stress symptoms over the past week. Each item is rated from 0 (*did not apply to me at all over the last week*) to 3 (*applied to me very much or most of the time over the last week*). The total is then doubled to align with the full version of the DASS-21, leading to a possible score range from 0 to 42, with higher scores indicating higher levels of stress.

Use of System

Patients in the intervention group were provided with the NEVERMIND system, which they were instructed to use for a period of 12 weeks. The system automatically collected data on each patient's use of the mobile app and sensorized shirt without relying on patient self-reports. Each module of the mobile app recorded use data by distinct days of use and log data, which reflected instances in which a patient opened the app but did not necessarily engage with it or the modules or send any data to the server. Similarly, the sensorized shirt, via a docking station, transmitted use data to a remote server. These data were also recorded in terms of distinct days of use and log data. We computed 2 use variables for analysis, the first reflecting system use in the initial 15 days (2 weeks) and the second variable representing use over the entire 12-week study period.

PEOU Questionnaire

A questionnaire about the PEOU was administered to patients after 4 weeks of use and again after using the system for 12 weeks. PEOU is a measure of acceptability and is defined as "the degree to which a person believes that using a particular system would be free of effort" [15]. The PEOU questionnaire was developed by the Polytechnic University of Madrid according to the TAM. The questionnaire is a 9-item Likert scale ranging from 1 (*very difficult*) to 5 (*very easy*). Patients rated, for example, how easy it was to report and manage diet goals. The questionnaire was used as a continuous scale. The full questionnaire can be found in Multimedia Appendix 1.

PU Questionnaire

PU is defined as the "subjective perception of users regarding how much using a certain technology will improve the performance of their work" [15]. The questionnaire is a 10-item Likert scale that was developed by the Polytechnic University of Madrid according to the TAM. The questionnaire includes 10 positively worded statements, and patients were asked to rate their agreement with the statements on a scale from 1 (*strongly disagree*) to 5 (*strongly agree*). The full questionnaire can be found in Multimedia Appendix 2. The questionnaire was used as a continuous scale.

Power

This study comprised a secondary data analysis using the data set from the primary NEVERMIND trial. For this analysis, we focused only on patients with breast and prostate cancer who were part of the intervention group, which consisted of 129 participants.

The sample size required for SEM analysis depends on various factors, such as the number of variables, the anticipated effect size, and the complexity of the model. For SEM, a rule of thumb is to have 10 to 20 cases per estimated parameter [21]. In the proposed model, we had 9 variables: baseline depressive and stress symptoms, sex, educational level, use at 2 weeks, PEOU at 4 and 12 weeks, PU at 12 weeks, and use at 12 weeks. On the basis of this recommendation, the sample size should be 90 to 180.

A total of 752 patients with breast cancer were approached to be included in the study. Of these 752 patients, 448 (59.6%) met the inclusion criteria. Of the 448 patients, 255 (56.9%) agreed to participate. These participants were then randomized, with 129 patients assigned to the NEVERMIND intervention group. In the intervention group, 83.7% (108/129) of patients completed the study, whereas 16.3% (21/129) of patients dropped out after completing the baseline questionnaires but before receiving the NEVERMIND system. Taken together, as patients were excluded if they had missing data on any of the variables of interest, the total sample size that we conducted the analysis on was 100. Although our sample size of 100 should be adequate to detect medium effects, it is worth noting that the power of SEM analyses can also be influenced by other factors, such as the nonnormality of data, missing data, and model misspecification [22].

Statistical Analysis

Overview

Descriptive statistics were calculated for all variables, including participants' demographic characteristics, baseline depressive and stress symptoms, and use patterns of the NEVERMIND system. Bayesian SEM was used as the statistical technique to analyze the relationships among the different parameters. Bayesian SEM was chosen for this specific research question for several reasons: (1) Bayesian SEM may be more robust with small sample sizes compared with traditional frequentist methods as it allows for the incorporation of previous information about model parameters, which can improve the precision of the estimates and produce reasonable results with small to moderate sample sizes [23]; (2) Bayesian SEM can estimate complex models with multiple parameters that might be too intricate for frequentist methodologies such as maximum likelihood [18], which is particularly relevant when examining the interrelationships among a large number of variables within a path analysis framework; and (3) Bayesian SEM enables us to incorporate previous knowledge of model parameters from previous research, which can enhance accuracy while estimating the posterior distribution for the model parameters [24].

In this study, a path analysis through Bayesian SEM was used to estimate relationships among different constructs simultaneously while accounting for previous information about the model parameters and estimating posterior distributions for these parameters based on the observed data. The steps outlined in the following sections were undertaken to set up the analysis for the Bayesian SEM.

Selection of Priors

The precision of Bayesian methods depends on accurate and informative prior distributions. Noninformative or default software settings can cause inaccurate estimates that are worse than frequentist estimates [18]. Consequently, choosing priors should incorporate previous beliefs gathered from relevant studies and meta-analyses or expert opinions. Prior distributions for the model parameters were chosen based on three different sources, in order of prioritization: (1) previous research, (2) weakly informed priors elicited from the authors of the study (ie, expert opinion), and (3) default prior from the *Blavaan* package in R (R Foundation for Statistical Computing) modified in the prior convergence analysis to avoid divergencies in the model to allow the model to run based on prior assumptions. Thus, expert opinions and default priors were only used when no previous empirical findings were available.

To identify effect sizes from previous research, a search was conducted on August 26, 2022, on PubMed. The search was broad enough to make sure that any relevant studies were reviewed. The search included the words “user characteristics” AND “usability” OR “usage” and “eHealth.”

Conversion and Aggregation of Effect Sizes

The effect size data obtained from previous research were in different formats, such as odds ratios for categorical variables and regression coefficients for continuous variables. All effect sizes were converted and aggregated to means and SDs for regression coefficients to be compatible with the input requirements of the *Blavaan* package in R. Odds ratios were recalculated into correlation coefficients in 2 ways. In case contingency table data were available, the ϕ coefficient was computed using the *ci.phi* function in R as it considers differences in group size. If only odds ratios were available, the effect size package in R with the function *oddsratio_to_r* was used. Data were aggregated when multiple studies reported the same effect and used the same methodology, as in a meta-analysis. The *meta* package in R, along with the *metacor* function, was used for this purpose. The aggregated value of the common effects was then used as the aggregate measure. When a single article reported an effect size, it was used as a prior for that specific pair of variables.

Conversion and Aggregation of SDs

Priors for the SDs were not reported for any of the effects. Thus, these were computed using the following formula:

where r is the correlation coefficient and n is the number of variables, which was 2 for all cases [25]. In cases in which several articles reported effect sizes, aggregation of the SDs was performed by converting them to variances and weighting each variance by the number of participants in the study size before dividing by the total number of participants in all the studies:

where sd_{agg} is the aggregated SDs, n_n is the number of participants in the study, and sd_n is the SD of the effect size of the same study.

When multiple articles reported effect sizes, the SDs were aggregated by first converting them to variances. Each variance was then weighted according to the study’s participant count and subsequently divided by the total number of participants across all the studies.

The last conversion step was to scale all correlation coefficients and SDs to the variables used in this study. This was performed by multiplying the coefficient with the quotient of the SD of the outcome variable by the SD of the predictor variable:

where b is the regression or SD, r is the correlation coefficient or SD, sd_y is the SD of the outcome variable y, and sd_x is the SD of the predictor x.

Using prior information and the observed data, a Bayesian structural regression was conducted using the *bsem* function of the *Blavaan* package (version 0.4-3) [26] in the R software (version 4.2.2; 2022-10-31 ucrt) through the RStudio graphical user interface (version 2023.03.0; Posit, PBC).

Sensitivity Analysis

To explore the impact of sampling size and different prior distributions on the Bayesian model, multiple variations of these factors were tested. The variations of the final model consisted of (1) variations in the number of adaption samples, burin samples, and samples and (2) variations in prior hyperparameters. Regarding sampling variations, the model was run with 3 variations in addition to the original model. Burin and sampling were set to the same amount in 3 steps: 5000, 10,000, and 25,000 samples. The adaption samples were in relation to these steps set to 1000, 1000, and 2500. Regarding prior hyperparameters, variations were constructed in the final model that had 5000 adaption samples, 50,000 burin samples, and 50,000 samples. They consisted of an iterative change in each intercept and slope parameter to a diffuse prior—$N(0,10^5)$. In addition, to investigate the more general effects of diffuse prior hyperparameters on intercepts, a model was run in which all intercepts had diffuse priors—$N(0,10^5)$. The results of this analysis are described in the following section.

Ethical Considerations

The study received ethical clearance from the local research ethics committees at the intervention sites. This included the ethics committee of Città della Salute e della Scienza di Torino University Hospital and the ethics committee of San Luigi Gonzaga University Hospital, Orbassano (ethics approval reference 185/2015). The Swedish Ethical Review Authority (Etikprövningsmyndigheten; Dnr 2020-04175) granted additional approval for the analysis of pseudoanonymized data. Before the start of the study, all participants were thoroughly briefed on the study's objectives and methods and provided informed consent by signing the necessary documentation.

Results

Overview

Most of the participants in the study were female, comprising 66% (66/100) of the total, and were also highly educated, with 81% (81/100) of participants reporting a college education. Patients indicated relatively good mental health scores, with a mean of 12.23 (SD 9.20) on the BDI-II, reflecting low depression levels. This was further supported by a mean score of 13.64 (SD 9.56) on the DASS-21, pointing to relatively low stress levels (Table 1).

Table 1. Descriptive statistics of variables in the structural equation modeling Bayesian path analysis model (N=100).

Variable	Values, mean (SD)	Values, median (range)
Depression (BDI-II[a])	12.23 (9.20)	10 (0-43)
Stress (DASS-21[b])	13.64 (9.56)	14 (0-38)
Use at 2 weeks (days)	5.52 (4.14)	6 (0-14)
Perceived ease of use at 4 weeks	32.5 (4.22)	33 (20-43)
Perceived ease of use at 12 weeks	32.7 (4.33)	33 (24-45)
Perceived usefulness at 12 weeks	37.1 (5.86)	38 (20-50)
Use at 12 weeks (days)	45.3 (28.14)	42 (2-100)

[a] BDI-II: Beck Depression Inventory–II.

[b] DASS-21: Depression, Anxiety, and Stress Scale–21.

The average use during the initial 2 weeks was 5.52 (SD 4.14) days. After 12 weeks, the average use was 45.3 (SD 28.14) days, showing a broad range of use volumes among participants. Participants rated the system favorably in terms of usefulness and ease of use (PEOU). The PEOU scored an average of 32.5 (SD 4.22) at 4 weeks and increased slightly to 32.7 (SD 4.33) at 12 weeks, indicating sustained positive impressions (scale maximum=45). The PU was also rated highly, with a mean score of 37.1 (SD 5.86) at 12 weeks, suggesting that the participants found the system beneficial (scale maximum=50).

Source of Prior Information

The following section describes how previous research was used to inform some of the prior parameters included in the Bayesian SEM. The literature search yielded 1641 articles. After reviewing based on titles and abstracts, 99.21% (1628/1641) of the articles were excluded. A total of 12 articles were included for full screening. Of the 12 articles, 2 (17%) were removed owing to the qualitative nature of the method and the focus of the topics and 1 (8%) focused on the older adult population (aged ≥65 years).

A summary of all the results of the recalculations and the assumed prior distributions for all variables in the path analysis can be found in Table 2.

Table 3 provides the prior specifications used for the intercepts of outcome variables in our analyses. For each value, the table outcomes the distribution, the associated hyperparameters, and the source or bases for the selected priors.

Convergence of the prior model was assessed through divergences, trace plots, Gelman autocorrelation plots, effective sample size, and R-hat measures. During prior model testing, divergences occurred because of previous settings of the variance (disturbance) priors (ie, γ[SD] in Table 4).

As a result, the Blavaan default prior γ(1,0.5)(SD) was changed to γ(2,1)(SD) for all variances except use at 12 weeks, which was changed to γ(25,1)(SD) based on the larger variance in the range of 1 to 100. With these changes, the prior model ran without divergence. All other convergence indexes were acceptable in the prior model: (1) trace plots of all variables were horizontal, with the distribution showing even amounts of variation around the mean over samples; (2) Gelman autocorrelations were very low after the initial samples, expected because of Hamilton Monte Carlo; (3) effective sample sizes (as indicated by "neff" in *Blavaan*) ranged from 125,424 to 264,497 (mean 178,767; median 164,100); and (4) R-hat measures were all 1 within at least 4 decimal points of accuracy.

Table 2. Summary of priors in the model: outcome and predictor variables, distribution types, hyperparameters, and sources.

Outcome	Predictor	Distribution	Hyperparameters, mean (SD)	Prior source
Use$_{\text{2 weeks}}$	Sex$_{\text{female}}$	Normal	0.21 (1.23)	Abdool et al [27], Coughlin et al [28], and Kontos et al [29]
Use$_{\text{2 weeks}}$	Education$_{\text{low}}$	Normal	−0.34 (1.09)	Abdool et al [27], Børøsund et al [30], Coughlin et al [28], Golsteijn et al [31], and Kontos et al [29]
Use$_{\text{2 weeks}}$	BDI-II[a]	Normal	0 (10)	Diffuse prior[b]
Use$_{\text{2 weeks}}$	DASS-21[c]	Normal	0 (10)	Diffuse prior
PEOU[d]$_{\text{4 weeks}}$	Use$_{\text{2 weeks}}$	Normal	0.22 (1.12)	Abdool et al [27]
PEOU$_{\text{12 weeks}}$	PEOU$_{\text{4 weeks}}$	Normal	0.61 (0.46)	No previous research was identified. The prior for the correlation coefficient (r=0.6) was set based on the expert assessment of the authors.
PU[e]$_{\text{12 weeks}}$	PEOU$_{\text{12 weeks}}$	Normal	0.71 (0.18)	Abdool et al [27], Almazroi et al [32], and Dünnebeil et al [33]
Use$_{\text{12 weeks}}$	PEOU$_{\text{12 weeks}}$	Normal	1.42 (2.95)	Abdool et al [27]
Use$_{\text{12 weeks}}$	PU$_{\text{12 weeks}}$	Normal	1.02 (2.19)	Abdool et al [27]
Use$_{\text{12 weeks}}$	Use$_{\text{2 weeks}}$	Normal	1.36 (3.40)	Authors' assessment (r=0.2)

[a] BDI-II: Beck Depression Inventory–II.

[b] Diffuse prior: noninformative prior distributions that assign broad probabilities across a wide range of parameter values, reflecting minimal prior beliefs or knowledge.

[c] DASS-21: Depression, Anxiety, and Stress Scale–21.

[d] PEOU: perceived ease of use.

[e] PU: perceived usefulness.

Table 3. Prior specifications for intercepts of outcome variables.

Variable	Distribution	Hyperparameters, mean (SD)	Prior source
Use$_{\text{2 weeks}}$	Normal	0 (7)	Diffuse prior[a] centered on 0, scale limits
PEOU[b]$_{\text{4 weeks}}$	Normal	0 (25)	Diffuse prior centered on 0, scale limits
PEOU$_{\text{12 weeks}}$	Normal	0 (25)	Diffuse prior centered on 0, scale limits
PU[c]$_{\text{12 weeks}}$	Normal	0 (25)	Diffuse prior centered on 0, scale limits
Use$_{\text{12 weeks}}$	Normal	0 (50)	Diffuse prior centered on 0, scale limits

[a] Diffuse prior: noninformative prior distributions that assign broad probabilities across a wide range of parameter values, reflecting minimal prior beliefs or knowledge.

[b] PEOU: perceived ease of use.

[c] PU: perceived usefulness.

Table 4. Prior specifications for error variances of outcome variables.

Variable	Distribution	Hyperparameters	Prior source
Use$_{\text{2 weeks}}$	γ(SD)	Shape=3; scale=1	Default and prior convergence modification
PEOU[a]$_{\text{4 weeks}}$	γ(SD)	Shape=3; scale=1	Default and prior convergence modification
PEOU$_{\text{12 weeks}}$	γ(SD)	Shape=3; scale=1	Default and prior convergence modification
PU[b]$_{\text{12 weeks}}$	γ(SD)	Shape=3; scale=1	Default and prior convergence modification
Use$_{\text{12 weeks}}$	γ(SD)	Shape=25; scale=1	Default and prior convergence modification

[a] PEOU: perceived ease of use.

[b] PU: perceived usefulness.

The sensitivity analysis of prior settings showed that sampling had some effects on point estimates and the distributional range when one variable was changed to have diffuse hyperparameters; this could also be seen when all intercepts' priors were changed to diffuse. However, regardless of these variations, no directional changes in the regression coefficients occurred (ie, from positive to negative or from negative to positive), and there were no changes that altered the interpretation of the level of uncertainty based on the 95% highest posterior density intervals. For single-variable diffusion variations, the median difference in point estimate was 1.6% (range −0.9% to 56.7%), and when all intercepts were changed to diffuse, the median difference was 0.2% (range 11.3%-37%). Changes in sampling had comparatively minor effects on the slopes, intercepts, and variances. On average, the sampling variations (n=5000|10,000|25,000) did not change the estimates at all (ie, the mean difference was 0), but the variable range changed somewhat between −3.4% and 2%.

Posterior Fit Assessment

We computed the model fit indexes using the *gl_fits_all* function from the *Blavaan* package. This function provides Bayesian analogous structure equation model fit indexes, as suggested by Garnier-Villarreal and Jorgensen [34]. The absolute fit index, the Bayesian root mean square error of approximation, analogous to the frequentist equivalent root mean square error of approximation, was estimated to be on average 0.036 with a credible interval from 0 to 0.068. The corresponding values for the Bayesian analogs of incremental fit indexes were as follows: the comparative fit index was 0.960 (credible interval 0.893-1.0); the Tucker-Lewis index was 0.958 (credible interval 0.875-1.033); and its normalized variant, the Bentler-Bonett normed fit index, was 0.785 (credible interval 0.724-0.841). Finally, the posterior predictive *P* value was .05. These indexes are similar to their frequentist counterparts; however, they should be interpreted with caution. The aforementioned measures show a reasonable fit [35], but that only describes how well the model fits compared with very liberal null models, and it has been argued that fit indexes for Bayesian models may be less valuable for fit assessment [36].

Bayesian Structural Regression Model Results

The model comprised a total of 10 regression slopes, which were the main focus of this study. Of these 10 regression slopes, 4 (40%) had slopes with lower and clearer associations among variables, whereas 6 (60%) had higher uncertainty in the direction and strength of the association (Figure 4).

Figure 4 shows that 4 regression paths, found in bold text, had clearer associations. The highest posterior density credibility intervals, noted by the asterisk, are in the same direction (positive or negative relation), thus not crossing 0. From these regressions, 2 main paths were found to predict use of the NEVERMIND system at 12 weeks. The first path is from PEOU after 4 weeks ($\beta_{\text{PEOU 12 weeks is predicted by PEOU 4 weeks}}$=.589) through PU after 12 weeks ($\beta_{\text{PU 12 weeks is predicted by PEOU 12 weeks}}$=.581) to the use of the system after 12 weeks ($\beta_{\text{use 12 weeks is predicted by PU 12 weeks}}$=.384). The second path is the association between the use of the system after 2 weeks and the use of the system after 12 weeks ($\beta_{\text{use 12 weeks is predicted by use 2 weeks}}$=.239). The prior and posterior distributions of these 4 paths are described in Figure 5. However, the third path going through PEOU at 12 weeks was unclear in its direction and strength ($\beta_{\text{use 12 weeks is predicted by PEOU 2 weeks}}$=−.130).

The 6 uncertain associations had posterior coefficient distributions that contained high probabilities of both negative and positive values. The estimates for the regression coefficients, SDs, highest posterior density intervals, and standardized β coefficients are presented in Table 5. The estimates for intercept and variance can be found in Table 6.

Figure 4. The Bayesian structural regression model results showing standardized regression coefficients (β) for all paths. *The highest posterior density credibility intervals are in the same direction (positive or negative relation), thus not crossing 0. BDI-II: Beck Depression Inventory–II; DASS-21: Depression, Anxiety, and Stress Scale–21; PEOU: perceived ease of use; PU: perceived usefulness.

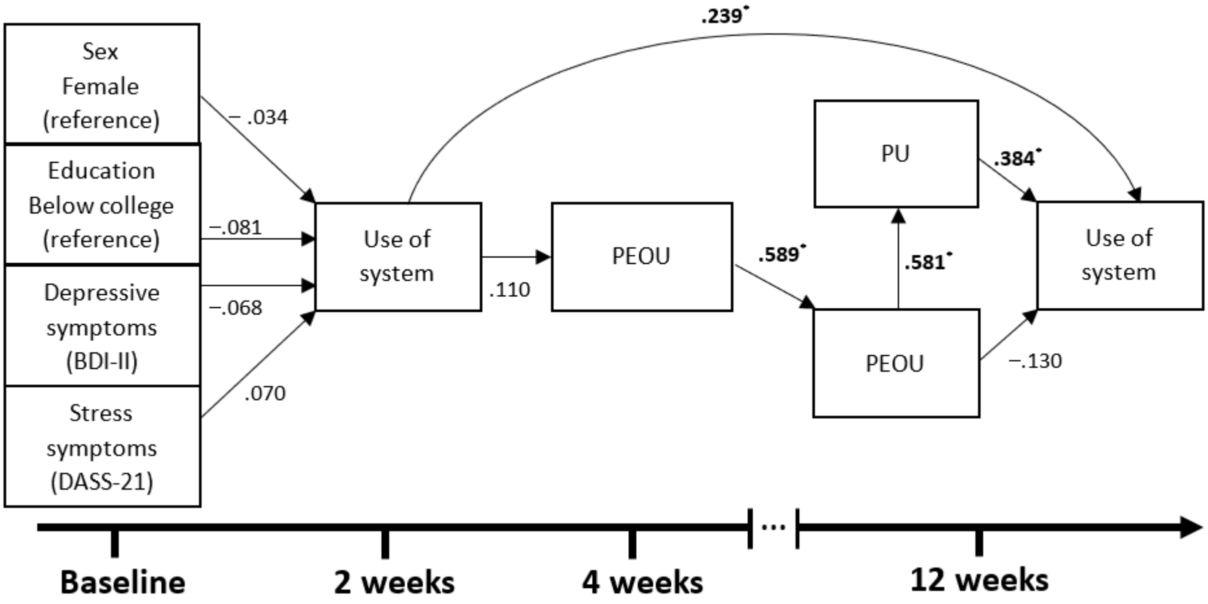


Figure 5. Prior and posterior distributions for the 4 associations with less uncertainty. The prior distributions are shown in blue, and the posterior distributions are shown in red. A and B show the direct predictors of use at 12 weeks. C and D show the indirect predictors of use at 12 weeks preceding the distribution in A. PEOU: perceived ease of use; PU: perceived usefulness.

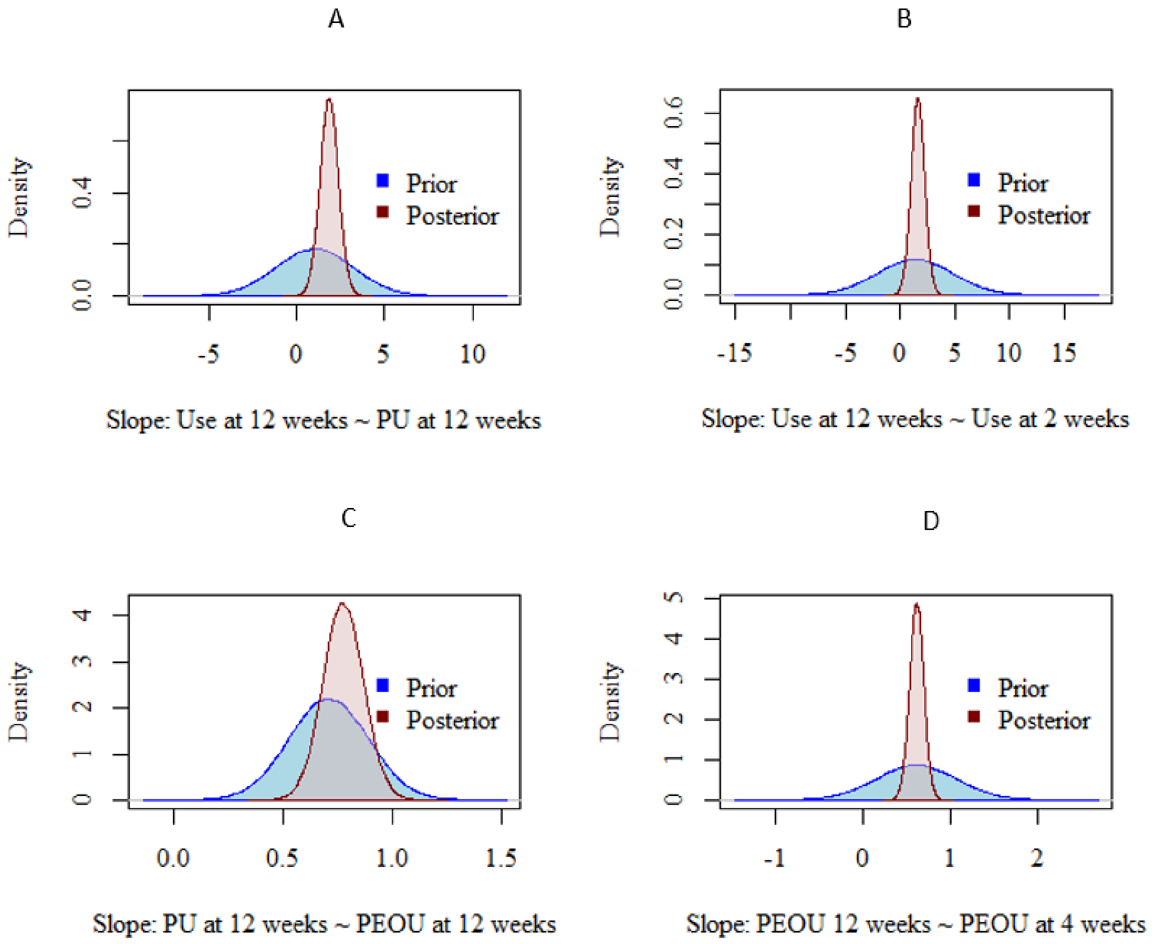


Table 5. Posterior parameter estimates.

Regressions	B (SD)	HPDI[a]	β
use_2w ~ sex_female	−0.279 (0.764)	−1.765 to 1.228	−.034
use_2w ~ education_low	0.871 (0.758)	−0.624 to 2.339	−.081
use_2w ~ bdi-II[b]	−0.346 (0.743)	−1.789 to 1.125	−.068
use_2w ~ dass-21[c]	0.352 (0.702)	−1.006 to 1.754	.070
Peou[d]_4w ~ use_2w	0.112 (0.102)	−0.089 to 0.312	.110
peou_12w ~ peou_4w	0.616 (0.082)	0.457 to 0.778	.589
pu[e]_12w ~ peou_12w	0.776 (0.093)	0.590 to 0.957	.581
use_12w ~ pu_12w	1.849 (0.523)	0.830 to 2.889	.384
use_12w ~ peou_12w	−0.839 (0.691)	−2.195 to −0.520	−.130
use_12w ~ use_2w	1.604 (0.620)	0.370 to 2.805	.239

[a] HPDI: high posterior density interval.

[b] BDI-II: Beck Depression Inventory–II.

[c] DASS-21: Depression, Anxiety, and Stress Scale-21.

[d] PEOU: perceived ease of use.

[e] PU: perceived usefulness.

Table 6. Posterior summaries for intercepts and variances of outcome variables.

	Estimate (SD)	HPDI[a]
Intercepts		
.use_2w	6.761 (2.181)	0.258 to 8.861
.peou[b]_4w	31.92 (0.707)	30.52 to 33.28
.peou_12w	13.13 (2.683)	7.434 to 18.00
.pu[c]_12w	11.82 (3.078)	5.666 to 17.78
.use_12w	14.51 (15.10)	−41.57 to 30.78
Variances		
.use_2w	17.566 (2.544)	12.85 to 22.55
.peou_4w	17.960 (2.574)	13.18 to 23.06
.peou_12w	12.384 (1.783)	9.072 to 15.94
.pu_12w	22.769 (3.239)	16.78 to 29.25
.use_12w	555.32 (70.65)	499.1 to 847.3

[a] HPDI: high posterior density interval.

[b] PEOU: perceived ease of use.

[c] PU: perceived usefulness.

Regarding how much variance was explained by the model, the variable with the most explained variance was PEOU at 12 weeks with r^2 of 0.358, followed by PU at 12 weeks with r^2 of 0.338. The use at 2 weeks, PEOU at 4 weeks, and use at 12 weeks variables had a variance value of 0.010, 0.012, and 0.166, respectively. Thus, the model can explain some variations in attitude variables at 12 weeks, whereas use and attitude variables earlier in time were less well explained.

Residual Covariances of Endogenous Variables

The residual covariances in the model indicate that there are some covariances that were not explained in the modeling of use at 2 and 12 weeks (Table 7). The first covariance was a positive association between female sex and system use at 12 weeks ($B_{\text{use 12 weeks is predicted by female}}$=0.240). With regard to sex in this study, it is important to note that sex is completely confounded by type of cancer (ie, breast cancer). Therefore, the implication may be that patients with breast cancer use the system more than patients with prostate cancer. This association was planned to be modeled but dropped because of the need to limit the number of parameter assessments owing to sample size. In addition, the prior assessment of how sex is related to eHealth use is that men use eHealth more, which is the opposite association compared with the residual covariation in this case [17].

Table 7. Truncated residual covariance matrix of association between model variables.

Variable	Use$_{2 \text{ weeks}}$	PEOU[a]$_{4 \text{ weeks}}$	PEOU$_{12 \text{ weeks}}$	PU[b]$_{4 \text{ weeks}}$	Use$_{12 \text{ weeks}}$
Sex (female)	−0.017	−0.223	−0.245	−0.119	0.240
Education (college)	0.032	0.228	0.220	0.129	0.054
Depression symptoms (BDI-II[c])	−0.011	0.171	0.126	0.186	−0.042
Stress symptoms (DASS-21[d])	−0.007	0.087	−0.023	0.060	−0.057
Use$_{2 \text{ weeks}}$	N/A[e]	−0.004	0.007	0.083	0.030
PEOU$_{4 \text{ weeks}}$	N/A	N/A	−0.002	0.106	0.208
PEOU$_{12 \text{ weeks}}$	N/A	N/A	N/A	0.030	−0.119
PU$_{12 \text{ weeks}}$	N/A	N/A	N/A	N/A	0.030

[a] PEOU: perceived ease of use.

[b] PU: perceived usefulness.

[c] BDI-II: Beck Depression Inventory–II.

[d] DASS-21: Depression, Anxiety, and Stress Scale–21.

[e] N/A: not applicable.

The second and third covariances are the associations between PEOU at 4 and 12 weeks and system use at 12 weeks. However, how to interpret these residuals is unclear as the 4-week coefficient shows a positive association, whereas the 12-week coefficient shows a negative association (Table 7). Finally, these residual covariances are point estimates, and proper analysis needs to be conducted to determine the level of uncertainty of the associations.

Discussion

Principal Findings

The purpose of this study was to model the use of the NEVERMIND eHealth system in relation to stable baseline factors and perceptual variables following the TAM. In the 100 patients with breast and prostate cancer analyzed, the strongest predictor of use at the end of the 12-week treatment period was the PU of the system, whereas PEOU had a possible indirect influence by affecting PU. Early engagement with the system also tended to predict its use at the end of the 12-week treatment period. Although the overall model fit was deemed acceptable, the structural regressions showed a significant amount of uncertainty for baseline variables such as sex, education, and mental health symptoms related to early use.

Interpretation of Key Findings

The PU of the NEVERMIND eHealth system at 12 weeks demonstrated the strongest association with system use at 12 weeks ($\beta_{\text{use 12 weeks is predicted by PU 12 weeks}}$=.384), indicating that patients who found the system useful were more likely to use it consistently. This finding aligns with previous research on technology acceptance, which suggests that users are more inclined to adopt and continue using a system if they perceive it as beneficial for achieving desired outcomes or addressing their problems [37]. Our findings largely supported the predictions of the TAM, highlighting the PU of the NEVERMIND system as a critical determinant of its consistent use while also highlighting the need for considering additional factors such as early engagement. For instance, adding *early engagement* as an important variable in the TAM framework may provide a more comprehensive understanding of the factors influencing eHealth adoption and sustained use. In addition, the PEOU at 4 weeks exhibited a positive association with PEOU at 12 weeks ($\beta_{\text{PEOU 12 weeks is predicted by PEOU 4 weeks}}$=.589), implying that patients' initial impressions of the system's user-friendliness persisted over time, influencing their continued engagement.

Despite these associations, the study revealed uncertainties in predicting the system's early use based on baseline variables. Variables such as education, sex, and mental health symptoms exhibited an uncertain relationship with system use at 2 weeks, suggesting that these factors may not reliably predict early engagement with the system. Notably, there was a substantial positive residual covariance between sex (confounded by type of cancer treatment) and system use at 12 weeks ($B_{\text{use 12 weeks is predicted by female}}$=0.240). This result suggests a potential difference in system use between patients with breast and prostate cancer, although further exploration is required owing to the confounding effect. Several explanations can be considered for the uncertainty surrounding baseline mental health symptoms' impact on the use of the NEVERMIND system. First, the system may be well designed and effective in addressing the challenges faced by individuals with varying levels of baseline depression and stress symptoms. The personalized modules of the NEVERMIND system may have aided users in engaging with the platform irrespective of their initial symptom severity. Second, the study may have lacked sufficient statistical power owing to the low variability in baseline symptom scores among users. The duration and timing of the measurements might not have been optimal for observing the hypothesized relationship as the effects of, for example, baseline depression symptoms on use may become apparent only after a longer duration given that the treatment for depressive symptoms can take 3 to 8 months [38]. Finally, there could be other unmeasured confounding factors such as individual differences in motivation or resilience that might mask the relationship between baseline mental health symptoms and use. Our findings suggest that the influence of external user characteristics within the TAM might differ in clinical contexts, emphasizing the need for theoretical flexibility when applying the TAM in diverse settings.

The findings of this study hold valuable implications for implementing eHealth systems such as NEVERMIND. An essential insight from this study is the significance of PU in determining system use. This suggests that, when introducing eHealth technologies, caregivers must provide a thorough explanation of how the technology will enhance patients' health, including any available evidence supporting the system's effectiveness. By doing so, we can foster a sense of PU in patients, thereby encouraging consistent use.

In addition, our findings highlighted the influence of early system engagement on its continued use. Therefore, it would be strategic to allocate resources primarily toward monitoring, supporting, and incentivizing system use in the initial stages of an intervention. Ensuring patients' engagement with the system early on appears more critical than maintaining these efforts throughout the entire intervention period.

Limitations

This study has certain limitations that should be acknowledged, including the relatively small sample size, which may have limited the statistical power to detect subtle relationships. The sample was also not diverse, comprising mostly highly educated participants and a healthy population, which could restrict the generalizability of the findings to other patient populations who may have a harder time adapting to technological systems. It should also be noted that a potential limitation of our study lies in the exclusion of 8 patients who failed to complete either the usability and acceptability questionnaires or the mental health follow-up questionnaires. Although these patients did not show significant differences in sociodemographic characteristics or baseline depressive and stress symptoms, their absence could introduce a potential bias as their lack of feedback might indicate challenges with the system's ease of use or PU.

Our approach to measuring the use of the NEVERMIND system also has certain limitations. Specifically, we considered multiple uses of the system within a single day as one instance of use because of constraints from the server-provided data for both the shirt and mobile app. This could potentially underestimate the system's use if a person used it multiple times per day but it was recorded as a single instance. Future research may benefit from more granular tracking of use patterns, including the frequency of use per day and duration of each use, to provide a more comprehensive understanding of user engagement. However, it is also important to consider, as supported by Lally et al [14], that the quality of user engagement and the ability to derive needed support might be more critical than the sheer frequency or duration of use.

In addition, there may have been unmeasured confounders that were not accounted for in this study.

Our study also assumes that the relationships described in the Bayesian SEM hold true; however, unmeasured confounding variables may distort these relationships, leading to biased estimates. Furthermore, the uncertainty observed in some of the regression coefficients points toward potential model specification issues or inherent variability in the data that were not captured in the model. This uncertainty might pose challenges in making robust predictions about system use based on baseline variables. From a methodological perspective, the significant residual covariances observed might suggest a need to revise the model. For instance, it might be beneficial to explore whether additional variables or paths should be included in the model or whether certain relationships might be nonlinear.

The changes made to the prior model owing to divergences in the initial runs are another limitation despite carefully considering the choice of prior distributions for most of the parameters. Although these adjustments helped the model converge, they may have also influenced the resultant estimates and the interpretation of the findings.

Overall, these statistical and methodological limitations need to be acknowledged when interpreting the findings of our study and should be addressed in future research.

Conclusions

This study offers valuable insights into the complex dynamics affecting patient engagement with eHealth systems, underscoring the importance of PU and early engagement. Therefore, it is paramount to educate patients on the system's benefits and effectiveness to encourage early and continued use. Given the complexities of patient behavior, further research is warranted to clarify the remaining uncertainties. Addressing these gaps will pave the way for a more effective deployment of eHealth systems in patient care.

Authors' Contributions

NGP made substantial contributions to the concept and design of the study, methodology, drafting of the first version of and subsequent revisions to the manuscript, and interpretation of the results. JA-H contributed significantly to the statistical analysis, methodology, visualization, and review of subsequent drafts and provided supervision. GH moderately contributed to the methodology and significantly contributed to the review, editing, and supervision of the project. DW made significant contributions to the review and editing of the drafts and provided supervision. MO contributed substantially to software development, definition of the protocol for assessing mobile interventions, and review of the subsequent drafts. SG-M developed the mobile app and provided use data. SC recruited patients for the study, provided patient data, and reviewed the final draft of the manuscript. EPS, as the principal investigator for the NEVERMIND project, reviewed the final draft of the manuscript. GV also reviewed the final draft of the manuscript. Finally, VC made substantial contributions to the concept and design of the study, methodology, supervision, and the review process.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Perceived ease of use questionnaire.
[PNG File , 36 KB - cancer_v9i1e49775_app1.png]

Multimedia Appendix 2
Perceived usefulness questionnaire.
[PNG File , 57 KB - cancer_v9i1e49775_app2.png]

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Abbreviations

BDI-II: Beck Depression Inventory–II
DASS-21: Depression, Anxiety, and Stress Scale–21
PEOU: perceived ease of use
PU: perceived usefulness
RCT: randomized controlled trial
SEM: structural equation modeling
TAM: Technology Acceptance Model

Edited by G Eysenbach, T de Azevedo Cardoso; submitted 13.06.23; peer-reviewed by P Lally; comments to author 12.07.23; revised version received 19.07.23; accepted 21.08.23; published 12.09.23.

Please cite as:
Petros NG, Alvarsson-Hjort J, Hadlaczky G, Wasserman D, Ottaviano M, Gonzalez-Martinez S, Carletto S, Scilingo EP, Valenza G, Carli V
Predictors of the Use of a Mental Health–Focused eHealth System in Patients With Breast and Prostate Cancer: Bayesian Structural Equation Modeling Analysis of a Prospective Study
JMIR Cancer 2023;9:e49775
URL: https://cancer.jmir.org/2023/1/e49775
doi:10.2196/49775
PMID:37698900

Original Paper

Telehealth Availability for Cancer Care During the COVID-19 Pandemic: Cross-Sectional Study

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Abstract

Background: Telehealth was an important strategy for maintaining continuity of cancer care during the coronavirus pandemic and has continued to play a role in outpatient care; however, it is unknown whether services are equally available across cancer hospitals.

Objective: This study aimed to assess telehealth availability at cancer hospitals for new and established patients with common cancers to contextualize the impact of access barriers to technology on overall access to health care.

Methods: We conducted a national cross-sectional secret shopper study from June to November 2020 to assess telehealth availability at cancer hospitals for new and established patients with colorectal, breast, and skin (melanoma) cancer. We examined facility-level factors to determine predictors of telehealth availability.

Results: Of the 312 investigated facilities, 97.1% (n=303) provided telehealth services for at least 1 cancer site. Telehealth was less available to new compared to established patients (n=226, 72% vs n=301, 97.1%). The surveyed cancer hospitals more commonly offered telehealth visits for breast cancer care (n=266, 85%) and provided lower access to telehealth for skin (melanoma) cancer care (n=231, 74%). Most hospitals (n=163, 52%) offered telehealth for all 3 cancer types. Telehealth availability was weakly correlated across cancer types within a given facility for new (r=0.16, 95% CI 0.09-0.23) and established (r=0.14, 95% CI 0.08-0.21) patients. Telehealth was more commonly available for new patients at National Cancer Institute–designated facilities, medical school–affiliated facilities, and major teaching sites, with high total admissions and below-average timeliness of care. Telehealth availability for established patients was highest at Academic Comprehensive Cancer Programs, nongovernment and nonprofit facilities, medical school–affiliated facilities, Accountable Care Organizations, and facilities with a high number of total admissions.

Conclusions: Despite an increase in telehealth services for patients with cancer during the COVID-19 pandemic, we identified differences in access across cancer hospitals, which may relate to measures of clinical volume, affiliation, and infrastructure.

(JMIR Cancer 2023;9:e45518) doi:10.2196/45518

KEYWORDS

telehealth; colorectal cancer; breast cancer; melanoma; access to care; COVID-19 pandemic; telemedicine; national survey; cross-sectional; cancer; oncology

Introduction

The COVID-19 pandemic disrupted the delivery of cancer care around the world [1,2]. For at least some period of time, most patients were unable to receive in-person care due to pandemic-related hospital restrictions and exposure risks. These delays are expected to have significant downstream effects—modeling studies have estimated a 15%-16% increase in deaths due to colorectal cancer and an 8%-10% increase in deaths due to breast cancer in the postpandemic period up to 5 years after diagnosis [3].

To maintain continuity of care during the pandemic, alternative mediums of health care delivery were used, primarily telehealth [4]. Although telehealth has long been available, most physicians did not offer telehealth services prior to the COVID-19 pandemic [5,6]. Due to the urgent need for remote provision of health care services triggered by the COVID-19 pandemic, government and health care providers temporarily removed reimbursement and access barriers and enhanced facility infrastructure [7,8]. As a result, telehealth use dramatically increased, with a 50- to 175-fold increase in the number of patients seen via telehealth compared to prepandemic practice [9,10]. In this way, the adoption of a technological platform, telehealth, served as a solution for the problem of access to health care generated by the COVID-19 pandemic crisis.

Despite the increased use of telehealth, the extent of access to telehealth for cancer care at a facility level during the COVID-19 pandemic is unknown. Although there has been a rapid proliferation of studies addressing telehealth during the pandemic, most existing studies addressing cancer care have not analyzed facility-level characteristics and telehealth uptake [10-18]. Therefore, we aimed to assess telehealth availability for cancer care in the United States during the COVID-19 pandemic at facilities recognized for cancer care excellence with the goal of understanding factors associated with initial uptake. We chose to investigate cancers with early treatment interventions—colorectal, breast, and skin (melanoma) cancer—as delays in health care services due to COVID-19 have been projected to have enduring downstream consequences. We hypothesized that despite increases in the use of telehealth during the COVID-19 pandemic, disparities in access to telehealth for cancer care persisted.

Methods

Study Sample and Data

The primary objective of this study was to characterize telehealth availability for cancer care for patients with colorectal, breast, or skin (melanoma) cancer. In addition, we investigated characteristics of facilities that provide high telehealth access for cancer care, defined as the provision of telehealth appointments for all 3 investigated cancer types. We examined telehealth availability by cancer site and separately evaluated access for new and established patients.

We conducted a national cross-sectional secret shopper study from June 3 to November 9, 2020. Secret shopper studies can effectively assess access to care from the patient's perspective by using simulated patient calls to physician offices to attempt to schedule appointments for surgical consults [19-23]. Trained investigators contacted specialty departments at identified facilities, posing as an individual seeking care for a family member (simulated patient) with a new cancer diagnosis. Institutions were not notified of the simulated patient call prior to the investigation, and no real patient information was used for the purpose of this study. Investigators recorded department referral location, telehealth availability for new patients (ie, initial appointment availability), and telehealth availability for established patients (ie, follow-up visit availability).

Variable Measures

We identified cancer care facilities using the American College of Surgeon’s Commission on Cancer Hospital Locator [24]. We excluded facilities with unique membership policies, as such policies are likely to skew facility-level characteristics and subsequent analysis. These facilities included Veterans Affairs and Kaiser Foundation hospitals; specialty programs, such as pediatric cancer, hospital associate cancer, freestanding cancer, oncology medical home, and rectal cancer–only programs; and facilities located in Puerto Rico. We then used a random number generator to create a representative sample of approximately one-third of eligible facilities.

We characterized facilities included in the sample using the 2016 American Hospital Association Annual Survey database and the publicly available Centers for Medicare and Medicaid Services (CMS) General Information database [25,26]. We investigated facility characteristics known to influence health care access and outcomes, including organization infrastructure, financials, and services provided. Example characteristics include types of cancer programs, ownership, medical school affiliation, major teaching hospital, Accountable Care Organization, and total facility admissions. Types of cancer programs include Community (facilities seeing <500 and >100 newly diagnosed cancer cases annually), Comprehensive Community (facilities seeing >500 cases annually), Academic Comprehensive (facilities seeing >500 cases annually, with postgraduate medical education provided), Integrated Network (multifacility systems with integrated, comprehensive cancer services), and National Cancer Institute (NCI)–designated cancer programs (facilities with NCI Cancer Center Support Grants) [24]. The CMS database provides information on facility performance, including overall rating, the effectiveness of care, and timeliness of care, defined as how often and quickly hospitals provide care shown to yield the best outcomes for patients with certain conditions (eg, cancer care, colonoscopy follow-up, preventative care, and sepsis care) [27].

We excluded facilities where at least 1 specialty department of interest was unable to be contacted as well as facilities that were not included in both the American Hospital Association and CMS databases.

Data Analysis Procedure

The primary study outcome was telehealth appointment availability for new and established patients with a presumptive cancer diagnosis (available vs not available). To evaluate whether the availability of telehealth services for 1 cancer type was associated with others within a given institution, we used a two-way mixed effects model with absolute agreement to determine single measures intraclass correlation coefficients. Additionally, we assessed facility characteristics associated with high access to telehealth for new and established patients. We used chi-square tests to evaluate associations between facility characteristics and telehealth access ($P<.05$ was considered statistically significant). We redefined continuous variables into quintiles and compared the highest quintile against the lowest 4 quintiles. The statistical analyses were performed using JMP 15 (SAS Institute) and IBM SPSS Statistics for Windows (version 28.0.0.0; IBM Corp). Facility locations and their telehealth appointment availability were mapped using ArcGIS software by Esri.

Ethical Considerations

The Yale School of Medicine Institutional Review Board deemed this study exempt from review (IRB #2000030368). This study was not identified as a human subject research.

Results

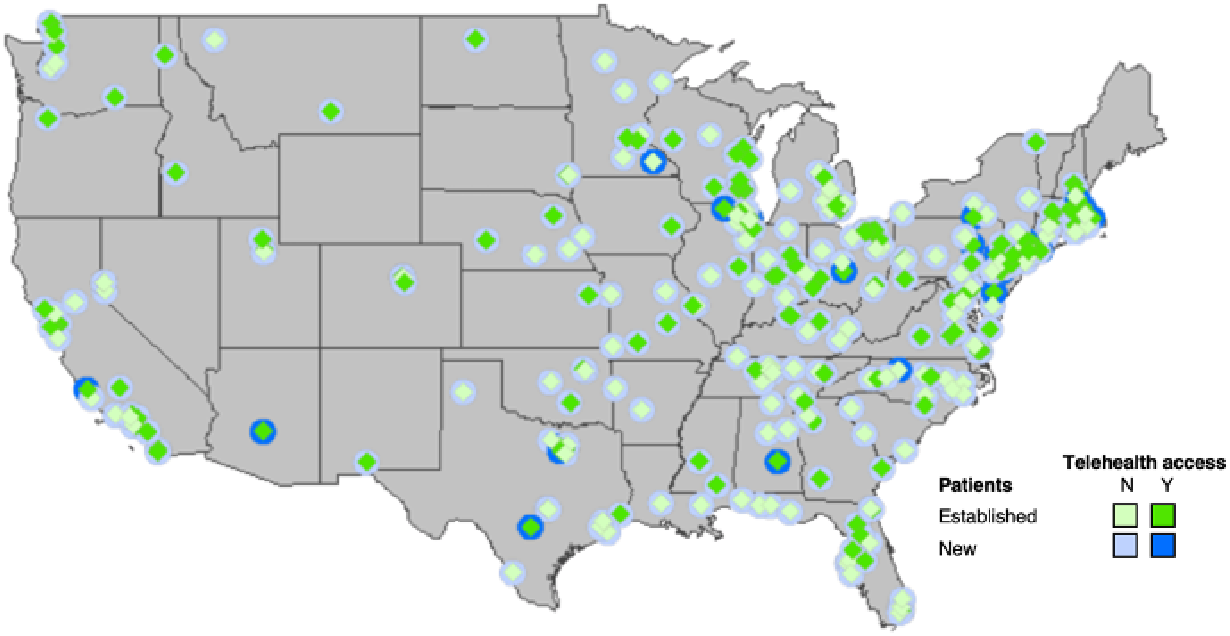
We contacted 312 Commission on Cancer (CoC)–accredited facilities for each of the 3 investigated cancer types, representing 27% of all facilities that met inclusion criteria. Overall, 97.1% (n=303) of facilities provided some form of telehealth for patients with cancer. At the time of the interview, 72.4% (n=226) of surveyed facilities offered new telehealth services for at least 1 cancer type, 39.1% (n=122) for at least 2, and 10.9% (n=34) for all 3 cancer types surveyed. Comparatively, 97.1% (n=303) offered telehealth for established patients for at least 1 cancer type, 85.3% (n=266) for at least 2, and 51.6% (n=161) for all 3 cancer types. Telehealth appointments for new versus established patients were offered at 39.7% (n=124) versus 74.4% (n=232) of facilities for colorectal cancer, 35.6% (n=111) versus 85.3% (n=266) of facilities for breast cancer, and 47.1% (n=147) versus 73.7% (n=230) for skin cancer care. Telehealth was not offered in 24.4% (n=76) of facilities for colorectal, 14.7% (n=46) for breast, and 26.0% (n=81) for skin cancer care (Table 1).

Table 1. Telehealth appointment availability for new and established patient visits in the United States during the COVID-19 pandemic (June-November 2020).

Telehealth appointment availability	All cancer types, n (%)	Colorectal cancer, n (%)	Breast cancer, n (%)	Skin cancer, n (%)
New patients	34 (10.9)	124 (39.7)	111 (35.6)	147 (47.1)
Established patients	161 (51.6)	232 (74.4)	266 (85.3)	230 (73.7)
Both new and established patients	32 (10.3)	120 (38.5)	111 (35.6)	146 (46.8)
No appointments available	149 (47.8)	76 (24.4)	46 (14.7)	81 (26.0)
Only new patients (no established patients)	2 (0.6)	4 (1.3)	0 (0)	1 (0.3)
Only established patients (no new patients)	129 (41.3)	112 (35.9)	155 (49.7)	84 (26.9)
Any form of telehealth appointment availability offered	163 (52.2)	236 (75.6)	266 (85.3)	231 (74.0)

Figure 1 shows the geographic distribution of high telehealth access facilities offering telehealth appointments for new and established patients for all investigated cancer types. Of note, even in regions with a lower density of cancer care facilities, few centers offered telehealth services for new patients with cancer.

Figure 1. Telehealth availability at cancer care facilities across the United States. State boundary data were extracted from the state (generalized) publicly available data set. N: No access to telehealth. Y: access to telehealth. Green: established patients. Blue: new patients.



When examining facilities providing high access to telehealth or access to telehealth appointments for all 3 investigated cancer types, 10.9% (n=34) provided high access for new patients, 51.6% (n=161) provided high access for established patients (Table 1), and 47.8% (n=149) of facilities offered no uniform telehealth availability for all cancer types (Table 1). Only 10.3% (n=32) of facilities offered telehealth appointments for both new and established patients for all 3 cancer types (Table 1). Although 41.3% (n=129) of facilities offered telehealth for established patients for all cancer types, less than 1% (n=2) of facilities offered telehealth for only new patients for all cancer types (Table 1). The correlation of telehealth availability across cancer types within facilities was weak for both new (r=0.16, 95% CI 0.09-0.23) and established patients (r=0.14, 95% CI 0.08-0.21).

Facility characteristics by telehealth access status are detailed in Table 2.

Table 2. Characteristics of facilities with high access to telehealth for new and established patient visits in the United States during the COVID-19 pandemic (June-November 2020). Statistically significant *P* values (*P*<.05) are italicized.

Characteristics	Total facilities, n (%)	Facilities with high access to telehealth for new patients		Facilities with high access to telehealth for established patients	
		Total, n (%)	*P* value	Total, n (%)	*P* value
Type of cancer care program			*<.001*		*.02*
Community	74 (23.7)	2 (2.7)		30 (40.5)	
Comprehensive Community	146 (46.8)	11 (7.5)		71 (48.6)	
Academic Comprehensive	44 (14.1)	11 (25.0)		30 (68.2)	
Integrated Network	36 (11.5)	5 (13.9)		23 (63.9)	
NCI[a] designated	12 (3.8)	5 (41.7)		7 (58.3)	
Ownership			.24		*.03*
For-profit	38 (12.2)	2 (5.3)		14 (36.8)	
Nongovernment, nonprofit	239 (76.6)	30 (12.6)		133 (55.6)	
Government	35 (11.2)	2 (5.7)		14 (40.0)	
Medical school affiliation			*.003*		*.002*
No	119 (38.1)	5 (4.2)		48 (40.3)	
Yes	193 (61.9)	29 (15.0)		113 (58.5)	
Major teaching hospital			*<.001*		*<.001*
No	254 (81.4)	17 (6.7)		119 (46.9)	
Yes	58 (18.6)	17 (29.3)		42 (72.4)	
Accountable Care Organization			.18		*.04*
No	120 (43.6)	10 (8.3)		54 (45.0)	
Yes	155 (56.4)	22 (14.2)		90 (58.1)	
Total facility admissions			*<.001*		*.002*
Lowest 4 quintiles	256 (82.3)	20 (7.8)		122 (47.7)	
Highest quintile	55 (17.7)	14 (25.5)		39 (70.9)	
Hospital overall rating			.15		.90
1 star (lowest)	20 (6.5)	1 (5)		12 (60.0)	
2 stars	72 (23.2)	12 (16.7)		35 (48.6)	
3 stars	77 (24.8)	9 (11.7)		38 (49.4)	
4 stars	93 (30.0)	5 (5.4)		48 (51.6)	
5 stars (highest)	48 (15.5)	7 (14.6)		26 (54.2)	
Effectiveness of care			.24		.07
Below national average	30 (9.7)	6 (20.0)		21 (70)	
Same as national average	266 (86.1)	27 (10.2)		133 (50)	
Above national average	13 (4.2)	1 (7.7)		5 (38.5)	
Timeliness of care			*.006*		.10
Below national average	159 (51.5)	26 (16.4)		91 (57.2)	
Same as national average	104 (33.7)	7 (6.7)		46 (44.2)	
Above national average	46 (14.9)	1 (2.2)		22 (47.8)	

[a] NCI: National Cancer Institute.

The sample mostly consisted of nongovernment, nonprofit facilities (239, 76.6%); medical school–affiliated facilities (193, 61.9%); and nonmajor teaching facilities (254, 81.4%). For new patients, NCI-designated facilities offered high access to telehealth (5/12, 41.7%), while Community Cancer Programs had the lowest access to telehealth (2/74, 2.7%; *P*<.001).

Medical school–affiliated facilities (29/193, 15.0% vs 5/119, 4.2%; *P*=.003), major teaching facilities (17/58, 29.3% vs 17/254 6.7%; *P*<.001), and facilities in the highest quintile of total admissions (14/55, 25.5% vs 20/256, 7.8%; *P*<.001) were significantly more likely to offer telehealth to new patients compared to facilities not affiliated with medical schools. Facilities with below-average timeliness of care (26/159, 16.4%) were also more likely to offer telehealth to all new patients compared to those with average (7/104, 6.7%) or above average (1/46, 2.2%) timeliness of care (*P*=.006).

Telehealth availability for all cancer types for established patients also significantly differed by cancer program, with Academic Comprehensive Cancer Programs most frequently offering high telehealth access (30/44, 68.2%), followed by Integrated Network (23/36, 63.9%), NCI-designated facilities (7/12, 58.3%), Comprehensive Community Cancer Program (71/146, 48.6%), and Community Cancer Program (30/74, 40.4%; *P*=.02). Nongovernment, nonprofit facilities (133/239, 55.6%) were more likely to offer high telehealth access compared to government-owned (14/35, 40.0%) and for-profit (14/38, 36.8%) facilities (*P*=.03). Medical school–affiliated facilities (113/193, 58.5% vs 48/119, 40.3%; *P*=.002), major teaching hospitals (42/58, 72.4% vs 119/254, 46.9%; *P*<.001), Accountable Care Organizations (90/155, 58.1% vs 54/120, 45.0%; *P*=.04), and facilities in the highest quintile of total admissions (39/55, 70.9% vs 122/256, 47.7%; *P*=.002) were also more likely to offer high access to telehealth services compared to facilities not affiliated with medical schools. There was no significant difference in telehealth access for new or established patients with varying overall hospital ratings or effectiveness of care ratings (Table 2).

Discussion

Principal Findings

Our findings from a national, cross-sectional secret shopper study indicate inconsistent access to telehealth services for patients with cancer during the initial period of the COVID-19 pandemic. Although nearly half of facilities offered access to telehealth services for at least colorectal, breast, or skin cancer care, only 11% (n=34) of facilities offered telehealth appointments for all patients across all 3 cancer types. Moreover, the availability of telehealth was only weakly correlated at the facility level, suggesting that access differences may exist between departments within facilities. Telehealth services were less accessible for new compared to established patients. Finally, we found that NCI-designated cancer centers, facilities with medical school affiliations, teaching hospitals, and higher-volume facilities were more likely to offer telehealth.

We found that access to telehealth varied both between and within facilities. Nearly half of the sampled facilities offered no telehealth for new or established patients with colorectal, breast, or skin cancer during the initial peak of the COVID-19 pandemic. This finding suggests that despite meaningful federal, state, and institutional-level policy initiatives to improve access to telehealth services during the COVID-19 pandemic, significant barriers to access persisted. Further, we found that access was weakly correlated across different cancer types within a given facility. High variation within facilities suggests at least some degree of decentralization and may imply room for shared policies within institutions to standardize access. The literature suggests that similar trends exist in the variation of access to in-person visits across departments for patients with cancer, although this may not specifically apply to new versus established patient populations [23].

Before the COVID-19 pandemic, reimbursement, interstate medical licensure, and access to necessary technology platforms were recognized as key barriers to telehealth adoption [28-31]. The COVID-19 pandemic catalyzed a rapid transformation of telehealth use nationally [9,10]. Federal and state legislation worked to ameliorate some of the key access barriers by broadening reimbursement eligibility for qualifying encounters, waiving or limiting cost-sharing, requiring reimbursement parity for telehealth and in-person services, and expanding practitioner telehealth jurisdiction, with private insurance companies largely following suit [7,8,32]. Facilities also quickly scaled up capabilities to support the shift to remote health care delivery. However, the findings from this study reveal that these initiatives did not eradicate at least the initial barriers to telehealth. Persistent issues barring telehealth access for patients during the pandemic may have included reimbursement—as policies often vary by state—and the facility-level startup costs of telehealth implementation, both financially and administratively [7,33]. This is in addition to patient-driven and socioeconomic barriers, such as patient interest, lack of access to appropriate technology platforms, understanding of the use of technology, and access to safe and private spaces to attend a telehealth interview [33]. Of note, although there are several initiatives in place to continue to enable and broaden the scope of telehealth practice, including the Omnibus FY 2022 Spending Bill, which extends Medicare telehealth flexibilities and coverage, many of the policies implemented to expand telehealth accessibility were temporary, with legislation now or soon to be expired [7,34,35]. To ensure sustained access to telehealth services, barriers to reimbursement, licensure, and technological platforms must be more permanently addressed.

Another key finding of this study is that telehealth appointment availability was significantly lower for new compared to established patients, even in areas with lower density of cancer care facilities, where in-person care may be even more difficult. This finding is in line with telehealth reimbursement expansion policies, such as Medicare waiver 1135, which originally did not extend to new patient visits, suggesting that telehealth availability is largely driven by insurance and reimbursement policies [7,32]. The accuracy of data collection, specifically via observation and physical exams, has also been cited as a concern with telehealth use by providers, given the consequential reluctance to establish surgical treatment plans based on the initial remote visit [33].

We also found that the Academic Comprehensive Cancer Program, medical school–affiliated facilities, major teaching hospitals, and facilities with greater admissions had greater access to telehealth for both new and established patients. These findings are consistent with prior studies, which have shown greater telehealth use among teaching hospitals [36,37]. Despite delivering most cancer care in the United States, Community and Comprehensive Community Cancer Programs provide the lowest access to telehealth services [24]. Reduced availability may be related to smaller institution size, smaller infrastructure, and fewer resources to rapidly implement telehealth.

This study, which broadens our understanding of the early uptake of telehealth services during the COVID-19 pandemic, is relevant for several reasons. First, disparities in accessibility of telehealth services may be indicative of persistent barriers to accessing care. Second, the study focuses attention on areas with the greatest interruption in care. Lastly, it indicates gaps in the infrastructure necessary to facilitate flexibility of health care delivery during health emergencies. Our findings underscore that despite improvements in access to the telehealth landscape during the COVID-19 pandemic, barriers to telehealth persist and identify potential sources of disparities in access to cancer care. These findings suggest that CoC centers may benefit from a more centralized approach to the provision of telehealth services. Improving access to telehealth, particularly during times of increased access barriers to health care (eg, social distancing mandate during a global pandemic), is important, as it has been shown to improve rates of early diagnosis, patient compliance, and treatment retention in addition to patient satisfaction [38-42]. As such, the risk factors highlighted in this study may be considered when constructing telehealth policies and implementation strategies. Future studies should evaluate trends in telehealth use throughout and beyond the COVID-19 pandemic. As with any study, these findings should be considered in the context of potential limitations. Because there was no reference study prior to the COVID-19 pandemic, it is difficult to assess the extent to which telehealth availability was directly affected by the pandemic. However, analysis of both prepandemic and peripandemic telehealth use supports a significant increase in telehealth use during the pandemic [9]. In a similar manner, the telehealth landscape rapidly evolved over the course of the pandemic. As such, telehealth policies for given institutions may have changed over the course of data collection and may not be reflected in the data. Additionally, it is important to note that these data reflect surgical care specifically and do not reflect telehealth availability for cancer care provided by other specialties. The data also do not reflect patient or staff factors affecting telehealth access nor does it reflect the number of treating surgeons at each site, although admissions volume may serve as a surrogate. Finally, our sample was drawn from CoC-accredited facilities, and therefore, does not necessarily represent telehealth access at all sites, with most facilities geographically concentrated in the eastern United States. However, as most of the cancer care is delivered at CoC facilities, we believe that this sample is likely to reflect early patterns of telehealth access for cancer patients during the pandemic.

Conclusions

In conclusion, in this national cross-sectional study, we assessed telehealth availability across cancer types during the COVID-19 pandemic. We found that 97.1% (n=303) of facilities provided some form of telehealth availability, although only 52.2% (n=163) offered telehealth for colorectal, breast, and skin (melanoma) cancer. We identified differences in the characteristics of facilities that offered access to telehealth for high-access centers, or facilities offering telehealth appointments for the 3 cancer types surveyed, including medical school–affiliated and higher-volume centers. We also uncovered substantial variation in early telehealth availability within cancer hospitals, suggesting that access to telehealth may not be centralized within facilities. Taken together, these findings highlight disparities in access to cancer care services during a national crisis when access to health care services was limited. They also highlight potential pitfalls that may be better addressed in future crises requiring the rapid upscale of technological health care platforms.

Data Availability

The data sets generated and analyzed during this study are not publicly available due to the use of proprietary American Hospital Association data and identification of specific health care organizations within the investigator-collected data set but are available from the corresponding author on reasonable request.

Authors' Contributions

VAM was responsible for data analysis and interpretation in addition to the writing of the manuscript, including the first draft. WRH contributed to the design of the project as well as the design and revising of intellectual content. JN helped with data analysis as well as the design and revising of intellectual content. WU, AH, BG, IP, and DK aided in data acquisition as well as the design and revising of intellectual content. MCS, HP, ERB, DJB, and JAC contributed to the interpretation of data as well as the design and revising of intellectual content. MSL aided in the design of the project as well as the design, drafting, and revising of intellectual content.

Conflicts of Interest

None declared.

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Abbreviations

CMS: Centers for Medicare and Medicaid Services
CoC: Commission of Cancer
NCI: National Cancer Institute

Edited by A Mavragani; submitted 04.01.23; peer-reviewed by M Coccia, J Zhang, A Dedeilia; comments to author 16.06.23; revised version received 07.07.23; accepted 14.09.23; published 02.11.23.

Please cite as:
Marks VA, Hsiang WR, Nie J, Umer W, Haleem A, Galal B, Pak I, Kim D, Salazar MC, Pantel H, Berger ER, Boffa DJ, Cavallo JA, Leapman MS
Telehealth Availability for Cancer Care During the COVID-19 Pandemic: Cross-Sectional Study
JMIR Cancer 2023;9:e45518
URL: https://cancer.jmir.org/2023/1/e45518
doi:10.2196/45518
PMID:37917149

Original Paper

Open-Source, Step-Counting Algorithm for Smartphone Data Collected in Clinical and Nonclinical Settings: Algorithm Development and Validation Study

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Abstract

Background: Step counts are increasingly used in public health and clinical research to assess well-being, lifestyle, and health status. However, estimating step counts using commercial activity trackers has several limitations, including a lack of reproducibility, generalizability, and scalability. Smartphones are a potentially promising alternative, but their step-counting algorithms require robust validation that accounts for temporal sensor body location, individual gait characteristics, and heterogeneous health states.

Objective: Our goal was to evaluate an open-source, step-counting method for smartphones under various measurement conditions against step counts estimated from data collected simultaneously from different body locations (“cross-body” validation), manually ascertained ground truth (“visually assessed” validation), and step counts from a commercial activity tracker (Fitbit Charge 2) in patients with advanced cancer (“commercial wearable” validation).

Methods: We used 8 independent data sets collected in controlled, semicontrolled, and free-living environments with different devices (primarily Android smartphones and wearable accelerometers) carried at typical body locations. A total of 5 data sets (n=103) were used for cross-body validation, 2 data sets (n=107) for visually assessed validation, and 1 data set (n=45) was used for commercial wearable validation. In each scenario, step counts were estimated using a previously published step-counting method for smartphones that uses raw subsecond-level accelerometer data. We calculated the mean bias and limits of agreement (LoA) between step count estimates and validation criteria using Bland-Altman analysis.

Results: In the cross-body validation data sets, participants performed 751.7 (SD 581.2) steps, and the mean bias was –7.2 (LoA –47.6, 33.3) steps, or –0.5%. In the visually assessed validation data sets, the ground truth step count was 367.4 (SD 359.4) steps, while the mean bias was –0.4 (LoA –75.2, 74.3) steps, or 0.1%. In the commercial wearable validation data set, Fitbit devices indicated mean step counts of 1931.2 (SD 2338.4), while the calculated bias was equal to –67.1 (LoA –603.8, 469.7) steps, or a difference of 3.4%.

Conclusions: This study demonstrates that our open-source, step-counting method for smartphone data provides reliable step counts across sensor locations, measurement scenarios, and populations, including healthy adults and patients with cancer.

(JMIR Cancer 2023;9:e47646) doi:10.2196/47646

KEYWORDS

accelerometer; cancer; open-source; smartphone; step count; validation; wearable

Introduction

Walking is the most common form of physical activity [1]. It is also important to prevent chronic disease and premature mortality [2-4]. The recent proliferation and integration of wearable activity trackers into public health and clinical research studies have allowed investigators to identify gait-related biomarkers, such as decreased daily step counts, as risk factors for cardiovascular disease, cancer, stroke, dementia, and type 2 diabetes [5-11].

Despite the potential for wearable activity trackers to increase physical activity, improve health, and provide unique behavioral insights, there are several important limitations. First, the adoption of wearables is uneven across the population, and most people stop using wearable activity trackers after 6 months [12-15]. Second, commercial devices rarely allow access to their raw (subsecond-level) data or provide open-source algorithms for processing data into clinically meaningful end points [16-18]. Third, the accuracy of step count estimates is affected by metrological and behavioral factors, such as the location of the wearable on the body and temporal gait speed [19-21].

Smartphones are a promising alternative for collecting objective, scalable, and reproducible data about human behavior [22-25]. Although smartphones can overcome many limitations of wearable activity trackers (eg, through access to raw sensor data [26] and increased adoption among older individuals [27]), the quantification of gait-related biomarkers remains challenging. This is largely because of the variation in the location and orientation of smartphones in relation to the body in real-life conditions, which affects the data collected from smartphones' inertial sensors [28-30].

To address this problem, we have recently proposed an open-source walking recognition method [30], which can be applied to accelerometer data collected from various locations on the body, making it suitable for smartphones. In this paper, we demonstrate how our method can be used for quantifying steps, and we validate its performance in 8 independent data sets. We validate this method in three ways: (1) "cross-body validation" compares step counts estimated from multiple sensors worn simultaneously at predesignated body locations; (2) "visually assessed validation" compares step counts estimated from a sensor worn at an unspecified body location against a visually assessed and manually annotated ground truth; and (3) "commercial wearable validation" compares step counts estimated from a sensor worn at an unspecified body location against estimates provided by an independent commercial activity tracker (Fitbit Charge 2) worn on the wrist. The first ("cross-body") and second ("visually assessed") validations involve healthy participants whose data were obtained from publicly available data sets collected in controlled, semicontrolled, and free-living conditions, while the third ("commercial wearable") validation includes data collected by our team from patients with advanced cancer receiving chemotherapy as outpatients in free-living conditions.

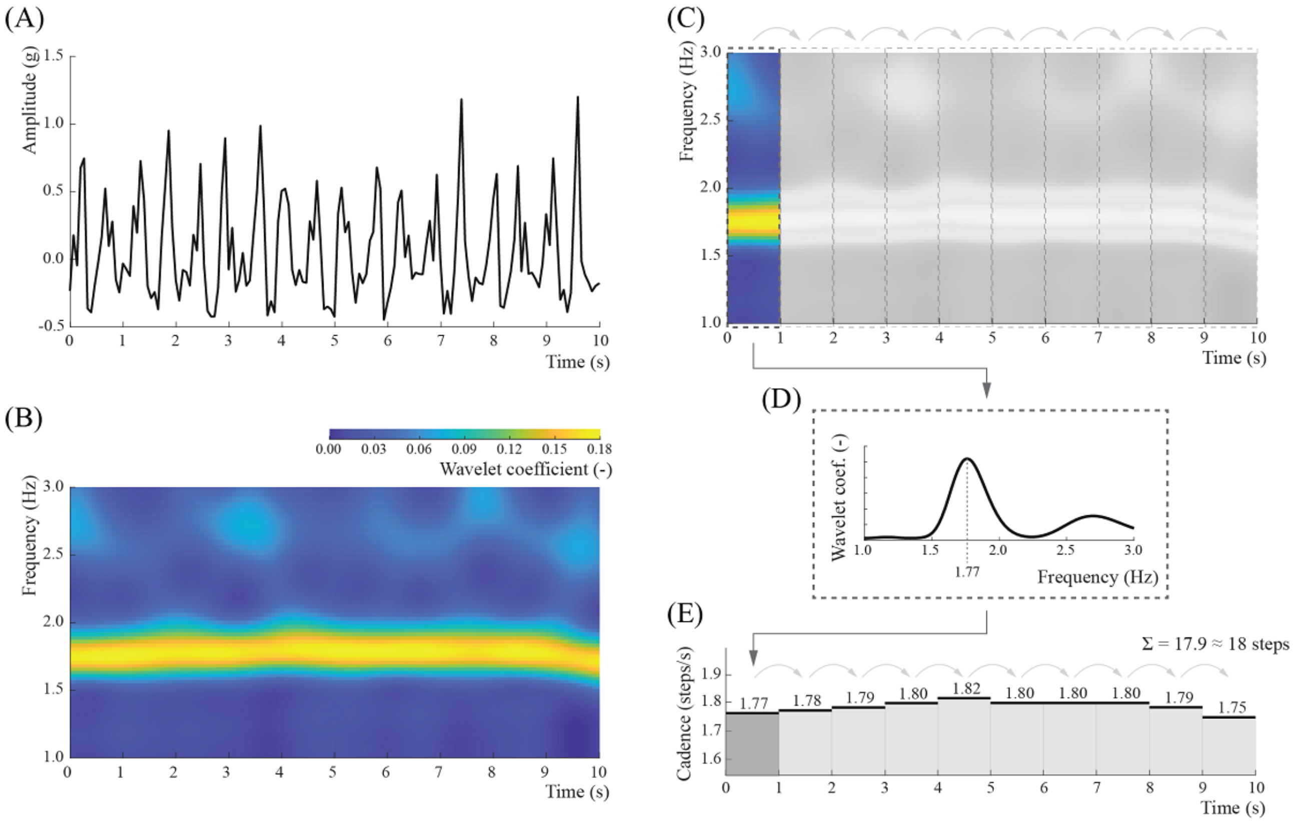
Methods

Step-Counting Algorithm

Our method leveraged the observation that regardless of the sensor location, orientation, or person, during walking, the activity device's accelerometer signal oscillates around a local mean with a frequency equal to the performed steps [30]. To extract this information, we used the continuous wavelet transform to project the original signal onto the time-frequency space of wavelet coefficients, which are maximized when a particular frequency matches the frequency of the observed signal at a given time point (Figure 1). To translate this information into the number of steps, we split the projection into nonoverlapping 1-second windows, and we estimated the temporal step frequency as a frequency with the maximum average wavelet coefficient. The estimated frequency reflects the number of steps a person performs within this time window. Finally, the total number of steps was calculated as a sum of all 1-second step counts calculated over the duration of the observed period of walking.

The step-counting method described above is embedded into the walking recognition algorithm published in the public domain [31,32].

Figure 1. The step-counting algorithm. (A) The original signal is projected onto (B) the time-frequency space using wavelet transformation, which shows the relative weights of different frequencies over time (brighter color indicates higher weight). (C) This scalogram is then split into nonoverlapping 1-second windows. (D) The temporal step frequency (cadence) is estimated as a frequency with the maximum average wavelet coefficient inside each window. (E) The total number of steps in a signal is calculated as a rounded sum of all 1-second counts in that signal.



Data Description

Overview

We evaluated the step-counting method in 3 ways, where each approach was selected to assess a different aspect of step-counting performance: (1) the cross-body validation aimed to determine the consistency of step counts across different body locations; (2) the visually assessed validation aimed to assess the method's accuracy against step counts assessed visually by an observer; and (3) the commercial wearable validation aimed to assess the method's step count compared with step counts obtained from a commercial, consumer-grade activity tracker (Fitbit Charge 2) worn at the wrist. Cumulatively, the entire validation was conducted using 8 independent data sets, including 7 data sets available in the public domain and 1 data set collected by our research team. All data sets are described in the following subsections.

Cross-Body Validation

For the cross-body validation, we identified 5 publicly available data sets, including Daily Life Activities (DaLiAc) [33], Physical Activity Recognition Using Smartphone Sensors (PARUSS) [34], RealWorld [35], Simulated Falls and Daily Living Activities (SFDLA) [36], and Human Physical Activity (SPADES) [37]. The data sets contained accelerometer data on walking activity collected simultaneously at several body locations that are representative of the everyday use of smartphones.

The aggregated cross-body validation data set included measurements collected from 103 healthy adults (Table 1) who performed walking activities in controlled environments (ie, all participants followed some predefined path), typically around a university campus (Table 2). One data set, RealWorld, involved participants walking outside in a parking lot and a forest.

Accelerometer data were collected using various wearable devices, including Android-based smartphones and research-grade wearable accelerometers from SHIMMER, Xsens Technologies, and ActiGraph. The devices were positioned at various locations across the body, that is, around the thigh, at the waist, on the chest, and on the arm (Table 3). Data set measurements differed based on data collection parameters, including the sampling frequency (eg, between 25 Hz in SFDLA and 204.8 Hz in DaLiAc) and measurement range (between ±6 g in DaLiAc and ±12 g in SFDLA). The measurement range was not provided in the PARUSS and RealWorld data sets.

Table 1. Demographics, body measures, and health status of participants involved in the data sets included in this study.

Validation scheme and data set	Participants, n	Male, n (%)	Age (years)		Height (cm)		Weight (kg)		BMI (kg/m^2)		Health status
			Range	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	
Cross-body											
DaLiAc[a]	19	11 (58)	18-55	26.5 (7.7)	158-196	177.0 (11.1)	54-108	75.2 (14.2)	17-34	23.9 (3.7)	Healthy
PARUSS[b]	10	10 (100)	25-30	N/A[c]	N/A	N/A	N/A	N/A	N/A	N/A	Healthy
RealWorld	15	8 (53)	16-62	31.9 (12.4)	163-183	173.1 (6.9)	48-95	74.1 (13.8)	18-35	24.7 (4.4)	Healthy
SFDLA[d]	17	10 (59)	19-27	21.9 (2.0)	157-184	171.6 (7.8)	47-92	65.0 (13.9)	17-31	21.9 (3.7)	Healthy
SPADES[e]	42	27 (64)	18-30	23.5 (3.1)	151-180	174.2 (8.5)	51-112	73.8 (15.0)	18-35	24.7 (4.1)	Healthy
Visually assessed											
WalkRec[f]	77	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Healthy
PedEval[g]	30	15 (50)	19-27	21.9 (52.4)	152-193	171.0 (10.8)	43-136	70.5 (17.6)	17-37	23.8 (3.7)	Healthy
Commercial wearable											
HOPE[h]	45	0 (0)	24-79	61.5 (11.8)	148-172	159.9 (6.1)	48-107	67.8 (13.0)	19-43	26.5 (4.9)	Patients with advanced cancer

[a] DaLiAc: Daily Life Activities.

[b] PARUSS: Physical Activity Recognition Using Smartphone Sensors.

[c] N/A: not applicable.

[d] SFDLA: Simulated Falls and Daily Living Activities.

[e] SPADES: Human Physical Activity.

[f] WalkRec: Walking Recognition.

[g] PedEval: Pedometer Evaluation Project.

[h] HOPE: Helping Our Patients Excel.

Table 2. Walking conditions in the data sets included in this study.

Validation scheme and data set	Measurement conditions	Activity description
Cross-body		
DaLiAc[a]	Controlled	• University campus
PARUSS[b]	Controlled	• University building
RealWorld	Controlled	• Paved (parking lot) and unpaved (forest) surfaces outdoors
SFDLA[c]	Controlled	• University building
SPADES[d]	Controlled	• University building
Visually assessed		
WalkRec[e]	Free-living	• Natural conditions, freely or following some basic premises
PedEval[f]	Controlled and semicontrolled	• 2 laps around a designated gym path at a normal walking pace (controlled) • Scavenger hunt: locating 4 objects in 4 rooms throughout a building (semicontrolled) • Building a small Lego toy by assembling pieces distributed among 12 bins around a room and pattern-simulatedly preparing a meal in a kitchen (semicontrolled)
Commercial wearable		
HOPE[g]	Free-living	• Natural conditions

[a] DaLiAc: Daily Life Activities.

[b] PARUSS: Physical Activity Recognition Using Smartphone Sensors.

[c] SFDLA: Simulated Falls and Daily Living Activities.

[d] SPADES: Human Physical Activity.

[e] WalkRec: Walking Recognition.

[f] PedEval: Pedometer Evaluation Project.

[g] HOPE: Helping Our Patients Excel.

Table 3. Measurement parameters for the data sets included in this study.

Validation scheme and data set, and sensing device	Sensor location	Measurement range (g)	Sampling frequency (Hz)
Cross-body			
DaLiAc[a]			
Wearable accelerometer: SHIMMER	Waist and chest	±6	204.8
PARUSS[b]			
Smartphone: Samsung Galaxy S2	Thigh, waist, and arm	N/A[c]	50
RealWorld			
Smartphone: Samsung Galaxy S4	Thigh, waist, chest, and arm	N/A	50
SFDLA[d]			
Wearable accelerometer: Xsens MTw	Thigh, waist, and chest	±12	25
SPADES[e]			
Wearable accelerometer: ActiGraph GT9X	Thigh and waist	±8	80
Visually assessed			
WalkRec[f]			
Smartphone: BQ Aquaris M5	Unspecified	N/A	100
PedEval[g]			
Wearable accelerometer: SHIMMER3	Waist	±4	15
Commercial wearable			
HOPE[h]			
Smartphone: various Android- and iOS-based	Unspecified	Various	Various

[a] DaLiAc: Daily Life Activities.

[b] PARUSS: Physical Activity Recognition Using Smartphone Sensors.

[c] N/A: not applicable.

[d] SFDLA: Simulated Falls and Daily Living Activities.

[e] SPADES: Human Physical Activity.

[f] WalkRec: Walking Recognition.

[g] PedEval: Pedometer Evaluation Project.

[h] HOPE: Helping Our Patients Excel.

Visually Assessed Validation

Visually assessed validation was performed using 2 publicly available data sets: Walking Recognition (WalkRec) [38] and the Pedometer Evaluation Project (PedEval) [39]. The aggregated data set consisted of both raw accelerometer data for 107 healthy participants and ground truth step counts for each walking activity performed by study participants.

In this approach, walking activities were performed in controlled, semicontrolled, or free-living conditions. Specifically, WalkRec data set participants walked in settings of their choice without specific instructions (eg, indoor and outdoor walking along flat surfaces and climbing stairs; free-living), while PedEval data set participants performed three prescribed walking tasks: (1) a 2-lap stroll along a designated path (controlled), (2) a scavenger hunt across 4 rooms (semicontrolled), and (3) a toy-assembling assignment using pieces distributed across a dozen bins located around a room (semicontrolled). In the PedEval data set, step counts were visually assessed and manually annotated by a research team member, while in the WalkRec data set, the ground truth annotation was further augmented by recordings from a separate smartphone placed on each participant's ankle.

The visually assessed validation data set was collected either by Android-based smartphones or a wearable accelerometer (SHIMMER3) placed around the waist (PedEval) or at various unspecified locations across the body (WalkRec). Each data set was collected with a different sampling frequency (WalkRec 15 Hz and PedEval 100 Hz), and only PedEval provided a measurement range (±4 g).

Commercial Wearable Validation

The commercial wearable validation data set was collected from patients with advanced gynecologic cancers receiving outpatient chemotherapy as part of the Helping Our Patients Excel (HOPE) study. The HOPE study aimed to assess the feasibility, acceptability, and perceived effectiveness of a mobile health intervention that used commercial wearable activity trackers and Beiwe, a digital phenotyping research platform, to collect accelerometer data, smartphone sensor data, and patient-reported outcomes. Patients were recruited from the outpatient gynecological oncology clinic at the Dana-Farber Cancer Institute in Boston, MA. The inclusion and exclusion criteria for study participation are described elsewhere [40].

The data set included 45 female patients with recurrent gynecologic cancers, including ovarian (n=34), uterine (n=5), cervical (n=5), and vulvar (n=1) cancers. Patients were asked to wear the Fitbit Charge 2 (Fitbit) on their nondominant wrist during all waking hours for a period of 6 months in a free-living setting. Each Fitbit was linked to the Fitabase analytics system (Small Steps Laboratories), which enabled the investigators to remotely monitor and export several metrics of patients' physical activity, including minute-level step counts.

At baseline, patients were also asked to install Beiwe, the front-end component of the open-source, high-throughput digital phenotyping platform designed and maintained by members of the Harvard T.H. Chan School of Public Health [41]. Among other passive data streams, Beiwe collected raw accelerometer data with the default sampling rate (typically 10 Hz on most phones, which is sufficient for step counting) using a sampling scheme that alternated between on-cycles and off-cycles, corresponding to time intervals when the sensor actively collected data and was dormant, respectively. The smartphone's accelerometer was configured to follow a 10-second on-cycle and a 20-second off-cycle. The sample scheme was identical on all participants' smartphones.

Data Preprocessing

Because each data set had different data collection parameters, we preprocessed the data sets to standardize the inputs in our algorithm. First, we verified if the acceleration data were provided in gravitational units (g); data provided in SI units were converted using the standard definition: 1 g = 9.80665 m/s^2. Second, we used linear interpolation to impose a uniform sampling frequency of 10 Hz across triaxial accelerometer data. Third, we transformed the triaxial accelerometer signals into sensor orientation-invariant vector magnitudes.

Statistical Analysis

The available accelerometer data were processed using the walking recognition and step-counting algorithm with default tuning parameters, as previously described [30]. Depending on the validation approach, the resulting 1-second step counts were then aggregated into step counts for the entire walking bout or specified time fragment. For the cross-body and visually assessed validations, step counts were calculated as a sum of all step counts in each walking bout and for each sensor location.

Additional analyses were required for commercial wearable validation. Here, step counts were first aggregated on a minute level, the smallest time resolution available to export from Fitabase. Because the Beiwe sampling scheme follows on and off cycles, we adjusted the observed smartphone-based step counts by a proportional recovery based on the ratio between the duration of data collection (20 seconds) and noncollection (40 seconds) in each 1-minute window by multiplying them by 3. Further, due to a lack of information on both wearable and smartphone wear-time and a potential time lag between measurements between the 2 devices, we removed minutes with 0 steps recorded by either method. Finally, to allow for a direct comparison, we summed the smartphone-based step counts for each day of observation.

Each validation procedure considered a different ground truth step count for comparison. In the cross-body validation sample, we compared step counts estimated from various body locations for the entire walking bout. For example, if the data set included data from 3 sensors located on the thigh, waist, and arm, we would compare step counts between the thigh and waist, thigh and arm, and waist and arm. In the visually assessed validation sample, we compared step counts estimated from the available sensor location to a visually assessed ground truth for the entire walking bout. In the commercial wearable validation sample, we compared the daily number of steps estimated from the smartphone to step counts provided by Fitbit. This procedure was performed using 2 days of observations for each patient. The first day was identified as the first full day of observations for each patient. Given that some patients recorded very few steps on that day (possibly due to limited wear time), we also compared step counts from the first day and a day with at least 1000 observed steps on the smartphone to allow for a more in-depth assessment of the algorithm. For a more detailed evaluation, we conducted an additional analysis on minute-level data collected during the first day of observation.

We created Bland-Altman plots for each data set, and all of the data sets were combined within each validation scheme. Mean bias and limits of agreement (LoA) were calculated to describe the level of agreement between step counts. The mean bias was calculated as the mean difference between 2 methods of measurement, while LoA were calculated as the mean difference ±1.96 SD. Participant demographics, body measures, and step count statistics were reported as a range and mean (SD), whenever available.

In addition, we evaluated our method for algorithmic fairness to demographic and anthropometric descriptors. Specifically, we fitted 3 linear regression models into the data set collected for commercial wearable validation. The first model was specified as $Y_i = \beta_0+\beta X_i+\varepsilon_i$, where Y_i is the difference between the step counts from the smartwatch and smartphone collected during the first day of observation for participant i, β is the vector of coefficients for the covariates, X_i is the vector of covariates (age and BMI), and ε_i is random noise. The second model was similar to the first, but Y_i is now the difference between step counts from the smartwatch and smartphone collected during the first day of observation for participants with at least 1000 observed smartphone steps. The third model used a linear mixed-effects regression analysis to account for the clustering of the data within participants. The model was specified as $Y_i = \beta_0+\beta X_i+b_i+\varepsilon_i$. In contrast to the first and second models, here we include a random intercept b_i for each participant i. In each analysis, we calculated 95% CI to assess statistical significance.

Step counts were calculated in Python using a previously published open-source method [32]. Statistical analysis and visualization were prepared in MATLAB (R2022a; MathWorks).

Ethical Considerations

The HOPE study was approved by the Dana-Farber/Harvard Cancer Center institutional review board (protocol 16-477).

Results

Cross-Body Validation

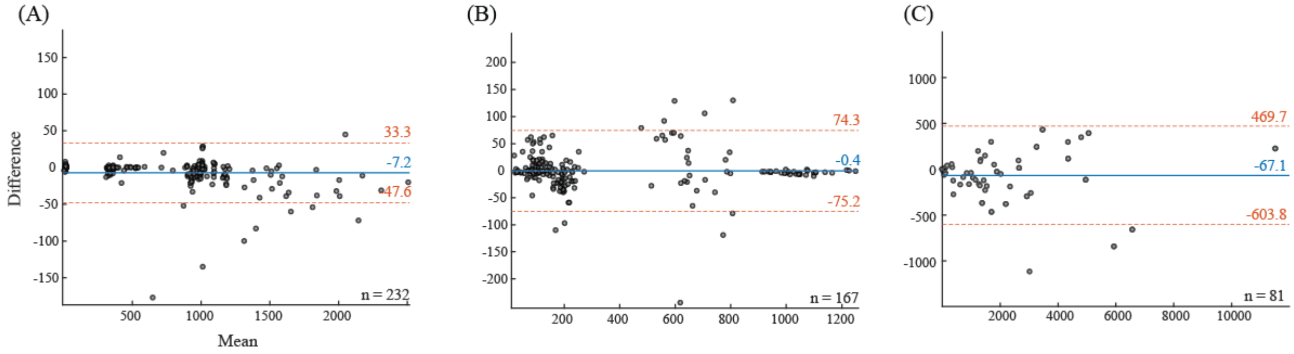
The aggregated cross-body validation data set consisted of data from healthy 103 participants (66 males, representing 64% of the data set) between 16 and 62 (mean 25.2, SD 7.1) years of age. All data sets, except for PARUSS, provided data on participants' height and weight, which ranged between 151 and 196 (mean 173.8, SD 8.5) cm and 47 and 112 (mean 72.2, SD 14.7) kg, respectively. Participants' BMI ranged between 17 and 35 (mean 23.8, SD 4.1) kg/m^2.

In this validation, step counts were aggregated separately for each walking bout across different body locations, including the thigh (n=83 bouts), waist (n=102), chest (n=51), and arm (n=25). Cumulatively, we examined 232 sensor body location pairs: thigh versus waist (n=83), thigh versus chest (n=32), thigh versus arm (n=25), waist versus chest (n=51), waist versus arm (n=25), and chest versus arm (n=15).

On average, in the aggregated cross-body validation data set, participants performed a mean of 751.7 (SD 581.2) steps per walking bout. Mean step counts varied by the data set (participants' mean step counts were 501.5, SD 127.2 in DaLiAc; 337.5, SD 14.6 steps in PARUSS; 1007.2, SD 79.6 steps in RealWorld; 14.6, SD 1.7 steps in SFDLA; and 1408.7, SD 561.5 steps in SPADES).

Figure 2A displays the Bland-Altman plots for the aggregated cross-body validation data set. Comparisons between individual studies are provided in Figures A-E in Multimedia Appendix 1. Across the aggregated data set, the mean bias was equal to –7.2 (LoA –47.6, 33.3) steps, or –0.5%. The largest relative overestimation observed was between the waist and chest in the SFDLA data set and equaled 1.2 (LoA –4.3, 6.8) steps, or 8.5% of the total steps. The largest underestimation was observed between the thigh and waist in the SPADES data set and equaled –28.7 (LoA –107.1, 49.7) steps, or –2.0% of the total steps.

Figure 2. Bland-Altman plots with comparison of step counts in 3 validation approaches: (A) internal, (B) manual, and (C) wearable. (A) The horizontal axis indicates a mean step count from the 2 body locations; (B) estimated steps and manually counted ground truth; and (C) estimated steps and step counts obtained from Fitbit. The vertical axis indicates a difference between step counts from the 2 methods. Blue solid lines indicate mean bias, while dashed red lines indicate ±95% limits of agreement calculated as ±1.96 SD of the differences between the 2 methods.



Visually Assessed Validation

The visually assessed validation of our method included 107 healthy participants. Demographic and anthropometric measurements were only available in the PedEval data set. This data set combined 30 participants, 15 of whom were males, whose ages ranged between 19 and 27 (mean 21.9, SD 52.4) years, whose heights ranged between 152 and 193 (mean 171.0, SD 10.8) cm, and whose weights ranged between 43 and 136 (mean 70.5, SD 17.6) kg. Participants' BMIs ranged between 17 and 37 (mean 23.8, SD 3.7) kg/m^2.

We estimated the step count bias based on 167 comparisons, including 77 comparisons from the WalkRec data set and 90 from the PedEval data set (30 per task). Participants' mean step count in the aggregated visually assessed validation data set was 367.4 (SD 359.4) steps according to the ground truth (Figure 2B). WalkRec data set participants' mean steps were 126.8 (SD 59.2) steps, while PedEval data set participants' steps varied by activity and were 1025.0 (SD 171.3) steps in task 1; 648.5 (SD 126.3) steps in task 2; and 179.2 (SD 22.7) steps in task 3 (Figures F-G in Multimedia Appendix 1). The corresponding estimations calculated using our method were a mean of 119.8 (SD 62.2) steps for the WalkRec data set; 1027.5 (SD 175.0) steps for task 1; 641.1 (SD 137.3) steps for task 2; and 210.8 (SD 18.7) steps for task 3. The mean bias across the aggregated data set was –0.4 (LoA –75.2, 74.3) steps, or 0.1%. The largest relative overestimation was +8.8 (LoA –32.1, 49.7) steps, or 6.9%, within the WalkRec data set. The largest underestimation was –32.3 (LoA, –80.4, 15.8) steps, or –18%, observed in task 3 in the PedEval data set.

Commercial Wearable Validation

Our commercial wearable validation included data from 45 female patients with advanced gynecological cancers. Their ages ranged between 24 and 79 (mean 61.5, SD 11.8) years. Their heights ranged between 148 and 172 (mean 159.9, SD 6.1) cm, weights ranged between 48 and 107 (mean 67.8, SD 13.0) kg, and BMIs ranged between 19 and 43 (mean 23.8, SD 3.7) kg/m^2.

Our Bland-Altman analysis included over 81 observations of daily step counts (Figure 1C), involving 45 days that constituted the first full day of observation (Figure G in Multimedia Appendix 1) and 36 first days with at least 1000 steps estimated from a smartphone (Figure H in Multimedia Appendix 1). A total of 9 participants did not have any days with more than 1000 steps observed, likely due to limited smartphone wear-time. In the aggregated data set, the algorithm estimated a mean daily step count of 1998.2 (SD 2350.3) steps, which included a mean daily step count of 1371.3 (SD 2343.1) steps observed during the first day and 2816.7 (SD 2123.6) steps during the first day with at least 1000 steps observed. Comparisons with data from Fitbit were similar, including a mean daily step count of 1931.2 (SD 2338.4) across participants, a mean daily step count of 1316.4 (SD 2320.2) steps during the first day, and a mean daily step count of 2733.7 (SD 2136.9) steps during the first day with at least 1000 steps observed, respectively. The aggregated estimation bias of the smartphone versus the Fitbit was –67.1 (LoA –603.8, 469.7) steps, or 3.4%, with an underestimation of –54.9 (LoA –485.3, 375.6) steps, or –4.2%, during the first day, and –83.0 (LoA –738.5, 572.6) steps, or –3.0%, during the first day with at least 1000 steps.

Further analysis showed that mean minute-level step counts from Fitbit and smartphone were equal to 51.4 (SD 37.1) and 53.5 (SD 34.3) steps, respectively, which underlines a close alignment between the 2 approaches. Additionally, Bland-Altman analysis (Multimedia Appendix 2) revealed that the estimation bias was equal to –2.1 (LoA –41.6, 37.3) steps and suggested that the smartphone algorithm predominantly overcounted steps in minutes with a few to several steps taken and undercounts steps in minutes with 100 steps and more. Unfortunately, due to the free-living nature of observation, we were unable to determine which activities are especially prone to overcounting steps, yet we hypothesize that it might occur during household activities that require taking a few steps at a time, preceded or followed by body rotations, such as preparing a meal or cleaning. The discrepancies might also result from the potential time lag between measurements.

The evaluation of algorithm fairness revealed no systematic bias for any included covariate (Table 4).

Table 4. Step-counting bias estimation in the commercial wearable validation data set.

Modeling approach and covariates	Estimate	SE	95% CI
First day			
Intercept	–90.6	258.8	–612.8 to 431.6
Age	–1.4	2.9	–7.3 to 4.5
BMI	4.5	7.0	–9.7 to 18.6
First day with ≥ 1000 steps			
Intercept	59.3	461.4	–879.4 to 998.0
Age	–1.3	4.7	–10.8 to 8.2
BMI	–2.4	14.2	–31.2 to 26.5
Both			
Intercept	–39.2	283.8	–604.2 to 525.9
Age	–1.3	3.2	–7.6 to 5.0
BMI	2.1	7.8	–13.5 to 17.6

Discussion

In this study, we conducted a 3-way validation of the open-source step-counting method for smartphone data and demonstrated that it provides reliable estimates across various sensor locations, measurement conditions, and populations. The validation was carried out using a previously published walking recognition method for body-worn devices that contain an accelerometer [30]. This method leverages the observation that regardless of sensor location on the body, during walking activity, the predominant component of the accelerometer signal transformed to the frequency domain, that is, step frequency, remains the same, enabling the calculation of the number of steps a person performed in a given time fragment. In our previous study, we validated this approach for walking recognition using data from 1240 participants gathered in 20 publicly available data sets, and demonstrated that our method estimates walking periods with high sensitivity and specificity: the average sensitivity ranged between 0.92 and 0.97 across various body locations, and the average specificity was largely above 0.95 for common daily activities (household activities, using motorized transportation, cycling, running, desk work, sedentary periods, eating, and drinking). Importantly, the method's performance was not sensitive to different demographics and metrological factors for individual participants or studies, including participants' ages, sexes, heights, weights, BMIs, sensor body locations, and measurement environments.

In this study, we further extend this work by validating the performance of the step-counting method using data collected from 255 participants in 8 independent studies with three goals in mind: (1) assessment of the concordance of step counts across various body locations, (2) comparison of the method's estimates with visually observed step counts, and (3) comparison of the method's estimates with indications of commercial activity tracker (Fitbit Charge 2). The first comparison, a cross-body validation, demonstrated very high agreement between step counts measured from smartphones located at most of the places where smartphones are typically worn, that is, the thigh, waist, chest, and arm. This result suggests that our method can be used to assess steps without restricting where participants wear their smartphones, which may reduce participant burden during data collection and help improve long-term study adherence.

Our visually assessed validation of uninterrupted walking revealed almost perfect agreement between the step counts estimated with our method and those denoted by a visual observer. In this case, the absolute difference observed between the 2 measures was consistently below 1% (Figure G in Multimedia Appendix 1), which is similar to the results achieved with deep learning methods validated on this data set in the past [42,43]. These results reinforce the utility of using this method in controlled conditions, for example, to evaluate participants' functional capacity using a 6-minute walk test, and indicate that the method provides highly accurate estimation of step counts across various sensor locations during regular flat walking.

The mean step-counting bias was also low for semicontrolled walking tasks recorded in the PedEval data set, free-living tasks recorded in the WalkRec data set, and for both scenarios within the commercial wearable validation (first day and first day with at least 1000 steps). In these instances, however, the analysis revealed a wider LoA, which may result from a more complex structure of the underlying data, which involved walking only a few steps at a time as well as sudden changes in walking direction and altitude (eg, stair climbing) [44]. As discussed previously [30], in walking signals with such characteristics, the step frequency tends to be modulated by its sub- and higher harmonics, which might be identified as dominant in the wavelet decomposition outcome and mislead our method.

Even more challenging data were analyzed in the commercial wearable validation cohort. Here, the data were collected at unspecified locations (including novel locations, eg, a bag or backpack) and included data representing various activities of daily living, such as grocery shopping, riding in a car, and doing dishes, which might artificially inflate the estimated step counts by either method. This is a likely reason why the comparisons had wider discrepancies, even after removing minutes with 0 steps recorded by either device. Nevertheless, the estimated bias remained low, which indicates that our validated method provides reliable step count estimates across populations and conditions.

Our analysis has several limitations that should be addressed in future studies. First, due to the lack of available data sets, our method was not validated in individuals with walking impairments or those requiring walking aids, such as cane or walkers. Similarly, this method has not been validated in children and many elders, although the mean age of participants in our commercial wearable validation set was 61.5 years, and over 11% (5/45) were 74 years of age or older. Further research is needed to understand the frequency-domain gait characteristics in the presence of limping, as well as the potential overlap between the step frequency of walking activity in children and that of running activity in adults [45,46]. The latter might be particularly important in studies that differentiate steps performed during leisure and exertional activities. Second, commercial wearable validation was performed with the use of a proprietary activity tracker (Fitbit Charge 2). Although this device has demonstrated reliable step counts during naturalistic gait performed in laboratory conditions [47,48], its accuracy in free-living conditions is inconclusive, and it is presumably dependent on the characteristics of the studied population [21,49,50]. Importantly, the selected activity tracker was placed on the wrist, a body location that can be activated by many repetitive movements (eg, gesticulating) while the rest of the body is still; hence, it is more likely to overestimate steps compared to locations closer to the body mass center. To improve comparisons with our method, in commercial wearable validation, we removed data instances when either method indicated 0 steps. Finally, the estimation of step counts in free-living studies must account for nonwear time of smartphones (eg, while the phone is charging or sitting on a table). Unlike many wearables that are attached to the body (eg, wristbands), smartphones can be easily set aside, sometimes for prolonged periods of time. Such situations introduce a considerable discrepancy between the estimated and actual number of steps a person performs during the day and should be reported, ideally with CIs. Future research should also consider systematic identification, estimation, and imputation of step counts during periods when the sensor is not being worn.

In conclusion, we performed a 3-way validation of a robust, reproducible, and scalable method for step counting using smartphones and other wearable activity trackers. This validation demonstrates that our approach provides reliable step counts across sensor locations and populations, including healthy adults and those with incurable cancers. The method performed well in multiple environments, including indoors, outdoors, and in day-to-day life across settings. This method is a promising strategy for studying human gait with personal smartphones that does not require active patient participation or the introduction of new devices.

Acknowledgments

We would like to thank the patients in the HOPE study for their dedication in the data collection. We would also like to thank the researchers for making their data sets publicly available.

MS and JPO are supported by the National Heart, Lung, and Blood Institute (award U01HL145386) and the National Institute of Mental Health (award R37MH119194). AAW and JPO are also supported by the National Institute of Nursing Research (award

R21NR018532). AAW is also supported by National Cancer Institute (award R01CA270040). UAM is supported by the Dana-Farber Harvard Cancer Center Ovarian Cancer SPORE (grant P50CA240243) and the Breast Cancer Research Foundation.

Authors' Contributions

MS contributed to the study concept and design, method development, data collection, data processing, data analysis, figure and table preparation, and manuscript drafting. NLK was involved in the study concept and design, data collection, and critical review of the manuscript. ET, UAM, and SMC were involved in the data collection and critical review of the manuscript. AAW was responsible for the study concept and design, data collection, data analysis, critical review of the manuscript, and scientific supervision. JPO was responsible for study concept and design, method development, data collection, data analysis, critical review of the manuscript, and scientific supervision.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Bland-Altman plots with comparison between step estimates in the included studies: (A) DaLiAc, (B) PARUSS, (C) RealWorld, (D) SFDLA, (E) SPADES, (F) WalkRec, (G) PedEval, and (H) HOPE. In PedEval, * indicates task 1, ** indicates task 2, and *** indicates task 3. In HOPE, † indicates analysis over the first full day past enrollment and †† indicates analysis over the first full day with more than 1000 steps. Algorithm performance was compared using step estimates from various body locations (A - E), manual annotation (F - G), and Fitbit (H).

[PNG File , 305 KB - cancer_v9i1e47646_app1.png]

Multimedia Appendix 2

Bland-Altman plots with comparison of minute-level step counts from wearable validation. The horizontal axis indicates a mean step count between estimated steps and step counts obtained from Fitbit. The vertical axis indicates a difference between step counts from the two methods. Blue solid lines indicate mean bias while dashed red lines indicate ±95% limits of agreement calculated as ±1.96 of standard deviations of the differences between the two methods.

[PNG File , 32 KB - cancer_v9i1e47646_app2.png]

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Abbreviations

DaLiAc: Daily Life Activities
HOPE: Helping Our Patients Excel
LoA: limits of agreement
PARUSS: Physical Activity Recognition Using Smartphone Sensors
PedEval: Pedometer Evaluation Project
SFDLA: Simulated Falls and Daily Living Activities
SPADES: Human Physical Activity
WalkRec: Walking Recognition

Edited by T de Azevedo Cardoso; submitted 28.03.23; peer-reviewed by D Rubin, M Matabuena, X Wang; comments to author 17.06.23; revised version received 25.07.23; accepted 25.09.23; published 15.11.23.

Please cite as:
Straczkiewicz M, Keating NL, Thompson E, Matulonis UA, Campos SM, Wright AA, Onnela JP
Open-Source, Step-Counting Algorithm for Smartphone Data Collected in Clinical and Nonclinical Settings: Algorithm Development and Validation Study
JMIR Cancer 2023;9:e47646
URL: https://cancer.jmir.org/2023/1/e47646
doi:10.2196/47646
PMID:37966891

Original Paper

Tailoring a Text Messaging and Fotonovela Program to Increase Patient Engagement in Colorectal Cancer Screening in a Large Urban Community Clinic Population: Quality Improvement Project

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Abstract

Background: Appropriate annual screenings for colorectal cancer (CRC) are an essential preventive measure for the second-leading cause of cancer-related death in the United States. Studies have shown that CRC screening rates are influenced by various social determinants of health (SDOH) factors, including race, ethnicity, and geography. According to 2018 national data, participation in screening is lowest among Hispanic or Latinx individuals (56.1%). At an urban Federally Qualified Health Center, a quality improvement project was conducted to evaluate a texting program with a motivational fotonovela—a short narrative comic. Fotonovelas have previously been used in programs to improve knowledge of cervical cancer and human papillomavirus, vaccinations, and treatments for depression.

Objective: This study aimed to encourage compliance with fecal immunochemical test (FIT) screening. Patient engagement involved a texting program with fotonovelas informed by behavior change techniques. This study sought to understand the qualitative characteristics of patient motivation, intention, and barriers to completing their screening.

Methods: A total of 5241 English-speaking or Spanish-speaking Federally Qualified Health Center patients aged 50 to 75 years were randomized to either intervention (a 4-week tailored 2-way texting program with a fotonovela comic) or usual care (an SMS text message reminder and patient navigator phone call). The texting vendor used a proprietary algorithm to categorize patients in the intervention group into SDOH bands based on their home addresses (high impact=high social needs and low impact=low social needs). Over 4 weeks, patients were texted questions about receiving and returning their FIT, what barriers they may be experiencing, and their thoughts about the fotonovela.

Results: The SDOH index analysis showed that most of the patient population was in the SDOH band categories of high impact (555/2597, 21.37%) and very high impact (1416/2597, 54.52%). Patients sent 1969 total responses to the texting system. Thematic analysis identified 3 major themes in these responses: messages as a reminder, where patients reported that they were motivated to return the FIT and had already done so or would do so as soon as possible; increasing patients’ understanding of screening importance, where patients expressed an increased knowledge about the purpose and importance of the FIT; and expressing barriers, where patients shared reasons for not completing the FIT.

Conclusions: The texting program and fotonovela engaged a subset of patients in each SDOH band, including the high and very high impact bands. Creating culturally tailored messages can encourage patient engagement for accepting the content of the messaging, confirming intentions to complete their FIT, and sharing insights about barriers to behavior change. To better support all patients across the continuum of care with CRC screening, it is important to continue to develop and assess strategies that engage patients who did not return their home-mailed FIT.

(JMIR Cancer 2023;9:e43024) doi:10.2196/43024

KEYWORDS

colorectal cancer screening; texting program; fotonovela; fecal immunochemical test; FIT; FIT kit; thematic analysis; mobile phone

Introduction

Background

Colorectal cancer (CRC) is the second-leading cause of cancer-related deaths in the United States, accounting for an estimated 53,200 deaths in 2020 [1]. CRC is mostly preventable with appropriate screening and can be treated successfully (5-year survival rate of approximately 90%) when found at early stages [1]. Fecal immunochemical test (FIT) is a screening tool for CRC, which has shown promise in increasing screening and early detection rates [2].

Social Determinants of Health and CRC Screening

Studies have shown that CRC screening rates are influenced by various sociodemographic factors, such as race and ethnicity, socioeconomic status (SES), and geography [3]. According to 2018 national data, participation in screening is lowest among Hispanic or Latinx individuals (56.1%), followed in order by American Indian or Alaska Native (62.1%), Asian and Pacific Islander (64.8%), Black (70%), and White (71%) individuals [3]. Among Hispanic or Latinx individuals, factors that affect screening rates include SES, language barriers, health literacy, education, undocumented status, lack of insurance, and limited access to health care services [3]. According to the Wisconsin County Health Rankings surveys, socioeconomic factors of education, income, and social disruption are 40% of the factors that influence health determinants [4], which underscores their contribution to health outcomes.

Specifically regarding SES, higher screening rates are seen in those with higher income [5]. In California, the 2018 Behavioral Risk Factor Surveillance System reported that 74% of insured residents completed CRC screening compared with 45% of uninsured residents [6]. Although factors such as SES can be confounded by race and ethnicity, studies show that these remain as factors even when controlling for SES effects in screening rates by race and ethnicity [3].

Use of Fotonovela as a Health Literacy Tool

A visual narrative approach using fotonovelas—comics that impart a message—has been piloted with a wide range of users and shows promise for narrowing the health literacy gap for underserved or marginalized populations [7-9]. Fotonovelas have been used in programs to improve knowledge about cervical cancer and vaccinations [7,9] and treatments for depression [10]. A 2019 study of an intervention using a print fotonovela for increasing CRC screening found that the intervention group had a higher rate of FIT completion than the comparison group, although the difference was not statistically significant [11]. A study by Thompson et al [9] is one of the few that developed a cancer risk fotonovela in a digital medium and curated it for a Latina patient population. Other digital uses of fotonovelas have included interventions to encourage COVID-19 vaccination adoption [12].

Texting in CRC Interventions

Reviews of mobile health interventions and their impact on cancer screening have found that these interventions increase screening rates, with larger increases in interventions that combine multiple modes of engaging patients [13,14]. This increase has been demonstrated in underserved patients and patients with English as a secondary language in the United States [15]. CRC interventions that use texting primarily use text messages as reminders for patients to complete their FIT and then combine the reminders with other modes of outreach, such as automated and live phone calls [14].

When SMS text message interventions result in a high volume of responses from patients, the use of machine learning and natural language understanding (NLU) can make it possible to respond to patients where the workload was too heavy before. They achieve this by categorizing and automating certain types of responses [16]. These tools provide quick, automated replies to a patient’s questions and responses, without the need to wait for a staff member’s involvement.

There is an opportunity to contribute to studies that look at screening uptake by social determinants of health (SDOH). According to the 2021 American Community Survey, 40% of low-income households do not have a mobile phone data plan, and among older adults, only approximately 50% own a smartphone [17]. This is relevant to patients eligible for CRC screening, which skews toward the age range of 50 to 75 years. In this Federally Qualified Health Center (FQHC) population, we previously reported that those who engaged in a texting program were more likely to have increased social needs [18]. In this paper, we further explored the behaviors that could explain this relationship through qualitative data analysis of patients’ SMS text message responses.

Patients face barriers to completing their FIT kits, which likely differ according to cultural context and other factors. Reviews have noted that there is a gap in the literature regarding barriers to using mobile health among older adult patients [19], although other studies have found that older adults are open to these text messages [20]. Previous qualitative analysis conducted internally at the FQHC found that 66% of interviewed patients (n=27) said that the screening was “scary because it elicited thoughts about life and death” [21]. These findings directly informed the messaging and educational information of this quality improvement project.

Objectives

This study describes the development of a culturally tailored digital fotonovela and bidirectional SMS text messaging program for CRC screening, in which we measured patients’ level of engagement and reviewed patient qualitative feedback on fotonovela acceptability. Additional results are intended to provide insights into the relationship between SDOH and the level of patient engagement.

This paper also reports on the design and development of bidirectional texting and digital fotonovelas as a collaborative, iterative process between the FQHC and the text message platform vendor mPulse Mobile.

Methods

Fotonovela Development

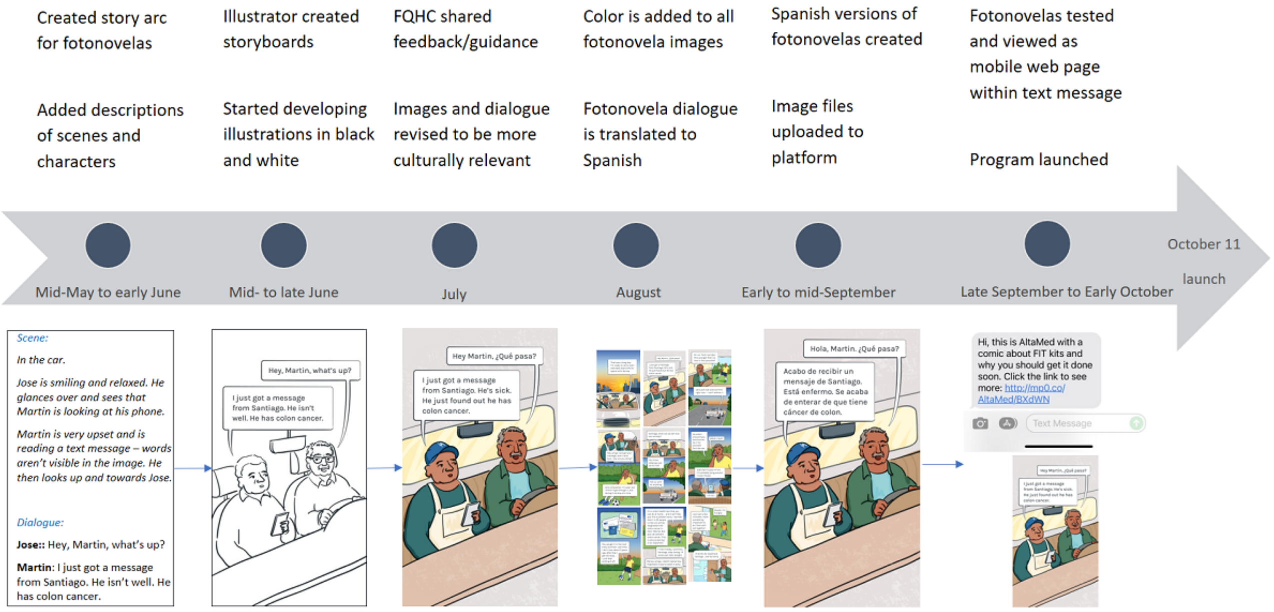
This quality improvement project was conducted in a large urban FQHC. Digital fotonovelas were developed by the texting vendor based on prior internal work at the FQHC [18]. The illustrations and storyline of the fotonovelas focused on depicting role models who were identified as peers of the population of interest: Hispanic or Latinx patients aged 50 to 75 years from a large urban FQHC, with similar cultural and social norms to communicate the message in English or Spanish.

The FQHC's CRC clinical team and the texting vendor collaborated on the narrative and visual content of the fotonovelas. The vendor brought expertise in behavioral science and experience creating similar programs. The FQHC team brought literature on screening barriers and knowledge about their specific patient population. A series of meetings led to 2 drafts: 1 for male participants and 1 for female participants. Revisions to the drafts included adding cultural elements to better reflect the appearances, practices, and preferences of FQHC age-eligible patients and to intensify user engagement and emotional connectedness with culturally aligned characters.

For example, the evolution of the fotonovela titled *Turning 50* (tailored for women) included changing the main characters' hairstyle and skin color and changing the beverage from tea to coffee. Other enhancements included adding images of family within the storyline, such as a child holding her mother's hand, and a mix of English and Spanish languages reflecting an informal setting (refer to Figure 1 for second fotonovela).

The final fotonovelas were translated into Spanish and saved as images. These images were uploaded to the vendor's platform, where both teams tested and revised the fotonovelas before launching the text message program. Figure 2 shows the 2021 timeline for both fotonovelas, with the version for female participants presented alongside the timeline.

Figure 1. Fotonovela development process for the fotonovela tailored for the male patient population. FQHC: Federally Qualified Health Center.



Scene:

In the car.

Jose is smiling and relaxed. He glances over and sees that Martin is looking at his phone.

Martin is very upset and is reading a text message – words aren't visible in the image. He then looks up and towards Jose.

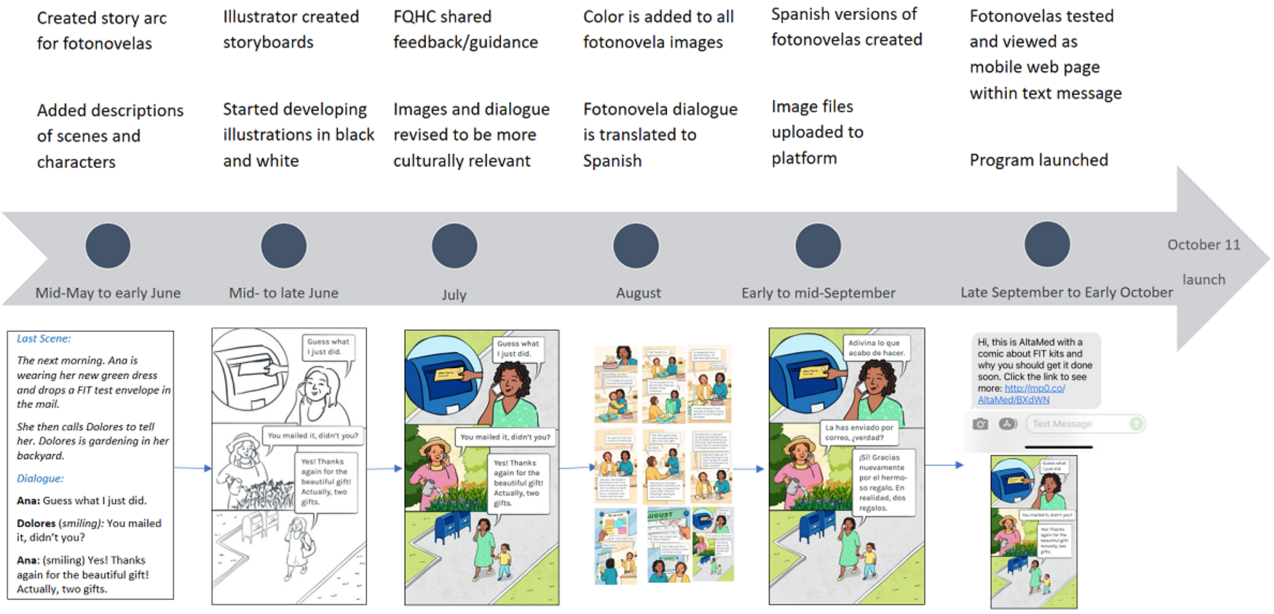
Dialogue:

Jose:: Hey, Martin, what's up?

Martin: I just got a message from Santiago. He isn't well. He has colon cancer.

Hi, this is AltaMed with a comic about FIT kits and why you should get it done soon. Click the link to see more: http://mp0.co/AltaMed/BXdWN

Figure 2. The 2021 timeline describing steps taken to develop the colorectal cancer screening fotonovela for female participants aged 50 to 75 years. FQHC: Federally Qualified Health Center.



Last Scene:

The next morning. Ana is wearing her new green dress and drops a FIT test envelope in the mail.

She then calls Dolores to tell her. Dolores is gardening in her backyard.

Dialogue:

Ana: Guess what I just did.

Dolores (*smiling*): You mailed it, didn't you?

Ana: (smiling) Yes! Thanks again for the beautiful gift! Actually, two gifts.

Hi, this is AltaMed with a comic about FIT kits and why you should get it done soon. Click the link to see more: http://mp0.co/AltaMed/BXdWN

The fotonovela link was texted as part of the 4-week texting program, which drew from the literature on increasing cancer screening rates. The first series of text messages confirmed that patients had received the FIT kit in the mail and then recommended setting a goal ("Complete the test" and "Mail it back in the next 2 days"). Subsequent messages were aimed at building health literacy ("It can help us find colon cancer early") and eliminating doubts about whether it was necessary ("We know you've completed colon cancer screening before, but you are due now"). Some barriers were addressed explicitly by a text sent during the second week of messaging that asked patients, "If you haven't done your kit yet, please tell us if any of these reasons apply (please pick your most important reason)." Patients chose from a list of (1) I'm not sure why I need it; (2) I feel fine, and I don't have any pain or symptoms; (3) I'm too busy right now; (4) I'm scared about the results; (5) It's embarrassing to do it and then mail it back; and a final option to text back with barriers in their own words. Other barriers were addressed, as presented in Multimedia Appendix 1, using NLU to reply to patient concerns with automated text messages.

Behavior change strategies and techniques, such as building self-efficacy, positive framing, goal setting, verbal persuasion, and addressing myths and misconceptions, were embedded within texts to patients. The text messages addressed the most common barriers to completing CRC screening, referenced the importance of family and consulting family in decision-making, explained not putting off the screening because it was uncomfortable or unfamiliar, and reinforced the importance of early cancer detection. The texting medium was thought to provide a level of openness and distance that would encourage patients to feel comfortable sharing information or asking questions that they might otherwise not pose in person, such as how to collect a sample from their stool. The teams designed the fotonovela to incorporate behavior change techniques consistent with patients' receptiveness to screening and to anticipate and address potential patient barriers, as presented in Multimedia Appendix 1.

NLU Classification

When patients texted back replies, the automated responses used NLU and conversational artificial intelligence (AI) to classify patient replies into expected categories and send appropriate follow-up messages. For example, to recognize that patients were avoiding the screening because they were worried about the results, the system looked for the following terms in text messages: "scared," "worried," "dread," "anxious," "panic," "frightened," "agitated," or "afraid." The system addressed these emotions in text replies such as, "We understand that it can be stressful to wait for test results. But the results are so important because they tell you about your colon health. The good thing about catching problems early is that they can be treated." There were 35 conversational AI- or NLU-based rules in place for many other anticipated themes in patient messages, such as procrastination, disgust, completed colonoscopy in the past, confusion about how to complete the screening, and not being clear about why it was necessary.

Bidirectional Texting Program Implementation—Mailing Kits

Since 2016, the FQHC has conducted an annual FIT mailing for patients who were overdue for CRC screening. Patients received an FIT kit in the mail at their home address on file, with written instructions (in English or Spanish based on the preferred language) and visual instructions on how to complete their FIT and return it in the mail. Building on the learnings from the Participatory Research to Advance Colon Cancer Prevention study [21], the 2021 FIT kit mailing targeted patients with (1) at least 1 clinic visit in the last 2 years (since July 2019); (2) a phone number on file; (3) an FIT kit completion status of "Never completed," "Last completed within 12-24 months," or "Last completed more than 24 months ago"; and (4) no gastrointestinal referral associated with rectal bleed symptoms.

In July 2021, a total of 11,000 eligible patients were mailed the FITs. All patients received the usual care clinical workflow to encourage FIT completion. First, patients received 2 automated texts from the FQHC's internal system: one primer before the mailing and another reminding them to return their FIT. In August, patient navigators called patients who had yet to return an FIT, answered any questions about the FIT, and encouraged screening test completion. At the end of September, 5241 patients had still not completed their FIT and were randomized for the next step of the quality improvement project that was previously described. Patients were block randomized by binary sex (male or female), age group (50-60 years and 61-75 years), and prior screening history [18].

The extent to which patients interacted with the program was characterized by 2 measures: engagement rate and time to respond to week 1 of the texting program. The engagement rate was calculated by taking the total number of unique patients who interacted with the system (text responses or clicks to links sent) without opting out and dividing it by the total number of unique intervention group patients outreached. The time taken by the patient to respond in week 1 of the program was calculated as the percentage of responses within the first minute that the texts were sent, within 10 minutes, and within the first hour.

Qualitative Data Analysis of Patients' Free-Text Responses Throughout Intervention

Data analysis was conducted only for patients in the intervention group. Over the course of 4 weeks, the patients received 2 to 4 texts weekly from the system. The program included questions, reminders, and opportunities for patients to engage in bidirectional texting with the system, that is, respond to the texts received. The patients were also able to text back unprompted at any time. Weekly thematic analysis was conducted on all the received texts to provide timely feedback to the FQHC team to act on.

At the end of the quality improvement project, these free-text responses were all translated into English, if needed, and then analyzed as a whole to identify broad themes, subthemes, and anonymized illustrative quotes. These responses informed the project on whether the patients found the program and fotonovelas acceptable, engaging, and culturally relevant. Each patient's quote was categorized by the SDOH band to provide more context to the patient's response. The number of responses that expressed a particular theme and subtheme were tallied, allowing a single patient to provide multiple responses, both within 1 theme and across multiple themes. Subthemes with a small N value were still included because of the value of the information being shared and the FQHC's interest in using the feedback to inform program changes.

Quantitative Data Analysis—SDOH

In the intervention group, patient home addresses were run through the texting vendor's proprietary algorithm to assign an SDOH index score (0-100) for each patient, where 0 represents a low needs census tract and 100 represents a high needs tract [22]. On the basis of the index score, the patient scores were sorted into 5 SDOH bands: very low impact (0-20), low impact (20-40), medium impact (40-60), high impact (60-80), and very high impact (80-100). If addresses were not recognized by the system, then the patient was placed in the unknown SDOH impact category. The patients' home addresses were plotted on a map to visually describe the SDOH gradient and language preference (English or Spanish) among those assigned to a clinic in Los Angeles or Orange County. The response to SMS text messaging engagement by the SDOH impact band and by patient-preferred language was previously reported [18].

Ethical Considerations

The Kaiser Permanente Washington Human Subjects Review Office reviewed and determined that this quality improvement project did not involve research and was therefore exempted from full review.

Telephone Consumer Protection Act Health Care Exemption

The texting program also adhered to the Telephone Consumer Protection Act health care exemption, under which health plan members and patients who provide a mobile number implicitly consent to receive phone calls or text messages related to their health. All communication must offer an easy opt-out (text STOP), and opt-out requests must be honored immediately.

Results

SDOH Distribution

For this project, 2644 patients were randomized to the usual care group, whereas 2597 patients were randomized to the intervention group to receive the usual care plus text messages and fotonovela. Of the 2597 intervention patients with an address, 2330 were sorted into an SDOH band. Most of the patient population were in the high and very high impact bands (555/2597, 21.37% and 1416/2597, 54.52%, respectively; Figure 3). The average SDOH index score was higher among patients whose preferred language was Spanish (84) compared with English (71; Figure 4).

Figure 3. Map of intervention group patients eligible for colorectal cancer screening by social determinants of health (SDOH). The circle size represents number of people by zip code and color indicates level of SDOH impact (SDOH Index is 0 to 100). If a circle has more than one color, there is varying SDOH impact (census tract level) within the same zip code.

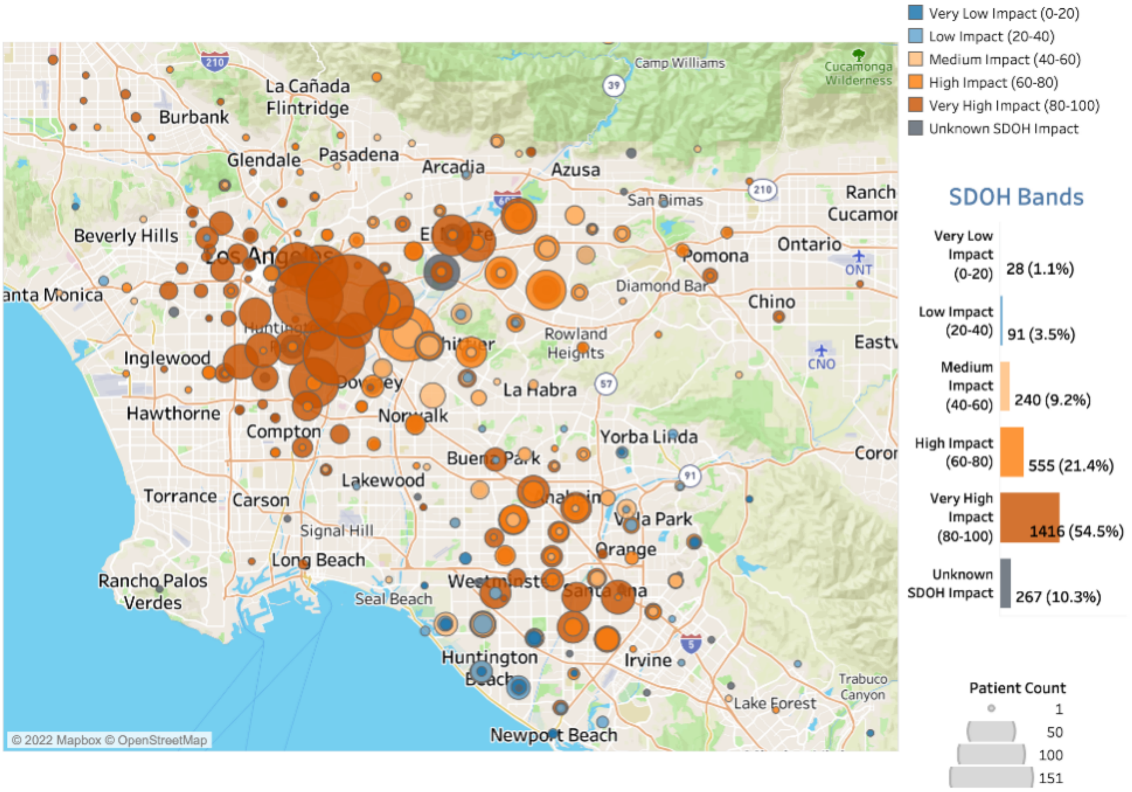
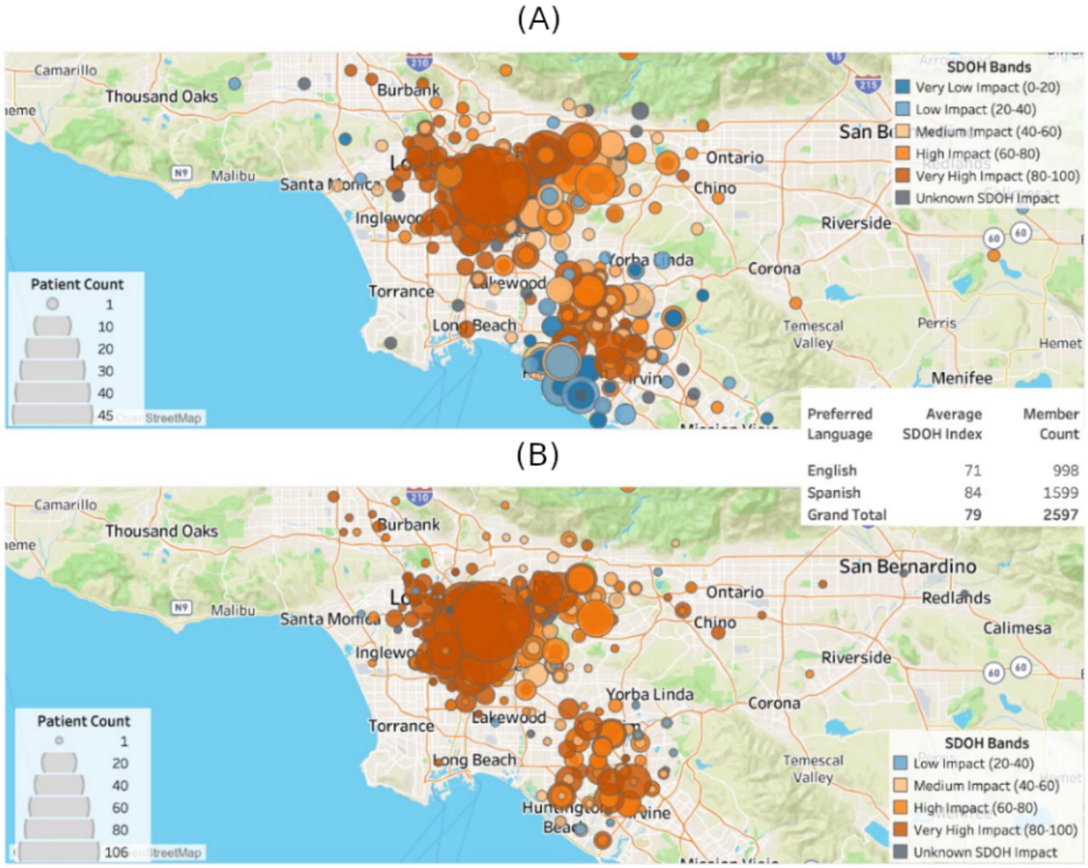


Figure 4. Map of intervention group patients eligible for colorectal cancer screening by social determinants of health (SDOH) and language preference. (A) SDOH Index by Language: English. (B) SDOH Index by Language: Spanish.



Preferred Language	Average SDOH Index	Member Count
English	71	998
Spanish	84	1599
Grand Total	79	2597

The overall engagement rate with the texting program was 39.51% (1026 patients responded to at least 1 text out of the 2597 patients in the intervention group) [18]. An analysis of responses for week 1 revealed that patients who responded (n=509) typically did so very quickly: 27.3% (139/509) within the first minute, 53.4% (272/509) within 10 minutes, and 86.1% (438/509) within the first hour.

A total of 1969 responses were received from the patients and analyzed. Three major themes emerged:

1. Messages as a reminder: patients were motivated to return the FIT and had already done so or would do so as soon as possible.
2. Increasing patients' understanding of screening importance: the intervention increased patients' knowledge about the purpose and importance of the FIT, and patients changed their minds to express readiness to complete the FIT.
3. Expressing barriers: patients shared barriers to or reasons for not completing the FIT.

Theme 1—Messages as a Reminder

This theme reflects that patients were motivated to return their FIT and had already done so or would do so as soon as possible. Some patients had positive intent and behavior toward completing their FIT and a renewed commitment to complete it, partly because of the reminders. Although most patients planned to mail back their tests, a proportion of patients expressed a preference to return their tests in person at the clinic. Subthemes from patients' responses were returned kit already, plan to complete soon, will pick up at clinic, and will drop off at doctor's office.

Table 1 summarizes the subthemes and shows example quotes from patients. For more example quotes, a full view of the table is available in the Multimedia Appendix 2.

Table 1. Theme 1: messages as a reminder.

Subtheme	Example quote
Returned kit already (n=209)	
• These patients returned their kits after receiving the reminder or, in some cases, even before the reminder messages.	• "I totally forget it when I go to use the toilet [1 week later] I sent mine in already." [Male, English speaker, aged 57 years, very high SDOH[a] impact] • "Yes, I already took it to the clinic." [Female, Spanish speaker, aged 62 years, very high SDOH impact]
Plan to complete soon (n=88)	
• These patients viewed the reminder as a call to action. They were not averse to completing the screening but needed a nudge to move forward. • Sentiment was positive, and a few patients apologized for the delay in getting this done.	• "Yes, we totally forgot. Will do. Thanks!" [Female, English speaker, age 73 years, low SDOH impact] • "No I haven‘t yet I have one though, I‘ll get it done asap." [Male, English speaker, aged 57 years, very high SDOH impact] • "Yes, thanks, I'll return it, don't worry." [Female, Spanish speaker, aged 68 years, very high SDOH impact]
Will pick up at clinic (n=25)	
• Others (who did not already have a kit) were keen to move things along by picking up an FIT[b] kit at a nearby clinic instead of waiting to receive one in the mail.	• "No...I can drive there & pick one up." [Male, English speaker, aged 62 years, medium SDOH impact] • "I'm going in to [FQHC[c]] today, I'll pick one up." [Female, English speaker, aged 64 years, high SDOH impact] • "I have not received one in the mail. I actually have an appointment this afternoon. Can I pick one up?" [Female, English speaker, aged 51 years, Unknown SDOH impact]
Will drop off at doctor's office (n=8)	
• These patients might be more comfortable with delivering the kit to their doctor. • The provider might have encouraged or recommended the screening and would be able to answer any questions relating to results of the screening).	• "I have an appt with Dr. [Redacted] on the 10/25, and will drop off the test at that time." [Female, English speaker, aged 68 years, medium SDOH impact] • "I was with my doctor and there they gave me the paper for the test so that I could take it to my next appointment which is this month." [Female, Spanish speaker, aged 70 years, very high SDOH impact] • "You mean the brush stool kit? I will bring with me on my doctor's visit tomorrow." [Male, English speaker, aged 55 years, high SDOH impact]

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[a] SDOH: social determinants of health.

[b] FIT: fecal immunochemical test.

[c] FQHC: Federally Qualified Health Center.

Theme 2—Increasing Patients’ Understanding of the Importance of Screening

Patients expressed that the program content was helpful in understanding the preventive value of screening. Furthermore, subthemes (Table 2) showed that messaging and fotonovela content played a part in helping patients change their minds, complete their FIT, or rekindle interest in completing it.

Table 2. Theme 2: increasing the patients’ understanding of screening importance.

Subtheme	Example quote
Changed mind because of text message or fotonovela content (n=46)	
- An important goal of the program was to change behavior by explaining why the screening was important—both in the text messages and in the fotonovela scenes and dialog.	- “I feel good I don’t feel symptoms, I feel good [1 week later] Thanks for convincing me. It convinces me. My mother suffers from the colon. I’ll take it Thursday.” [Male, Spanish speaker, aged 62 years, very high SDOH[a] impact] - After viewing fotonovela and being asked “Are you more likely to get [your FIT[b]] done this week after reading the comic?” “Yes I want to do it thanks.” [Female, Spanish speaker, aged 57 years, high SDOH impact].
Misplaced or ignored the kit but interest is now rekindled (n=26)	
- These patients lost or threw away the kit and forgot all about it but are now interested in getting a new FIT kit and completing the screening.	- “I’m not sure I will have to look for the kit. Is it still good or do I need a new one?” [Female, English speaker, aged 57 years, very high SDOH impact] - “I don’t have it anymore... [2 weeks later] Please send me a new kit and I will complete it thank you.” [Female, English speaker, aged 58 years, very low SDOH impact] - “It got thrown in trash by accident. Please send another.” [Male, English speaker, aged 65 years, high SDOH impact]
Understands preventive value of screening (n=12)	
- After viewing the fotonovela, patients were asked why they would be more likely to complete the test and return the kit. The broad theme was to protect health and prevent cancer.	- “Yes thank you for caring about me and I returned that.” [Female, Spanish speaker, aged 68 years, very high SDOH impact] - “To prevent cancer.” [Male, Spanish speaker, aged 58 years, very high SDOH impact] - “It’s better to prevent.” [Male, Spanish speaker, aged 59 years, high SDOH impact] - “For my own health and safety.” [Male, English speaker, aged 57 years, very high SDOH impact]
Willing to redo test if lost in the mail (n=3)	
- The importance of the screening was clear to patients like this who requested another kit and were willing to redo the test as it might have been lost in the mail.	- “I got the kit, filled the kit and mailed some time ago. The mail is horrible here. We have constant problems. Send me another kit and will try again.” [Female, English speaker, aged 71 years, high SDOH impact]

[a] SDOH: social determinants of health.

[b] FIT: fecal immunochemical test.

Theme 3—Expressing Barriers

This last theme reflected that patients were willing to share barriers and explanations for why they had not completed the screening. Subthemes in Table 3 included patients who replied that they did not receive an FIT and who were then mailed another one by the care team. Other subthemes were patients who have health or mobility issues, who faced barriers and tradeoffs in terms of the physical requirements for being able to complete the kit; patients who were planning on getting a different screening; patients who were putting off or avoiding because it is unpleasant; and patients who shared reasons why they had other priorities competing for their attention.

There was also a subset (n=10) of responses where patients stated that they were not interested in getting screened. For the full list of example quotes from patients, see table in the Multimedia Appendix 3.

Table 3. Theme 3: expressing barriers.

Subtheme	Example quote
Did not receive an FIT[a] kit (n=290)	
- These patients did not receive the FIT kit in the mail and were requesting another kit to complete and send back. - The tone was generally polite and positive.	- "I don't have a package for the test." [Male, Spanish speaker, aged 60 years, very high SDOH[b] impact] - "I have not received the FIT kit. Please mail it to me and I'll complete it." [Female, English speaker, aged 63 years, unknown SDOH impact]
Have health or mobility issues (n=16)	
- These patients had health issues and needed assistance, more time, or a good reason to complete the test.	- "Well it might be quick and easy for you that have 2 working arms and legs. It's difficult for me to balance." [Female, English speaker, aged 56 years, very low SDOH impact] - "I had a car accident and I had surgery on my leg and it is very painful." [Female, Spanish speaker, aged 51 years, very high SDOH impact]
Planning to get a different colon screening (n=13)	
- The FIT test was not appropriate in these cases because they had recently completed a colonoscopy (or had one scheduled soon).	- "Had a colonoscopy last month. They said I didn't need to do that until next year!" [Female, English speaker, aged 59 years, very high SDOH impact]
Not interested in the screening (n=10)	
- These patients were not open to influence or persuasion and made it clear that they would not do the test.	- "I don't want you to send me one." [Female, Spanish speaking, aged 57 years, very high SDOH impact] - "I don't want to do it." [Female, Spanish speaking, aged 58 years, very high SDOH impact]
Putting off or avoiding because it is unpleasant (n=9)	
- These patients found the test disgusting or unpleasant but might also be confusing the FIT test with preparation for a colonoscopy.	- "I can't stomach drinking the solution that clears the intestines. It is a painful process that my body won't allow me to go through with it." [Male, English speaker, aged 60 years, very high SDOH impact] - "Because it disgusts me to see that test, I'm going to do it." [Female, Spanish speaker, aged 53 years, medium SDOH impact]
Understands importance but life gets in the way (n=6)	
- These patients took the time to explain why they were putting off completing the test and shared a mix of family concerns and other commitments.	- "I am so busy packing I am moving to a smaller apt. Everything is everywhere. I will worry about this after the new year" [Female, English speaker, aged 62 years, low SDOH impact] - "No, I have been taking care of my mom I'm sorry" [Male, English speaker, aged 61 years, very low SDOH impact] - "I'm focused on a professional exam. Excuse me, tonight I complete it." [Male, Spanish speaker, aged 67 years, high SDOH impact] - "I haven't had a chance to see it. I've got other big worries right now financially and I'm on a mission, I'll get back with you shortly." [Male, English speaker, aged 52 years, high SDOH impact]

[a] FIT: fecal immunochemical test.

[b] SDOH: social determinants of health.

Discussion

Principal Findings

In this quality improvement project, we described the steps to create a culturally tailored bidirectional text messaging program with fotonovelas for underserved patients to motivate the return of mailed CRC screening kits. The FQHC team and the texting vendor partnered on the iterative development of the texting program prompts and responses, including the creation of a digital fotonovela. We found that this type of culturally relevant messaging engaged English- and Spanish-speaking patients from every SDOH band. Patients responded to the messages, showing increased knowledge of the severity of CRC and their intentions to complete their FIT. They were also engaged in sharing personal health reasons and life situations for not returning their FIT.

We observed a 40% engagement rate in our primarily Medicaid population, which was higher than the engagement rates in vendors' other health care texting programs of 10% to 20% [22,23]. Interestingly, there was no increase in attrition or patient opt-outs at the 4-week point, which suggests that the outreach struck an appropriate balance between too few and too many messages, and the perceived relevance and value of automated messaging remained high.

Messaging patients at multiple time points over the course of a few months was highly valuable. Patients could text back to say that they did not have an FIT, and the data were shared weekly with the FQHC staff, allowing them to mail new FIT kits to patients in a timely manner. Patients also texted back to share why they could not complete the FIT, which allowed for tailored motivational responses to be texted back. Most reasons were aligned with known barriers, and we plan to continue our usual care in response, including patients having existing plans to get a different colon screening and not receiving an FIT kit the first time. We used patient-reported screenings to retrieve medical records and update patient screening history for patients who reported having other screening plans, and we remailed patients who did not receive an FIT kit the first time.

One barrier that we did not know of was the health and mobility issues shared by patients. We have made our patient navigators aware of this barrier.

Our analysis of engagement by SDOH bands yielded several interesting results that could support future research. The maps illustrated that the intervention group patients spanned across the SDOH index and were drawn from both preferred language groups. Our project previously reported that the intervention resulted in patients who were engaged across all SDOH bands, from high to low social needs, with few patients opting out (78/2597, 3%). This suggests that the program is acceptable to most patients [18]. The themes and subthemes that we identified here also suggest that across all SDOH bands, patients share the same intentions to complete their FIT. The FQHC may have built trust through its multimodal FIT outreach program, as reflected in 2 subthemes: "Changed mind because of text message or fotonovela content" (n=46) and "Misplaced or ignored kit but interest is now rekindled" (n=26).

Being able to maintain engagement with patients was another positive program outcome. The positive sentiment and tone with which patients responded ("Plan to complete [their FIT] soon" and "Didn't receive a FIT") suggest that the frequency and level of messaging were acceptable and within patients' tolerance. Other subthemes further confirmed and quantified prior positive patient feedback, including "Understands importance but life gets in the way" and "Putting off or avoiding because it is unpleasant." The FQHC will work toward developing strategies to address these barriers [18]. Patients who remained hard to influence were represented in each of our SDOH bands, suggesting that continued attention to social needs is important in our screening efforts.

Limitations

Although the texting program and fotonovela-incorporated barriers have been reported in the literature, there was no direct patient feedback on the materials.

One of the subthemes that received the most patient responses was "Returned kit already" (n=209). Patients may have returned their FIT before the program's week 1 reminder text, with the FIT still in the mail or yet to be updated in the FQHC's database.

When enrolling patients in the intervention group, we validated patient phone numbers as mobile phone numbers, but we did not validate the patient's home address. Thus, it is possible that the information presented in the SDOH maps is inaccurate.

Conclusions

For other FQHCs seeking to increase patient engagement with patients with the goal of completing fecal CRC screening, our findings suggest that culturally tailored text messaging can encourage patient engagement and ultimately FIT completion. Engagement can also generate insights into the gaps in patient care and barriers to behavior change. Intervention patients who replied provided actionable information for addressing gaps in care, such as mailing out kits never received. We also remain aware of barriers where patients understand the importance of their screening, but "life gets in the way." We tried to address this through the fotonovela storyline; however, this barrier still persists and requires more work to understand how to bridge it.

The results of the thematic analysis of patient responses were positive overall, and there were no explicit objections to the fotonovelas. However, because this feedback was not linked at the individual patient level to whether a patient had clicked on the fotonovela, determining this rate and its relationship with screening rates is an area for future work. In addition, fotonovelas are a static asset that may require changes as time progresses. For example, the *Turning 50* fotonovela was updated to reflect the US Preventive Services Task Force recommendation to begin screening at the age of 45 years [24]. Collecting patient input from this newly eligible age group will be critical to identifying potentially different barriers to screening compared with those for patients aged ≥50 years [25].

Fotonovelas also have the potential to be developed to address other behaviors in the CRC screening pathway, such as responding to an abnormal result or preparing for a colonoscopy. It is also important to consider a unidirectional versus a bidirectional texting program, as the latter, with much more costly AI and natural language decision trees, may be unsustainable for community clinics. Areas for future work include the cost analysis of these texting program options.

Finally, to better support all patients undergoing CRC screening, we must continue to explore and test additional strategies to engage patients who did not respond to the program.

Acknowledgments

The authors would like to thank the patient navigators, care team, and patients who engaged in the texting program for sharing their experiences.

Data Availability

The data sets generated or analyzed during this project are available from the corresponding author upon reasonable request.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Addressing patient colorectal cancer screening barriers using tailored text messaging and fotonovelas informed by behavioral frameworks.
[DOCX File , 17 KB - cancer_v9i1e43024_app1.docx]

Multimedia Appendix 2
Theme 1: messages as a reminder.
[DOCX File , 15 KB - cancer_v9i1e43024_app2.docx]

Multimedia Appendix 3
Theme 3: expressing barriers.
[DOCX File , 18 KB - cancer_v9i1e43024_app3.docx]

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Abbreviations

AI: artificial intelligence
CRC: colorectal cancer
FIT: fecal immunochemical test
FQHC: Federally Qualified Health Center
NLU: natural language understanding
SDOH: social determinants of health
SES: socioeconomic status

Edited by A Mavragani; submitted 27.09.22; peer-reviewed by M Kapsetaki, C Thomson; comments to author 23.01.23; revised version received 17.03.23; accepted 19.03.23; published 10.08.23.

Please cite as:
Guo M, Brar Prayaga R, Levitz CE, Kuo ES, Ruiz E, Torres-Ozadali E, Escaron A
Tailoring a Text Messaging and Fotonovela Program to Increase Patient Engagement in Colorectal Cancer Screening in a Large Urban Community Clinic Population: Quality Improvement Project
JMIR Cancer 2023;9:e43024
URL: https://cancer.jmir.org/2023/1/e43024
doi:10.2196/43024
PMID:37561562

Patient Perspective

How I Built My Personal, Patient-Centered Health Care Team: Instead of Doctors, I Started With Students

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Abstract

As a patient with cancer, I witnessed how beneficial it was to be treated by a multidisciplinary health care team. I realized I already had my own team, in a sense. That is because I had treated my research students as colleagues from the get-go, and I did not abandon them when they graduated and moved on.

(JMIR Cancer 2023;9:e44693) doi:10.2196/44693

KEYWORDS

prostate cancer; mentorship; medical education; students; patient with cancer; urologist; support; researchers; patient-centered; colleagues; health care training

Access to health care is challenging these days. Wait times to see a doctor in a walk-in clinic or emergency room have become inordinately protracted. For anyone not in critical condition, but still not feeling well, waiting for health care can become an activity of daily living. Even if you are lucky enough to have a general practitioner and are a Doctor of Medicine yourself, getting a timely appointment is not easy.

By the time I was in my mid-50s, I knew a day would come when I would need a health care team I could access quickly and trust explicitly. I hoped—whatever medical problem might emerge—I would have a team in place well in advance of needing their professional services.

What brought this to mind was getting diagnosed with prostate cancer when I was in my early 50s. In relatively short order, I was treated by a urologist, a radiation oncologist, and a medical oncologist. I experienced firsthand how comprehensive cancer care requires many specialists upfront and more backing them up. For instance, a pathologist confirmed my diagnosis based on biopsy samples collected by a urologist. The urologist, who removed my prostate gland, had another surgeon assisting him in the operating room. An anesthesiologist in the same room made sure that I got out of there with no functional losses other than those that went with the cancerous organ the surgeon removed.

Despite having witnessed how beneficial it was as a patient with cancer to be treated by a multidisciplinary health care team, I did not immediately set out to build one. In retrospect, however, that is what I managed to do, and I feel lucky that I did—for blood markers suggest that my cancer will eventually return.

So here is how I built that team, and how others can do it.

Though I lack any training in health care, I was a university science professor with a lot of contact with undergraduates. So that is what I had to work with, and that is where my team-building program began.

I did not particularly care if the students taking my classes wanted to be medical specialists or doctors of any ilk. Many of them were still teenagers, too early in their training to make that call; but I needed research collaborators; so, whenever I came across brilliant, enthusiastic, curious students with solid A transcripts, I made them an offer. The offer was a chance to do original research with me worthy of publication. As luck would have it, many accepted the offer.

Since the students were overall superb, I was genuinely happy to support them in whatever professional pursuits caught their interest. Many chose postbachelor training in health care, which demands a passion for problem-solving. That fit well with my research.

Over the years, I learned from the students about the intricacies of health care training in a variety of fields. Increasingly, I found myself encouraging my student collaborators toward careers in health care. Indeed, the same traits of brilliance, enthusiasm, and curiosity that make for good scientists also make for good health care providers.

“What,” you may ask, “was the outcome?” Here is a summary, without naming specific students.

Let us start with the general practitioners, since health care typically starts with a family doctor. There are currently 5 licensed general practitioners who started working with me long before they went to medical school. One ex-student is now in internal medicine with specialist training as an intensivist. That is especially good because I might end up at some point in the intensive care unit. Two are oncologists. I consider that a big win. One, who is still in medical school, is heading for surgery, and another is a resident in anesthesiology. Thus, the surgeon will have a wing man in the operating room. Another is finishing her training as a pulmonologist, which is great, as I have now got some pulmonary issues that need monitoring.

That is pretty good coverage in terms of the medical specialists I may need. But my personal health care team is not complete.

Another undergraduate collaborator, who is still in medical school, tells me she likes her rotation in gerontology (yes!), but also says she likes pediatrics (sigh). I cannot win them all and have already had to accept some failures. For example, one of my ex-undergraduates is a resident in pediatrics, and another is a board-certified obstetrician. Those specialties are no use to me, but I know those women well enough to know that many others will benefit from their diligence and commitment to excellence. It was indeed a joy collaborating with them for they are natural researchers (and remain close friends).

I like to believe I am sane, but I realize that if my heart, lungs, and kidneys can fail, so can my brain. Thus, it is nice to know that one ex-student co-author is now a resident in psychiatry, and another is a psychiatric nurse. Broadening my coverage, 3 ex-students who have published extensively with me are now board-certified PhD clinical psychologists.

We do not live forever, and life will get rough when the asymptomatic tumors I have start to grow. In that regard, I am pleased that one of the general practitioners has specialist training in palliative care. I cannot avoid dying, but I am glad to have someone with expertise in managing pain whom I might confer with if my cancer reemerges.

What all these professionals have in common is that they started their training as researchers long before they became health care providers. Collectively we tackled a slew of fun projects in a wide variety of fields. Few of our projects had anything to do with health care, but that did not matter. The students were willing to take on whatever weird project I thought worth investigating. I, in turn, was willing to back them in pursuing whatever career caught their eye.

Back then, I treated my research students as colleagues from the get-go and not as transient laborers just passing through the lab. I also did not abandon them when they graduated and moved on.

Admittedly, over the decades, many of these colleagues drifted away from the university where we first met, and they are now dispersed across 6 Canadian provinces and 3 countries. Online communication has kept them, my health care team, in my view.

I realize, in retrospect, that I constructed a personal, patient-centered health care team. I cannot claim that my team-building enterprise was perfect. Modern medicine is vastly complex—hence the need for not just individual clinicians but health care teams—and there were limits on how many students I could manage at any one time. However, none of the students I worked with are to me distant and detached intimidating folks in white coats. They are real friends and colleagues *from way back when*.

The implicit social contract was that I never abandoned my students regardless of their evolving interests and pursuits, and I do not anticipate that they will abandon me.

I have never liked the lopsided egotism when patients cry out for more *patient-centered care* as they complain about health care providers who they felt did not give them enough time and attention. What is too often missed from these demands is much understanding that our health care providers are people too. In reciprocal fashion, if we want health care providers to care about us, we should care about them. I made my personal, patient-centered health care team by first running a student-centered program. Core to that exercise was treating students as colleagues, not underlings.

You Do Not Need a Research Laboratory

Good health care starts with truly caring for others. Health care professionals are humans just like us, who need care at all stages of their lives. Getting good health care providers, who work as a team on our behalf, can start with us demonstrably caring for them even before they are qualified to care for us.

Sure, I want to be the center of attention if and when I go back to being a patient with cancer, in need of intensive care. But in reciprocal fashion, we all can preemptively care for the health care providers of the future long before they start their professional training. This requires recognizing brilliant, enthusiastic, curious youth and endorsing their commitment to excellence however it is manifested.

What I have learned from life as both an educator and patient with cancer is that getting patient-centered care can be accomplished in the long run by starting with student-centered care. The key was building personal, equalitarian relationships with students long before they had locked into training as health care providers.

Over the years, I have met Doctors of Medicine with undergraduate degrees in a vast array of fields, including English literature, music, and philosophy. Most did not begin university committed to health care, but they were committed to excellence.

In that regard, educators in almost any field can build a health care team simply by inviting their very best students to be their collaborators. Those students do not need to be initially committed to health care, but they do need to be committed to excellence in whatever they do… and we should be committed to them as early as possible.

I am confident that these health care providers, who I worked with early in their schooling, will be caring professionals when I need them.

Conflicts of Interest

None declared.

Edited by A Mavragani; submitted 29.11.22; peer-reviewed by N Khan; accepted 23.01.23; published 06.02.23.

Please cite as:
Wassersug R
How I Built My Personal, Patient-Centered Health Care Team: Instead of Doctors, I Started With Students
JMIR Cancer 2023;9:e44693
URL: https://cancer.jmir.org/2023/1/e44693
doi:10.2196/44693
PMID:36745488

Original Paper

Patient and Caregiver Perceptions of Advanced Bladder Cancer Systemic Treatments: Infodemiology Study Based on Social Media Data

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Abstract

Background: In 2022, it was estimated that more than 80,000 new cases of bladder cancer (BC) were diagnosed in the United States, 12% of which were locally advanced or metastatic BC (advanced BC). These forms of cancer are aggressive and have a poor prognosis, with a 5-year survival rate of 7.7% for metastatic BC. Despite recent therapeutic advances for advanced BC, little is known about patient and caregiver perceptions of different systemic treatments. To further explore this topic, social media can be used to collect the perceptions of patients and caregivers when they discuss their experiences on forums and online communities.

Objective: The aim of this study was to assess patient and caregiver perceptions of chemotherapy and immunotherapy for treating advanced BC from social media–posted data.

Methods: Public posts on social media in the United States between January 2015 and April 2021 from patients with advanced BC and their caregivers were collected. The posts included in this analysis were geolocalized to the United States; collected from publicly available domains and sites, including social media sites such as Twitter and forums such as patient association forums; and were written in English. Posts mentioning any line of chemotherapy or immunotherapy were qualitatively analyzed by two researchers to classify perceptions of treatments (positive, negative, mixed, or without perception).

Results: A total of 80 posts by 69 patients and 142 posts by 127 caregivers mentioning chemotherapy, and 42 posts by 31 patients and 35 posts by 32 caregivers mentioning immunotherapy were included for analysis. These posts were retrieved from 39 public social media sites. Among patients with advanced BC and their caregivers, treatment perceptions of chemotherapy were more negative (36%) than positive (7%). Most of the patients' posts (71%) mentioned chemotherapy factually without expressing a perception of the treatment. The caregivers' perceptions of treatment were negative in 44%, mixed in 8%, and positive in 7% of posts. In combined patient and caregiver posts, immunotherapy was perceived positively in 47% of posts and negatively in 22% of posts. Caregivers also posted more negative perceptions (37%) of immunotherapy than patients (9%). Negative perceptions of both chemotherapy and immunotherapy were mainly due to side effects and perceived lack of effectiveness.

Conclusions: Despite chemotherapy being standard first-line therapy for advanced BC, negative perceptions were identified on social media, particularly among caregivers. Addressing these negative perceptions of treatment may improve treatment adoption. Strengthening support for patients receiving chemotherapy and their caregivers to help them manage side effects and understand the role of chemotherapy in the treatment of advanced BC would potentially enable a more positive experience.

(JMIR Cancer 2023;9:e45011) doi:10.2196/45011

KEYWORDS

bladder cancer; social media; patient; caregiver; chemotherapy; immunotherapy; qualitative research; cancer treatment; first-line therapy; patient support; adverse event; peer support; cancer; oncology; perception; pharmacotherapy; opinion; attitude

Introduction

In 2022, an estimated 81,180 new cases of bladder cancer (BC) and 17,100 BC-related deaths occurred in the United States [1]. Of these new BC cases, 12% were diagnosed as locally advanced (7%) or metastatic (5%) BC (hereafter collectively referred to as advanced BC). Advanced BC is an aggressive disease with a poor prognosis. In particular, the 5-year survival rate for metastatic BC is 7.7% [1]. BC occurs predominantly in men, accounting for approximately 75% of all cases and deaths [1]. BC is staged according to tumor size, lymph node invasion, and extension of disease. In the early stages, BC is localized within the bladder but may extend beyond the bladder, initially into the adjacent regions and organs; in later stages, BC metastasizes throughout the body [2,3].

Current standard-of-care first-line treatment for advanced BC comprises platinum-based chemotherapy followed by avelumab (immunotherapy) maintenance for nonprogressive disease on chemotherapy [4]. Chemotherapy with cisplatin or carboplatin combined with gemcitabine is recommended [3,4]. Alternatively, other nonpreferred first-line therapies can be used, including atezolizumab in patients not eligible for platinum-based chemotherapy or patients not eligible for cisplatin-containing chemotherapy with tumors expressing programmed death-ligand 1, and more recently, pembrolizumab in patients not eligible for platinum-based chemotherapy [4]. After failure of first-line platinum-based chemotherapy, other therapies such as avelumab, erdafitinib, pembrolizumab, nivolumab, enfortumab vedotin-ejfv, or chemotherapy are approved for use [4].

Patients with BC experience various physical symptoms (including pain, bleeding, and sexual dysfunction, as well as urinary frequency, incontinence, and obstruction) depending on the disease stage [5-7]. BC also provokes significant social, cognitive, functional, and relational problems, as well as emotional distress, including anxiety and depression [5-7]. It is critical that physicians consider the impact of these symptoms on patient quality of life and treatment satisfaction when making therapeutic decisions. Traditionally, symptoms and quality of life data from the patient's perspective have been collected during clinical trials using standardized patient-reported outcome questionnaires such as the Functional Assessment of Cancer Therapy-General Scale (FACT-G), Functional Assessment of Cancer Therapy-Bladder Symptom Index-18 [8], European Organization for Research and Treatment of Cancer Core Quality of Life 30-item questionnaire (QLQ-C30) [9], and EuroQol 5-level (EQ-5D) [8].

The studies assessing quality of life in cancer have mainly focused on the patient's perspectives and, to a much lesser extent, on the caregiver's perspective. This is despite the development of several instruments that were specifically designed to collect data concerning the effect of cancer on the caregiver's quality of life [10], such as the Caregiver FACT-G [11], the Comprehensive Needs Assessment Tool for Cancer-Caregivers [10,12], and the Quality of Life in Life-Threatening Illness: Family Carer Version [13]. Indeed, few studies have assessed cancer treatment from the caregiver's perspective [5,10]. In those that did, caregivers reported anxiety, depression, and decreased quality of life. However, information about caregivers may be challenging to collect and analyze in clinical trials due to many factors, including the heterogeneous population, varying levels of involvement in care, and possibility of bias such as caregivers feeling guilty when reporting caregiving as a burden [5].

Another approach to exploring patients' and caregivers' perspectives on cancer is to use social media. Social media offer unprompted discussions between patients and caregivers, which may capture more genuine perspectives than traditional surveys, questionnaires, or interviews [14-16]. Social media also allow the collection of data from a much broader, geographically dispersed sample (ie, from a wide range of countries or locations), which may mitigate issues with sample size when examining very specific, nuanced patient groups. Moreover, social media allow patients and caregivers to access communities with other patients, caregivers, and health care professionals. In these communities, patients and caregivers can request information, share experiences, voice concerns, learn about treatments, and connect with others for support [17]. This was particularly evident during the COVID-19 pandemic, which exacerbated the need for online support. Strict social distancing and containment measures isolated patients, and in response, many patients and caregivers began to seek emotional support and information through social media [18]. The provision of an ever-increasing amount of information and communication to these patients and caregivers is a matter of prevention and public health, especially concerning cancer [19,20].

The aim of this retrospective study was to assess patient and caregiver perceptions of advanced BC treatments, specifically any line of chemotherapy or immunotherapy, using data from US social media posts.

Methods

Study Design

This retrospective, real-world study retrieved and analyzed data posted by patients and caregivers on social media concerning the treatment of advanced BC. Data posted between January 1, 2015, and March 4, 2021, were considered for the study. Posts on publicly available domains, written in English, and geolocalized in the United States were included. Posts from all public sites, including social media sites such as Twitter and forums such as patient association forums, were included. In contrast, posts on Facebook and Instagram were not included, since not all posts on these sites are publicly available.

Social Media Content Extraction and Selection

Data (social media posts) were retrieved from publicly available social media sites by identifying and extracting posts, eliminating irrelevant data, and then filtering the posts to obtain only messages concerning advanced BC. The Brandwatch extractor (Cision Ltd, Chicago, IL) software was used to identify all public posts available on the web using combinations of words related to BC (the full query is available in Multimedia Appendix 1). These discussions were extracted with the associated metadata (eg, publication date or country) and anonymized. Irrelevant posts such as those from discussion forums not related to BC, those not pertaining to patients or caregivers, and those not featuring advanced BC were then eliminated by applying a three-step process.

Initially, posts from irrelevant sources such as potential advertising sites or forums related to pets and animals were removed. Then, a machine learning algorithm was applied to the data set. The algorithm recognized three different variables (lexical field, syntactic aspects of the post, and semantic style) to identify and classify patients and caregivers according to their respective vocabulary and grammar. Next, a manual review was performed to remove inconsequential posts unrelated to patient and caregiver perceptions. Finally, the messages were filtered using keywords characteristic of advanced BC (eg, stage IV BC or terminal BC). Once these relevant posts had been identified, the users or usernames associated with these posts were considered to be directly concerned with advanced BC. Thus, all messages from these users in the data set mentioning BC were retained, even if they did not mention advanced BC.

The algorithm used in this study was previously developed using a training set of 12,330 messages related to different health domains (eg, dermatology, tobacco use, and oncology). The method consists of a pipeline featuring two extreme gradient boosting [21] classifiers (one for caregivers' experiences and one for patients' experiences) applied successively. This method allowed identification of whether a post belonged to a patient, a caregiver, or neither. Both classifiers were based on features combining pronouns and lexical fields describing relatives and pathologies (eg, "my [pronoun] father [relative] has cancer [pathology]"). We trained the algorithm by first identifying the caregivers; this was carried out on the whole data set. To determine patients' messages, we then reapplied the algorithm on the rest of the data set (excluding the already identified caregiver messages). Evaluation of performances yielded F1-scores (a measure of accuracy combining precision and recall) of 88.0% and 87.0% for the caregiver and patient classifier, respectively. In this work, manual review following the application of the algorithm ensured validation of the results. Prediction mistakes were corrected by the annotator.

The data sets corresponding to the patients and caregivers were then filtered using keywords associated with cancer therapy, such as "chemotherapy" and "immunotherapy." The complete list of search terms is available in Multimedia Appendix 1. Posts containing both "chemotherapy" and "immunotherapy" were classified in both therapeutic categories.

Data Analysis

Age and Sex

When possible, the age and sex of the patient/caregiver were determined by a manual review of the messages (eg, "My 56 [year old] husband has stage 4 bladder cancer"). Otherwise, the data for age and sex were coded as "undetermined."

Qualitative Analysis

Qualitative analysis was based on the manual annotation of caregiver or patient posts by two independent analysts (PL and SR). Annotation guidelines were agreed on prior to analysis. This manual analysis aimed to identify the BC treatments used, treatment modalities, patient or caregiver perceptions of treatments, and disadvantages or benefits of the treatments.

Treatment Characteristics

The manual analysis identified data characterizing the systemic treatment of advanced BC. The posts were used to determine the treatment and whether the treatment was administered or taken, based on the messages (eg, "[…] I never heard of [treatment]. I will have to look into that" or "[…] he did 7 rounds of chemo"). Data concerning the chemotherapy and immunotherapy administered, including numbers of cycles and duration of treatments, were collected.

Treatment Perceptions

Treatment perception was evaluated through manual analysis. Depending on the message posted by patients or caregivers, the treatment perception was classified as positive, negative, mixed, or no perception. A positive opinion of a treatment, such as posts mentioning that the treatment was effective or that the BC had stabilized, were classified as having a positive perception (eg, "Highly recommend [treatment]"). A poor treatment perception, such as indicating that treatment was unsuccessful or had significant side effects or that the disease relapsed, was classified as a negative perception (eg, "[…] chemo didn't work"). Mentions of both positive and negative expressions were also analyzed and classified as mixed. Messages without treatment perception (eg, "I've been on [treatment] since April") were classified as no perception. The disadvantages and benefits of treatments associated with treatment perception were also collected.

Ethical Considerations

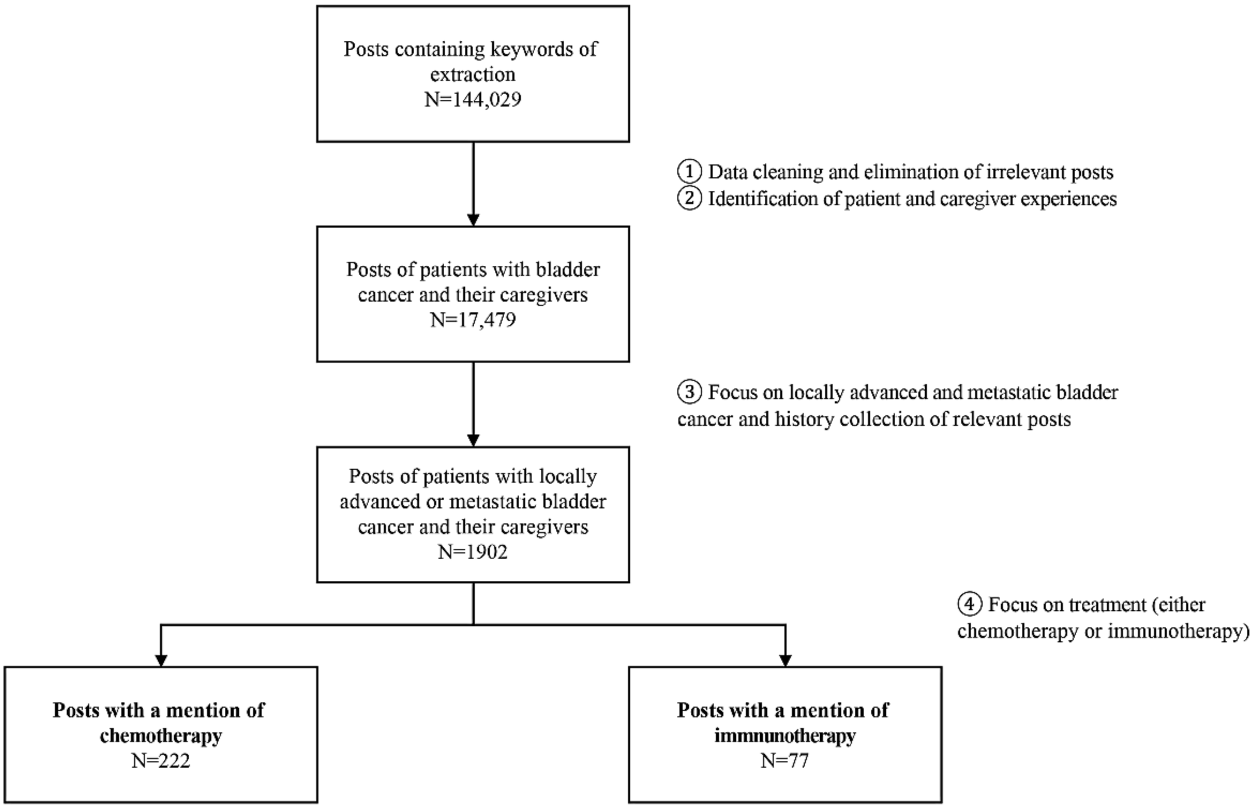
This study used data from publicly available sources; thus, private groups or web pages were not included in our data extraction process. We did not seek permission since users automatically consent to the reuse of their data when they post on public platforms. Moreover, the study's findings contain no identifiable information and are presented in aggregate. Names, usernames or handles, geographic locations, and any other sensitive data were not included.

Results

Identification of Posts With Treatment Mentions

Advanced BC treatments, either chemotherapy or immunotherapy, were mentioned in 299 posts; 222 mentioned chemotherapy and 77 mentioned immunotherapy (Figure 1).

Figure 1. Post identification and selection.



Population

The details of the posts mentioning treatments by patients and caregivers are described in Table 1. There were 80 posts by 69 patients and 142 posts by 127 caregivers mentioning chemotherapy from 38 discussion sources (Table 1). In addition, there were 42 posts by 31 patients and 35 posts by 32 caregivers mentioning immunotherapy from 13 discussion sources (Table 1). The forums and social media sites where patients and caregivers discussed specific BC treatments are described in Table 2.

Among the 222 posts mentioning chemotherapy, only 21 of 69 patients (30%) and 35 of 127 caregivers (28%) mentioned an age. In addition, 40 patients (58%) and 121 caregivers (95%) indicated a sex. Of the 40 patients with known sex, 20 (50%) were female and 20 (50%) were male, whereas of the 121 caregivers with known sex, 87 (72%) were male and 34 (28%) were female. Among the 77 posts mentioning immunotherapy, 18 of 31 patients (58%) and 30 of 32 caregivers (94%) indicated a sex, while 11 of 31 patients (35%) and 8 of 32 caregivers (25%) mentioned an age (Table 1). For internet users with a known sex, the majority were male for both patients (12/18, 67%) and caregivers (21/30, 70%).

Table 1. Characteristics of patients and caregivers who posted social media messages.

Characteristics	Patients		Caregivers	
	Chemotherapy	Immunotherapy	Chemotherapy	Immunotherapy
Users, n	69	31	127	32
Posts, n	80	42	142	35
Social media users, n (%)				
Bladdercancersupport.org	23 (33.3)	4 (12.9)	24 (18.9)	8 (25.0)
Twitter	9 (13.1)	5 (16.1)	20 (15.8)	3 (9.4)
Inspire.com	21 (30.4)	17 (54.8)	8 (6.3)	3 (9.4)
Reddit	6 (8.7)	2 (6.5)	21 (16.5)	8 (25.0)
Others	10 (14.5)[a]	3 (9.7)[b]	54 (42.5)[c]	10 (31.2)[d]
Sex, n (%)				
Female	20 (29.0)	6 (19.4)	34 (26.8)	9 (28.1)
Male	20 (29.0)	12 (38.7)	87 (68.5)	21 (65.6)
Undetermined	29 (42.0)	13 (41.9)	6 (4.7)	2 (6.3)
Age (years), n (%)				
<40	4 (5.8)	2 (6.5)	2 (1.6)	0 (0)
40-59	7 (10.1)	2 (6.5)	12 (9.4)	1 (3.1)
≥60	10 (14.5)	7 (22.5)	21 (16.6)	7 (21.9)
Undetermined	48 (69.6)	20 (64.5)	92 (72.4)	24 (75.0)

[a] These 10 patients expressed themselves on eight other forums such as cancer.org, navigatingcancer.com, or ic-network.com.

[b] These three patients expressed themselves on three other forums (cancer.org, cafemom.com, and delphiforums.com).

[c] These 54 caregivers expressed themselves on 28 other forums such as cancer.org, cancercompass.com, or babycenter.com.

[d] These 10 caregivers expressed themselves on seven other forums such as cancer.org, healingwell.com, or cancercompass.com.

Table 2. Forums and social media where users mentioned specific bladder cancer treatments.

Forum	Chemotherapy posts, n	Immunotherapy posts, n
Bladdercancersupport.org	49	13
Twitter	35	10
Inspire.com	32	24
Reddit	30	12
Cancer.org	15	6
Cancercompass.com	6	0
Navigatingcancer.com	5	0
Other forums	50[a]	12[b]

[a] Sources with fewer than 5 posts, 31 additional forums.

[b] Sources with fewer than 5 posts, 8 additional forums.

Treatments

Chemotherapy in Any Line of Treatment

Overall, 222 posts mentioned chemotherapy; 80 (36%) of these were posted by patients and 142 (64%) were posted by caregivers. Analysis of patient posts revealed that 87% of patients had undergone chemotherapy. Furthermore, 74 patient and caregiver posts mentioned chemotherapy administration. The numbers of chemotherapy cycles taken or planned were expressed in 39 posts by patients or caregivers. The numbers of chemotherapy cycles most frequently reported were four cycles in 12 posts (31%), three cycles in eight posts (21%), and six cycles in six posts (15%). The duration and frequency of chemotherapy were discussed in 10 of 222 posts (5%) by patients or caregivers. Most patients had chemotherapy once a week.

Table 3 provides some examples of posts describing patient and caregiver perceptions of chemotherapy. Concerning chemotherapy, 71% of patient posts and 41% of caregiver posts expressed no perception. Among the caregiver posts, 44% were negative, 8% were mixed, and 7% were positive. Overall, among both patients and caregivers, 36% of posts were negative and 7% were positive (Figure 2). Among patient and caregiver posts containing positive comments about chemotherapy, 19 mentioned the perceived benefits, of which 13 (68%) were related to the effectiveness of chemotherapy. Patients and caregivers expressed effectiveness generally, without going into detail; two posts expressed the opinion that chemotherapy allowed patients to live longer.

The disadvantages of chemotherapy were mentioned in 87 of 222 posts (39%). Patients with BC and their caregivers were most commonly burdened by side effects in 30 of 87 posts (34%). Chemotherapy being ineffective was mentioned in 29 of 87 posts (33%). Indeed, after initial promising results during the first cycles of chemotherapy, patients and caregivers reported a decline in effectiveness or ineffectiveness with further cycles, leading to a change in treatment when possible. Not being eligible to start or continue chemotherapy was considered a disadvantage for which patients and caregivers expressed disappointment or frustration in 12 of 87 posts (14%). Indeed, some patients could not start or continue chemotherapy because it was contraindicated, they did not meet the treatment criteria (mainly in clinical trials), and/or they were not considered fit enough for chemotherapy.

Table 3. Examples of posts by patients and caregivers about chemotherapy.[a]

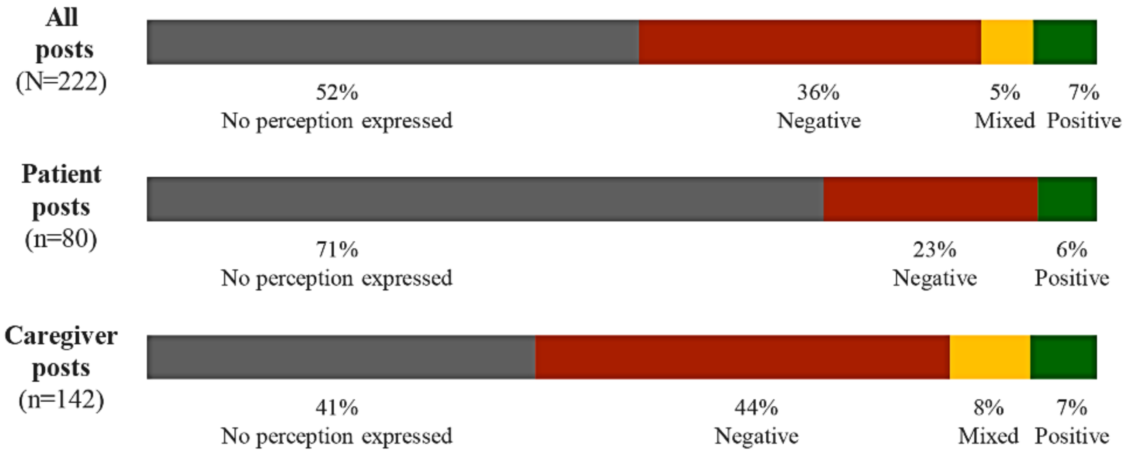
Characteristics	Example of post
Number of chemotherapy cycles	I have stage 4 bladder cancer. I was given 6 months. Did *7 rounds of chemo*[b] […] [Patient]
Duration and frequency of chemotherapy	He’s scheduled to have *chemo once a week*, let’s see what happens. [Caregiver]
No perception expressed	[…] My wife has Stage 4 Bladder Cancer. She is going through what the Oncologist refer to as an ‘Aggressive’ schedule of Chemo. Two days back to back of MVAC[c]. She had her first two days this Tuesday and Wednesday. [Caregiver]
Negative perception because of side effects	[…] *The weeks that I’m on cisplatin [are] the worst, mostly fatigue and upset stomach. […] My worst side effects occur on days 2-4 of my treatment, so I’m over it and ready to gorge myself on day 5.* […]. [Patient]
Positive perception with a good response	Glad to know the great team & really *glad to be a stage 4 bladder cancer patient that responded to chemo.* [Patient]

[a] This table describes some representative patient/caregiver perceptions verbatim that were observed on social media, but any conclusions on safety or efficacy of treatments cannot be inferred from them.

[b] Italicized text indicates specific text relevant to the characteristic.

[c] MVAC: methotrexate, vinblastine sulfate, doxorubicin hydrochloride (Adriamycin), and cisplatin.

Figure 2. Overall perception of chemotherapy.



Immunotherapy in Any Line of Treatment

Overall, 77 posts mentioned immunotherapy, 42 (55%) of which were from caregivers. Of the 35 patients who posted messages, 31 (89%) had received immunotherapy. Details regarding immunotherapy administration were mentioned in 18 of 77 posts (23%). The numbers of administered or planned rounds (ranging from three to eight) were stated in 4 of 77 posts (5%). Immunotherapy duration and frequency were mentioned in 6 of 77 posts (8%). The immunotherapy administration modalities appeared in 18 of 77 posts (23%). Most immunotherapies mentioned in the posts lasted for more than 1 year and were most often administered once every 3 weeks. Table 4 provides some examples of posts describing patient and caregiver perceptions of immunotherapy.

Immunotherapy was perceived positively in 36 of 77 posts (47%), while 17 of 77 (22%) posts perceived immunotherapy negatively (Figure 3). The perception of immunotherapy was negative in 13 of 35 (37%) caregiver posts and in 4 of 42 (10%) patient posts. Benefits of immunotherapy were cited in 25 posts (patients or caregivers), including treatment efficacy in 10 (40%), few side effects in 8 (32%), and prolonged life in 2 (8%) posts.

The disadvantages of immunotherapy were mentioned in 25 posts by patients or caregivers. The major disadvantages were perceived lack of effectiveness in 12 of 25 posts (48%) and presence of side effects in 10 of 25 posts (40%). Patients or caregivers described persistent sequelae after immunotherapy in 2 of 25 posts (8%).

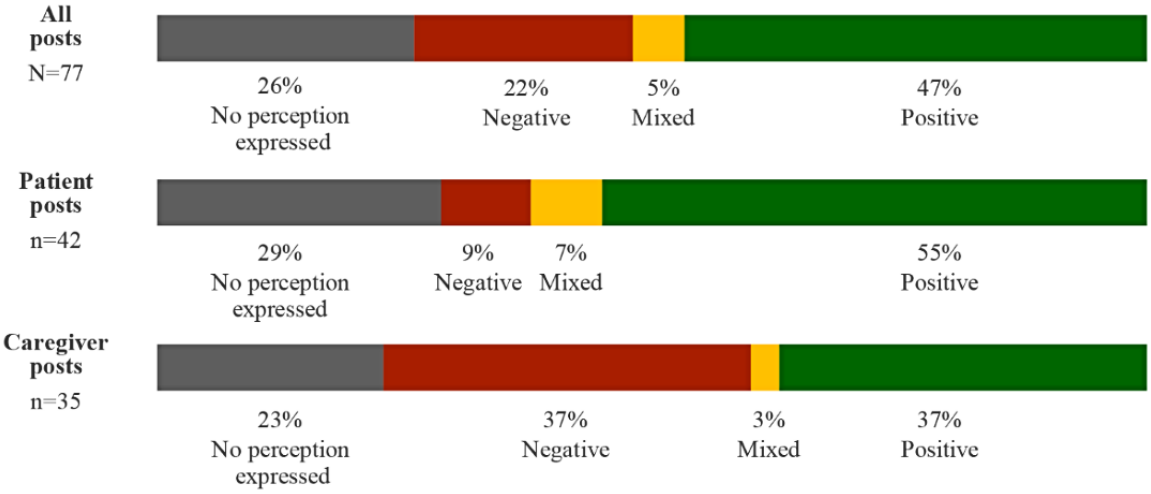
Table 4. Examples of posts by patients and caregivers about immunotherapy.[a]

Characteristics	Example of post
Data about administration	I have been on immunotherapy for this for about *16 months now*[b] and am expecting my 2nd child any day now! [Patient] Interestingly this is the immunotherapy they are giving my elderly uncle with metastatic bladder cancer, *it's every 3 weeks one week off, in another week and half he gets his 2nd treatment.* [Caregiver]
Positive perception	If so I just want you to know that [immunotherapy] *an immunotherapy drug caused my metastatic lymph nodes to disappear in 2 weeks. […] the life saving [immunotherapy] is keeping the cancer that would kill me sooner at bay.* [Patient] […] *I was given [immunotherapy]. I am now in remission!!!!! There is hope!* Immunotherapy can be given should anything return and *so far side effects are minimal!!!* FINALLY!! [Patient]
Negative perception because of side effects or perceived lack of effectiveness	[…] I've been on [immunotherapy] since April after chemo didn't work. *It wasn't too bad at the beginning, itching, dizziness and fatigue, but the latest couple of treatments have left me with sore aching muscles and joints which is one of the less common side effects.* [Patient] My husband […] is currently taking immunotherapy […] *which has had numerous side effects like loss of taste buds and loss of the adrenal and pituitary glands.* [Caregiver]
Negative perception because of persistent sequelae	I was able to travel to [cancer center] and join a clinical trial, and then another trial and finally a third trial of [immunotherapy] and [immunotherapy] which seems to be working for the cancer *but which destroyed my lungs.* [Patient]

[a] This table describes some representative patient/caregiver perceptions verbatim that were observed on social media, but any conclusions on safety or efficacy of treatments cannot be inferred from them.

[b] Italicized text indicates specific text relevant to the characteristic.

Figure 3. Overall perception of immunotherapy.



Discussion

Principal Findings

To our knowledge, this is the first study to examine perceptions of advanced BC systemic treatments in social media posts by patients and their caregivers. Despite recent therapeutic advances for advanced BC, little is known about patient and caregiver perceptions of these therapies. Our results provide valuable insights into their perceptions. Concerning chemotherapy, we found that 71% (n=57) of patient posts expressed no perceptions. They described chemotherapy objectively, as an inevitable part of their health care journey. In contrast, caregivers were more likely to express their opinion of chemotherapy, with 44% (n=62) of their posts being negative, 8% (n=11) mixed, and 7% (n=10) positive. Only 9% (n=19) of all posts contained positive perceptions about chemotherapy, and these were mainly focused on effectiveness. Chemotherapy disadvantages were discussed in 39% (n=87) of posts and were mostly related to side effects and perceived lack of effectiveness. Conversely, patients expressed their opinions about immunotherapy, with 55% (n=23) of posts being positive and 29% (n=12) expressing no perceptions. Positive comments focused on treatment effectiveness, few side effects, and extending the patient's life. Interestingly, caregivers were more likely to express a negative perception about immunotherapy than patients, accounting for 37% (n=13) and 10% (n=4) of the posts, respectively. Negative perceptions about immunotherapy focused on perceived lack of effectiveness, side effects, and persistent sequelae.

In our study, more patients and caregivers shared their perceptions of chemotherapy (222 posts) than immunotherapy (77 posts). This is expected since platinum-based chemotherapy has been the preferred standard first-line treatment for patients with advanced BC for a long time [3,4]. Furthermore, immunotherapy was only authorized as part of the advanced BC treatment pathway in 2016; therefore, during the first 2 years of the study, chemotherapy was the only treatment option for advanced BC. More positive perceptions were noted for immunotherapy among overall posts (patients and caregivers), possibly because these are newer treatments with favorable safety profiles and their increased use in advanced BC has received positive press, including the recent positive results reported with avelumab as the new standard of care in first-line maintenance of advanced BC [22].

Among caregiver posts, a mostly negative perception of advanced BC treatments was revealed. This negative perception may be explained by the fact that caregivers often feel poorly equipped to support patients, with limited knowledge about BC and treatments [6,23]. Furthermore, treatment side effects severely impact both patient and caregiver quality of life and can be expected to negatively influence treatment perceptions [24]. Considering the pivotal role that many caregivers assume in the lives of patients with BC and the importance of their involvement in patient care, their level of understanding should be acknowledged by clinicians and other members of the multidisciplinary care team. It is thus crucial that caregivers be informed and provided with the support required to effectively assist patients with their cancer treatments.

While patients with BC may use social media to share their experiences, there is a paucity of literature using social media data to gauge patient perceptions [25]. Overall, we found that caregivers engaged more frequently and actively on social media than patients. These results are consistent with a recent systematic review in which the authors noted that most patients with BC were older men with lower electronic literacy [25]. Therefore, it is the caregivers, on behalf of patients, who may be actively engaging on social media to obtain further information. The increased social media presence of caregivers could also be due to the severe grief or burden related to end-of-life care that they experience, with messages often posted several years after the patient's death [26]. Interestingly, most caregivers identified in the Renner et al [26] study were women, who have been found to seek emotional support in online health communities more often than men [26,27].

Study Strengths and Limitations

This study design has several strengths. A large sample size collected over a 6-year period was analyzed. The results include data from a variety of social media sources and could provide another dimension to research on treatment perceptions. Accessing publicly available social media data is quick, inexpensive, and has no access restrictions.

However, our innovative research approach does entail several limitations. The posts extracted were limited to publicly available sites, which excluded popular social media networks such as Facebook and Instagram, meaning that many data were not included. Furthermore, relevant posts may have been inadvertently discarded during the filtering process. Duplication may have also been possible if users were active on more than one forum. Additionally, our analysis is based on the spontaneous declarations of internet users about their experience of the disease or their treatment. Although this type of data collection allows us to be representative of the population of internet users that post on social media, it is not necessarily representative of the general population.

A further limitation with using social media posts is that posts only have limited information. Critical information to place the post in context (such as the disease stage or treatment details) may be missing. This lack of data also makes it difficult to compare our results with those of traditional epidemiological studies. Furthermore, few forum users shared demographics such as age, sex, and location in the publicly accessible data that were used for this study, making it impossible to judge whether the data are representative of patients with advanced BC and their caregivers in the United States. The data quality depends on patient and caregiver electronic literacy, their experiences and perceptions, and their capacity to understand and accurately communicate BC information, including the type or stage of BC and treatment administered. Patients and caregivers do not necessarily include all details about their treatment, such as type of treatment, duration, lines of treatment, and response information. These self-reported data may be subject to recall bias. In addition, we cannot verify the authenticity of the published posts.

It is also possible that since the data came from social media, posts may be more negative [28,29]. Twitter has more anonymity than sites such as Facebook, meaning that more negative behavior could be provoked [30,31]. Since most of our data came from Twitter, this could partly explain our findings. Finally, our study is prone to selection bias, as included patient and caregiver posts may not represent all patients with BC and their caregivers. Indeed, engagement with social media depends on age and sex, ethnicity, socio-professional class, and income, as well as levels of education and technological and health literacy.

Future Work and Impact on Care

This study revealed areas that need to be addressed. Patients and caregivers indicated that they lacked information about patient experiences with advanced BC and its treatments. This is consistent with the fact that studies on social media reported that BC remains underrepresented online compared with other cancers [25,32]. There is therefore a need for clear, accurate, and accessible information about BC treatments for patients and caregivers.

Currently, chemotherapy is the recommended first-line treatment for patients with advanced BC. The negative perception of chemotherapy identified in this study needs to be investigated and considered, as it may influence the choice of treatment of patients seeking advice in social media forums. Therefore, a reflection work could be initiated in partnership with physicians who treat patients with advanced BC. This reflection work could help to identify the levers of improvement and communication to best manage the potential stress and anxiety associated with chemotherapy for patients and caregivers. Subsequently, it would be interesting to study the impact of chemotherapy perception on the adherence to treatment and the quality of life of patients and caregivers using social media [33].

This study also highlights that social media posts from patients and caregivers may provide real-world insights into treatment perceptions and quality of life, as previously shown in other studies [34]. It would also be interesting to cross-reference this or a future study applying our methodology with other qualitative studies on patients with advanced BC to compare the different signals and analyze their potential complementarity [16]. The extension of our research method to other countries or regions may be also valuable to identify initiatives that could improve treatment perceptions, quality of care, and quality of life for patients with BC and their caregivers.

Conclusion

Real-life data from social media posts may generate further insights into the impact of BC treatments on patients and caregivers not captured in standardized clinical study questionnaires. In advanced BC, chemotherapy remains the cornerstone of first-line therapy. Despite this, there appear to be some negative perceptions of chemotherapy among patients with advanced BC and more so among their caregivers. Addressing these negative perceptions of treatment may improve treatment adoption. Additional support and information could be offered to patients and their caregivers on BC therapy and how to manage side effects. This may allow them to have a more positive experience, which has increased importance given the survival benefits associated with first-line platinum-based chemotherapy followed by avelumab maintenance in those whose disease has not progressed on chemotherapy.

Acknowledgments

Medical writing support was provided by Nathalie Baudry of the microenterprise NB-Pharmaconsult and Joelle Malaab of Kap Code, Paris. Editing assistance was provided by Speak the Speech Consulting and Clinical Thinking. Medical writing support and editorial assistance were funded by the healthcare business of Merck KGaA, Darmstadt, Germany (CrossRef Funder ID: 10.13039/100009945), and Pfizer. Data from this study were previously presented in poster format at the ISPOR 2022 meeting.

Data Availability

The derived data sets generated and analyzed during this study are not publicly available due to Kap Code’s private ownership of this database. Indeed, these public social media data have been extracted, cleaned, and consolidated in a database using Kap Code tools and are not found anywhere else in this format. If, however, this database is to be reused in a future study, a partnership with Kap Code could potentially take place. For this, please contact the Kap Code team at the following email address: hello@kapcode.fr

Authors' Contributions

MB, SR, and PL conceptualized and designed the study. All authors were responsible for developing the search strategy; SR, PL, PF, and A Mebarki contributed to data acquisition and quality control of data. All authors contributed to data extraction, analysis, and drafting the manuscript. All authors have critically reviewed, edited, and approved the final version of the manuscript.

Conflicts of Interest

MB is employed by EMD Serono, and holds stock in Merck KGaA, Darmstadt, Germany. A Marrel and VB are employed by ICON, which has contracts with the healthcare business of Merck KGaA, Darmstadt, Germany. SR, PL, PF, A Mebarki, and SS are employed by Kap Code. Kap Code was contracted by ICON to conduct this study.

Multimedia Appendix 1
Query used for extraction on Brandwatch and keywords used for the focus on treatment.
[DOCX File , 15 KB - cancer_v9i1e45011_app1.docx]

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Abbreviations

BC: bladder cancer
EQ-5D: EuroQol 5-level
FACT-G: Functional Assessment of Cancer Therapy-General Scale
QLQ-C30: European Organization for Research and Treatment of Cancer Core Quality of Life 30-item questionnaire

Edited by A Mavragani; submitted 20.12.22; peer-reviewed by M Leveridge, V Patel; comments to author 18.01.23; revised version received 01.03.23; accepted 02.03.23; published 27.03.23.

Please cite as:
Renner S, Loussikian P, Foulquié P, Marrel A, Barbier V, Mebarki A, Schück S, Bharmal M
Patient and Caregiver Perceptions of Advanced Bladder Cancer Systemic Treatments: Infodemiology Study Based on Social Media Data
JMIR Cancer 2023;9:e45011
URL: https://cancer.jmir.org/2023/1/e45011
doi:10.2196/45011
PMID:36972135

Original Paper

Exploring the Acceptability of Text Messages to Inform and Support Shared Decision-making for Colorectal Cancer Screening: Online Panel Survey

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Abstract

Background: While online portals may be helpful to engage patients in shared decision-making at the time of cancer screening, because of known disparities in patient portal use, sole reliance on portals to support cancer screening decision-making could exacerbate well-known disparities in this health care area. Innovative approaches are needed to engage patients in health care decision-making and to support equitable shared decision-making.

Objective: We assessed the acceptability of text messages to engage sociodemographically diverse individuals in colorectal cancer (CRC) screening decisions and support shared decision-making in practice.

Methods: We developed a brief text message program offering educational information consisting of components of shared decision-making regarding CRC screening (eg, for whom screening is recommended, screening test options, and pros/cons of options). The program and postprogram survey were offered to members of an online panel. The outcome of interest was program acceptability measured by observed program engagement, participant-reported acceptability, and willingness to use similar programs (behavioral intent). We evaluated acceptability among historically marginalized categories of people defined by income, literacy, and race.

Results: Of the 289 participants, 115 reported having a low income, 146 were Black/African American, and 102 had less than extreme confidence in their health literacy. With one exception, we found equal or greater acceptability, regardless of measure, within each of the marginalized categories of people compared to their counterparts. The exception was that participants reporting an income below US $50,000 were less likely to engage with sufficient content of the program to learn that there was a choice among different CRC screening tests (difference –10.4%, 95% CI –20.1 to –0.8). Of note, Black/African American participants reported being more likely to sign up to receive text messages from their doctor's office compared to white participants (difference 18.7%, 95% CI 7.0-30.3).

Conclusions: Study findings demonstrate general acceptance of text messages to inform and support CRC screening shared decision-making.

(JMIR Cancer 2023;9:e40917) doi:10.2196/40917

KEYWORDS

text messages; shared decision-making; colorectal cancer; cancer screening; mHealth; cancer; health care; marginalized groups

Introduction

The undisputed importance of shared decision-making (SDM) to the ethical engagement of patients when they “arrive at a crossroads of medical options” has led some to call SDM the pinnacle of patient-centered care [1]. At its core, SDM is an interactive process where patients and providers reach a decision by sharing the best available evidence and patient preferences when considering care options [2]. Innovative and diverse approaches are needed to engage patients in health care decision-making and to support equitable SDM. Many health care organizations now use patient portals to provide patients with personalized health-related information. However, only 15%-30% of patients use these platforms [3], with well-documented racial and socioeconomic disparities [4-7]. Based on data from 2021, most Americans now own a cell phone (97%) [8], including smartphones (85%). Furthermore, people aged 50 years and older send and receive an average of 16 text messages a day [8]. As cell phones and smartphones become omnipresent, text messaging could effectively reach and engage diverse individuals to support informed and shared cancer screening decisions. This is particularly relevant for colorectal cancer (CRC), where multiple evidence-based screening modalities (ie, colonoscopy screening, computed tomography-colonography, sigmoidoscopy, fecal immunochemical test DNA, or stool testing) are available but remain underutilized [9-11].

A prior review highlighted the predominance of text message–based interventions among mobile health interventions to improve cancer screening and early detection [12]. Multiple studies, including two systematic reviews, evaluated the use of text message reminders alone or in combination with additional interventions such as providing behavioral information to improve adherence to recommended CRC screening (eg, [10,13-18]). Similarly, multiple studies have explored the use of text messaging to support colonoscopy attendance and adequate bowel preparation in the context of CRC screening [19-22]. At least one of each of these types of studies successfully targeted people who have been historically marginalized because of racism or language barriers [17,22]. Additionally, there are ongoing research networks at the National Cancer Institute—Accelerating Colorectal Cancer Screening and Follow-Up Through Implementation Science—that aim to improve CRC screening, follow-up, and referral among underserved groups that have low CRC screening rates using a variety of approaches, some of which may include the use of text messaging. However, to our knowledge, no prior study has explicitly explored how a text message intervention might facilitate shared and informed decision-making at the time of cancer screening. We are, however, aware of one such study among patients undergoing total joint arthroplasty, which found a positive relationship between perioperative text message communications and patient reports of SDM [23], as well as two ongoing studies that are both being conducted within other clinical contexts [24,25].

Patients increasingly desire technology options that allow them to ask questions and receive health information [26,27]. Text messages can address patient questions to overcome barriers when not in the physical presence of a health care provider [28], and ultimately could encourage cancer screening and other preventive services, perhaps even among those who historically have not engaged with patient portals.

Despite strong evidence that CRC screening reduces overall CRC-related morbidity and mortality, patients are infrequently offered a choice among available tests, notwithstanding evidence that recommending one screening modality (eg, colonoscopy alone) reduces CRC screening adherence [29,30]. Offering patients SDM for CRC screening decisions could facilitate patients’ awareness of testing options and screening adherence.

In this study, we evaluated the acceptability of text messages embedded with SDM support for CRC screening among categories of people who have been historically marginalized as defined by low income, low literacy, and Black/African American race.

Methods

Setting and Study Sample

Participants were recruited from an online panel of US adults maintained by a commercial online health survey company (Lightspeed, a division of Kantar), which issues points and offers prize draws to panel members for completing surveys. To be consistent with the published United States Preventive Services Task Force guidelines for CRC screening among average-risk adults at the time of the study [9], study eligibility was limited to panel members who reported being aged 50-75 years and having no personal history of cancer. We also limited the sample to those who consented to study participation and provided a working cell phone number. For the analyses, we further limited the sample to those who (1) completed an online screener questionnaire, (2) interacted with the text message program, and (3) responded to at least one question on an online postsurvey. To ensure diversity of the study sample, we used sampling quotas to ensure that half of the study sample were (1) Black/African American or Asian/Other (eg, Asian Indian, Chinese, Filipino, Japanese) race and (2) had no history of CRC screening. Data were collected from July 2020 to August 2020.

Procedure

The study was advertised to Lightspeed Health panel members via email. Those who were interested in participating completed an online screener to determine study eligibility. Once deemed eligible, respondents were sent an online study consent form and asked to provide a valid US cell phone number. Those who consented and provided a working cell phone number were delivered experimental decision-support message content regarding CRC screening and screening test options via text message. Participants were randomly assigned to one of three experimental conditions: General Support, Doctor's Office Support, and Standard. Participants' responses to program-embedded questions and branching logic determined what and how much program content was sent to them. The speed with which a person completed the text message program depended on their own responses (which guided what content was pushed to them). Although the length of time it took for participants to read and respond to a received text message also varied, the program was designed to be completed in one sitting followed by the postsurvey. However, study participants were not limited to one sitting and faced no time constraints on engagement with the text message(s). Upon program completion, participants were provided with a link to an online postintervention survey.

Text Message Content

The text message program offered educational information on CRC screening intended to address three of the most common components of SDM [31] that have been advocated as critical to its implementation in practice: choice awareness, option awareness, and decision-making [32]. The program initially provided information on who should be screened and descriptions of available screening tests (ie, colonoscopy and stool testing) to create decision or choice awareness. The content of the program also provided information regarding the testing process and the pros and cons of each test to describe treatment options and facilitate option awareness. Finally, the program prompted the user to talk to their doctor about CRC screening and which screening test might be right for them (ie, supporting making the decision). Within each section of the program (choice awareness, option awareness, and decision-making), users were prompted to input questions they might have and asked if they would like to continue or stop receiving messages.

Text message content was identical across experimental conditions except for the two introductory messages (see Multimedia Appendix 1). Based on the types of introductory messages, the three experimental conditions were General Support, Doctor's Office Support, and Standard. Figure 1 shows text message examples appearing on the cell phone screen. According to prior analyses identifying no differences in any measure of acceptability by experimental condition, we considered all participants regardless of their experimental condition for the current analyses.

Figure 1. Example text messages.

Hello, this is Devon from Heath Txts. If you think that colon cancers affect only a certain type of person, then you are not alone. Text "9" to learn more.

Most people don't realize that testing is recommended for everyone ages 50 – 75 because anyone can be impacted – regardless of sex, race, or family history. Text "9" to learn more.

Do you have questions? (Standard messaging rates apply).
1 – I have a question
2 – I don't have a question
3 – Stop receiving these messages

Text your question below.

Thank you for your question. This helps us understand the types of questions people like you may have. Please text "9" to continue.

There are two common ways to test for colon cancer. Text "9" to learn more.

Colonoscopy Option: A doctor uses a narrow lighted tube with a small camera to search for small growths called polyps in the colon. During the test, polyps can be removed. Text "9" to learn more.

Stool Test Option: You collect a stool sample at home. It's checked for blood or other signs of colon cancer that you can't see. Text "9" to learn more.

Do you have questions? (Standard messaging rates apply).
1 – I have a question
2 – I don't have a question
3 – Stop receiving these messages

Text your question below.

Thank you for your question. This helps us understand the types of questions people like you may have. Please text "9' to continue.

Data Sources

Study data were derived from (1) the online presurvey administered prior to initiating any interaction with the text message program (ie, eligibility screener questions), (2) the online postsurvey accessed via a link provided within the final text message received, and (3) program metadata. The presurvey included questions inquiring about the participants' sociodemographic characteristics (eg, age, race), history of cancer, and screening history. Regarding race, respondents were asked in the survey to indicate the racial categories that pertained to them among 14 different options (eg, white, Black or African American, American Indian or Alaska Native, Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Other Asian, Native Hawaiian, Guamanian or Chamorro, Samoan, and Other Pacific Islander). The postsurvey was designed to assess program acceptability and other perceptions regarding the text message program. The postsurvey also included additional sociodemographic questions (eg, education, income, and health literacy). We used metadata from participants' responses to text messages to identify where within the text message program the participant indicated they no longer wanted to receive additional messages (ie, observed program engagement).

Conceptual Framework

The Technology Acceptance Model (TAM) suggests that a person's use of technology can be explained by their *perceived ease of use* and *perceived usefulness*, which collectively have a direct influence on behavioral intention. Previous health care studies have used the TAM to examine acceptance of technology-based interventions such as clinical reminder system, electronic health record, and portal use among different users, including health care professionals and patients [33,34]. Due to the importance of understanding *acceptability* among those receiving health care interventions, Sekhon and colleagues [35] developed a multiconstruct theoretical framework of acceptability of health care interventions. This framework consists of constructs that conceptually overlap with the TAM (eg, ease of use and burden, perceived usefulness, and perceived effectiveness). We therefore used a similar notion of acceptability (ie, affective attitude, burden, perceived effectiveness, and self-efficacy) and incorporated the assumption that acceptability is related to behavioral intention and the actual use of the intervention (ie, program engagement) to inform and guide our research.

Outcome Measures

Primary Outcomes

The primary outcome of interest was program acceptability as measured by observed program engagement, participant-reported acceptability, and participant-reported intention to use the text message program in the future.

Observed Program Engagement

Participants were given the option to stop receiving additional text messages at two points. The first was after being provided with information regarding the need for CRC screening and that two common screening tests (colonoscopy and stool testing) were available (ie, after the program made them aware that there was a decision to be made). The second stopping point occurred when participants were provided with an opportunity to learn more about one and/or two screening tests, but before being provided with additional information regarding the pros and cons of at least one screening method (ie, before the program provided information on available alternatives or option awareness). We used these stopping points to create binary constructs reflective of whether the participant engaged sufficiently to have (1) choice awareness and (2) information on alternatives/option awareness.

Participant-reported Acceptability

Participant-reported acceptability was measured with survey items mapped to a subset of constructs proposed by Sekhon and colleagues [35] (ie, affective attitude, burden, perceived effectiveness, and self-efficacy) to examine participants' perception of the text message program. *Affective attitude* was based on the following question: "If I received this text message from my doctor's office, I would feel: (1) supported; (2) worried." Each had the response options of "not at all," "a little," "somewhat," "quite a bit," and "very much." *Burden* was based on the rating of the statement "These text messages would be easy to use" responded on a 5-point Likert scale (ie, strongly disagree, somewhat disagree, neither agree nor disagree, somewhat agree, and strongly agree). *Perceived effectiveness* was based on the following statements about all the text messages they received: (1) These text messages would be useful for knowing what questions to ask my doctor; (2) These text messages would improve my ability to talk to my doctor about colon cancer testing; (3) These text messages would be useful for learning about colon cancer screening; (4) These text messages would help me make colon cancer screening decisions. The response options for these statements were the same as those used for the *burden* construct. *Self-efficacy* was based on a single statement, "Learning to interact with these text messages would be easy for me," with the same response options on a 5-point Likert scale as mentioned above.

Participant-reported Intention

We measured the participant-reported intent to interact with the text messages and to sign up for this type of text message program as indicative of behavioral intention. This concept was measured using responses for the following two statements: "I would interact with these text messages if from my doctor" and "I would sign up to get messages like this from my doctor's office." The responses to these statements were similarly rated using a 5-point Likert scale ranging from strongly disagree to strongly agree.

Statistical Analyses

We present descriptive statistics for study participant demographics. As mentioned above, the outcomes of interest were all rated using a 5-point Likert scale ranging from strongly disagree to strongly agree. To improve interpretability, we dichotomized these outcomes into agree (answered "agree" or "strongly agree") and disagree (remaining scales). We used 95% CIs to describe the difference in percent agreement between races, health literacy levels, and household income levels. Multivariable modified Poisson analyses [36] were used to calculate adjusted relative risks of agreement by participant race, health literacy, and household income while adjusting for age, experimental condition, residential area, and educational attainment; these patient characteristics were selected for inclusion in final regression models based on previous literature on disparities of portal use [4-7] and bivariate associations with the outcomes. Because multivariable results did not alter the results or conclusions, we only present bivariate results.

Differences by experimental condition were evaluated using Wilcoxon rank-sum tests for continuous participant characteristics and Fisher exact tests for categorical characteristics. All analyses were performed using SAS software (version 9.4). All statistical tests were 2-tailed, with the probability of a type I error set at $P<.05$ and no adjustments for multiple comparisons.

Ethical Considerations

The study protocol was reviewed and approved by the Institutional Review Board at the University of North Carolina, Chapel Hill (21-1417). Online informed consent was obtained from all participants before their enrollment in the study.

Results

Sample Characteristics

Participant characteristics (N=289) are detailed in Table 1. The mean age was approximately 60 years. Nearly 70% of participants were male, 39% were white, 51% identified as Black or African American, and 10% identified as Asian or other minority race (eg, Asian Indian, Chinese, Filipino, Japanese). Due to the small number of study participants reporting a race other than Black/African American or white, we elected to focus on Black/African American versus white comparisons when considering participant race. Most participants were confident in their health literacy, with approximately 60% expressing extreme confidence. Nearly 40% of participants reported an annual income less than US $50,000. Most participants were educated, with more than three-quarters receiving more than high school education. Slightly over one-quarter of the participants reported never having been screened for CRC.

Table 1. Baseline characteristics of the study sample (N=289).

Characteristics	Value
Age, mean (SD)	60.0 (6.55)
Gender identity, n (%)	
Male	196 (69.0)
Female	87 (30.6)
Other	1 (0.4)
Race, n (%)	
White	113 (39.1)
Black/African American	146 (50.5)
Asian/Others	30 (10.4)
Residential area, n (%)	
Urban	80 (28.3)
Suburban	152 (53.7)
Rural	51 (18.0)
Health literacy (confidence), n (%)	
Less than extreme	102 (36.0)
Extreme	181 (64.0)
Household income (US $), n (%)	
<50,000	115 (40.6)
≥50,000	168 (59.4)
Educational attainment, n (%)	
High school or less	34 (12.0)
Above high school	249 (88.0)
Screening history, n (%)	
Yes	209 (72.3)
No	80 (27.7)
Type of introductory messages, n (%)	
General support	96 (33.2)
Doctor's office support	103 (35.6)
Standard	90 (31.1)

Observed Program Engagement

Almost 84% of participants engaged with the text message program long enough to receive information on multiple ways to be screened for CRC (choice awareness), but only 39.4% engaged with the program long enough to learn about the pros and cons of at least one CRC screening modality (alternative pros/cons or option awareness). We found no significant differences in either measure of observed program engagement by participant race, health literacy, or screening history (Table 2). However, compared to participants who reported lower incomes, participants with an annual household income of US $50,000 or more were more likely to engage with the program long enough to learn there is a choice regarding CRC screening modality (choice awareness).

Table 2. Observed program engagement by participant race, income, health literacy, and screening history (unadjusted) (N=289).

Participant characteristic	Choice awareness	Option awareness (alternative pros/cons)
Race		
Black/African American, n (%)	121 (82.9)	63 (43.2)
White, n (%)	95 (84.1)	36 (31.9)
Unadjusted difference, % (95% CI)	–1.2 (–11.1 to 8.7)	11.3 (–1.3 to 23.8)
Household income (US $)		
<50,000, n (%)	90 (78.3)	44 (38.3)
≥50,000, n (%)	149 (88.7)	69 (41.1)
Unadjusted difference, % (95% CI)	–10.4 (–20.1 to –0.8)[a]	–2.81 (–15.1 to 9.5)
Health literacy		
Less than extreme confidence, n (%)	91 (89.2)	43 (42.2)
Extreme confidence, n (%)	148 (81.8)	70 (38.7)
Unadjusted difference, % (95% CI)	7.5 (–1.6 to 16.5)	3.48 (–9.2 to 16.2)
Screening history		
Yes, n (%)	177 (84.7)	78 (37.3)
No, n (%)	64 (80.0)	36 (45.0)
Unadjusted difference, % (95% CI)	4.7 (–6.2 to 15.6)	–7.7 (–21.3 to 5.9)

[a] Statistically significant difference (*P*=.03).

Participant-reported Acceptability

Perceived acceptability per postprogram survey items varied from 63.0% to 91.7%. Among the 289 participants, the majority indicated that the program was easy to use (n=261, 90.3%) and would not be a burden (n=265, 91.7%). Similarly, most participants reported that the program was useful for learning about CRC screening (n=254, 87.9%). Participants were slightly more varied in their reports that the program would be useful for them identifying questions to ask their physician (n=230, 79.6%) or deciding about CRC screening (n=228, 78.9%) and talking to their doctor about CRC screening (n=213, 73.7%). Substantially less participants felt supported by the program (n=182, 63.0%) and 28.4% (n=82) indicated that interacting with the program would make them feel worried. Those who did not indicate having a previous screening history reported that they would feel worried relatively more than those who had a previous screening history (difference 16.1%, 95% CI 3.0-29.1). However, only 28.4% (n=82) of those who indicated potentially feeling worried engaged with the text message program long enough to learn about the different types of screening modalities.

Black/African American participants reported that they would feel more supported than white participants if they were to receive these types of messages from their doctor’s office. Compared to white participants, Black/African American participants were also more likely to report that the text messages were useful for (1) improving the ability to talk to their doctors about CRC screening and (2) learning about CRC screening, but otherwise we did not find racial differences in participants reports of acceptability. We found no significant differences in patient-reported measures of acceptability by household income or health literacy (Table 3).

Table 3. Participant-reported text message acceptability by participant race, income, health literacy, and screening history (unadjusted) (N=289).

Participant characteristic	Feel supported	Not worried	Self- efficacy	Burden	Helpful question	Talking to the doctor	Useful learning	Help them decide
Race								
Black/African American, n (%)	103 (71.0)	103 (70.6)	130 (89.7)	8 (5.5)	123 (84.8)	117 (80.7)	134 (93.7)	119 (82.1)
White, n (%)	63 (55.8)	85 (75.2)	105 (92.9)	13 (11.5)	85 (75.2)	72 (63.7)	94 (83.2)	87 (77.0)
Unadjusted difference, % (95% CI)	15.3 (2.7 to 27.8)[a]	–4.7 (–16.3 to 7.0)	–3.3 (–10.9 to 4.4)	–6.0 (–13.7 to 1.8)	9.6 (–1.1 to 20.3)	17.0 (5.2 to 28.7)[b]	10.5 (1.8 to 19.3)[c]	5.1 (–5.7 to 15.8)
Household income (US $)								
<50,0000, n (%)	68 (59.7)	80 (69.6)	102 (88.7)	8 (7.0)	90 (78.3)	86 (74.8)	100 (88.5)	94 (81.7)
≥50,000, n (%)	110 (65.5)	124 (73.8)	158 (94.1)	14 (8.3)	136 (81.0)	122 (72.6)	151 (89.9)	130 (77.4)
Unadjusted difference, % (95% CI)	–5.8 (–18.1 to 6.4)	–4.2 (–15.7 to 7.2)	–5.4 (–12.9 to 2.2)	–1.4 (–8.4 to 5.6)	–2.7 (–13.0 to 7.6)	2.2 (–9.0 to 13.3)	–1.4 (–9.6 to 6.8)	4.4 (–5.9 to 14.6)
Health literacy								
Less than extreme confidence, n (%)	61 (59.8)	68 (66.7)	92 (90.2)	7 (6.9)	83 (81.4)	78 (76.5)	91 (90.1)	82 (80.4)
Extreme confidence, n (%)	117 (65.0)	136 (75.1)	168 (92.8)	15 (8.3)	143 (79.0)	130 (71.8)	160 (88.9)	142 (78.5)
Unadjusted difference, % (95% CI)	–5.2 (–17.8 to 7.4)	–8.5 (–20.3 to 3.4)	–2.6 (–10.3 to 5.0)	–1.4 (–8.5 to 5.7)	2.4 (–8.0 to 12.8)	4.7 (–6.6 to 15.9)	1.2 (–7.0 to 9.4)	1.9 (–8.6 to 12.5)
Screening history								
Yes, n (%)	133 (63.9)	159 (76.1)	193 (92.3)	15 (7.2)	169 (80.9)	154 (73.7)	186 (89.9)	166 (79.4)
No, n (%)	49 (61.3)	48 (60.0)	71 (89.9)	8 (10.1)	61 (77.2)	59 (74.7)	68 (86.1)	62 (78.5)
Unadjusted difference, % (95% CI)	2.7 (–10.7 to 16.1)	16.1 (3.0 to 29.1)[d]	2.5 (–6.0 to 10.9)	–3.0 (–11.3 to 5.4)	3.7 (–7.9 to 15.2)	–1.0 (–13.2 to 11.2)	3.8 (–5.8 to 13.3)	0.9 (–10.5 to 12.4)

[a] Statistically significant difference (*P*=.01).

[b] Statistically significant difference (*P*=.004).

[c] Statistically significant difference (*P*=.01).

[d] Statistically significant difference (*P*=.02).

Participant-reported Behavioral Intention

Among the 289 participants, the majority indicated a willingness to interact with similar programs from their doctor's office (n=253, 87.5%), as well as a willingness to sign up for similar programs from their doctor's office (n=210, 72.7%). Black/African American participants, compared to white participants, were more likely to indicate an intent to (1) interact with a similar text message program from their doctor's office and (2) sign up for a similar program. We found no significant differences in participant-reported behavioral intention by household income, health literacy, or screening history (Table 4).

Table 4. Behavioral intention by participant race, income, health literacy, and screening history (unadjusted) (N=289).

Participant characteristic	Interact with the program	Sign up for the program
Race		
Black/African American, n (%)	134 (92.4)	117 (82.4)
White, n (%)	93 (82.3)	72 (63.7)
Unadjusted difference, % (95% CI)	10.1 (1.1 to 19.2)[a]	18.7 (7.0 to 30.3)[b]
Household income (US $)		
<50,000, n (%)	101 (87.8)	87 (75.7)
≥50,000, n (%)	148 (88.1)	121 (72.0)
Unadjusted difference, % (95% CI)	–0.3 (–8.3 to 7.7)	3.6 (–7.5 to 14.7)
Health literacy		
Less than extreme confidence, n (%)	91 (89.2)	76 (74.5)
Extreme confidence, n (%)	158 (87.3)	132 (72.9)
Unadjusted difference, % (95% CI)	1.9 (–6.6 to 10.4)	1.6 (–9.8 to 13.0)
Screening history		
Yes, n (%)	188 (90.0)	154 (74.4)
No, n (%)	65 (82.3)	56 (71.8)
Unadjusted difference, % (95% CI)	7.7 (–2.6 to 17.9)	2.6 (–9.9 to 15.1)

[a] Statistically significant difference (*P*=.02).

[b] Statistically significant difference (*P*=.002).

Discussion

Principal Findings

Among an online panel of socioeconomically diverse US adults aged 50-75 years maintained by a commercial online health survey company, we found high acceptability for the use of text messaging to inform and support SDM for CRC screening. In a subset of measures, Black/African American participants showed even greater acceptability and behavioral intention than their white counterparts. We did, however, find that participants reporting an income less than US $50,000 were less likely than those reporting higher income to engage long enough with the program to learn that multiple CRC screening tests are available (choice awareness). Our findings support promising opportunities that text messaging–based programs might enable health care organizations and others to reach broader populations than they could by relying solely on online patient portals, but nonetheless illustrate caution regarding the extent to which text messaging can be used to support components of SDM.

Comparison With Prior Work

Many health systems have turned to online portals to deliver health education materials to engage and support SDM outside of office visits. Because of well-documented disparities in patient portal use [4-7], identifying additional communication channels to support these efforts is imperative. Consistent findings from the mobile technology and public health literature is that text messages for behavioral change (eg, weight loss) are most effective when perceived as relevant, personalized, and simple [37,38]. Our findings suggest additional evidence that text message–based programming may facilitate patients' decision awareness regarding CRC screening and that such text message–based programming is generally acceptable to sociodemographically diverse populations. Over 80% of study participants engaged with enough of the text messaging program to receive information about multiple evidence-based CRC screening tests available. Even among participants who reported an income less than US $50,000, over three-quarters engaged with the program long enough to view content informing them that multiple types of CRC screening tests are available. This is important, as decision awareness is often underlooked in practice and, in the case of CRC screening, may drive down screening rates [29,30]. Importantly, almost three-quarters (72.7%) of participants voiced a willingness to sign up for similar programs should they be available from their doctor's office.

The program was only partially successful in helping participants learn about the pros and cons of alternative CRC screening tests (option awareness). Only 39.4% of study participants engaged with the program long enough to view the pros and cons of at least one of the available CRC screening tests. The consequence of this is that while most participants reported that the program was useful, relatively less participants reported that it would help them to decide or communicate with their physicians.

Taken together, our findings add to the emerging understanding that SDM is not a single event but rather a multistep process consisting of multiple components [31]. This view may support a broader implementation of SDM through text messages. Our results clearly support the use of text messaging to inform people that there are multiple ways to screen for CRC (ie, choice awareness). For a subset of people, learning about the screening alternatives also seemed feasible using text messages, whereas for others, text messages may not have been useful for acquiring in-depth information (eg, pros and cons of each screening modality).

Limitations

Our study has several limitations. First, the sample was limited to commercial online panel members whose perspectives may not reflect the broader CRC screening–eligible population, especially those who do not routinely engage online. We also did not require study participants to be actively engaged in a CRC screening decision at the time of study participation. Second, the survey questions were adapted from existing instruments [39-41] and mapped to the conceptual framework of acceptability presented here, but they may not capture all relevant constructs as acceptability is a multifaceted concept [42]. Third, while behavioral intention is highly correlated with observed behaviors [43], the extent to which our high participant-reported intent to engage with similar text message programs would translate into actual engagement in practice is uncertain. Finally, 28.4% of participants responded in the postsurvey about how continued interaction with the program would make them "feel worried." This indicates a potential limitation of the text message program in that "worried" people, many of whom have not previously been screened for CRC, may self-select to not interact with such programs perhaps as a coping mechanism to avoid additional worry. In other words, if "worry" is a barrier to screening, text messages may not be the best platform to engage people in learning about new information such as cancer screening modalities.

Conclusions and Future Implications

Findings from this study demonstrate the general acceptance of text messages to engage patients in decisions regarding CRC screening as well as to support SDM in the context of CRC screening. Among people who have been historically marginalized due to racism, low income, or low literacy, the use of text messaging rather than online patient portals may better support informed and shared decision-making by enhancing decisional awareness. As our study focused on an online panel to explore initial feasibility, additional research is needed to assess acceptability among the general population, as well as to consider different ways to improve the acceptability of text message programs, particularly among lower-income populations whose mobile phone plans may cap or charge per text message use.

Acknowledgments

JEL received a Developmental Award from the University of North Carolina Lineberger Comprehensive Cancer Center. SH was supported by the University Cancer Research Fund from the University of Gillings School of Global Public Health. Portions of this study were presented at the 2021 International Conference on Communication in Healthcare. We thank the 289 individuals who participated in the study.

Data Availability

The deidentified data from our study are available upon request. Requests for access to the data sets and custom code generated, used, or analyzed in this study should be directed to the corresponding author.

Authors' Contributions

JEL, AJL, MKRC, AB, SDC, and DSR designed the study. AJL and MKRC recruited study participants. SH, HMH, AMD, and JEL collected and analyzed the data. SH, HMH, AMD, and JEL interpreted the results. SH and JEL drafted the manuscript. All authors read, revised, and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Study procedure and introductory messages.
[PPTX File , 181 KB - cancer_v9i1e40917_app1.pptx]

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Abbreviations

CRC: colorectal cancer
SDM: shared decision-making
TAM: Technology Acceptance Model

Edited by T Leung; submitted 11.07.22; peer-reviewed by L Guo, W LaMendola; comments to author 19.12.22; revised version received 23.03.23; accepted 31.03.23; published 05.05.23.

Please cite as:
Hwang S, Lazard AJ, Reffner Collins MK, Brenner AT, Heiling HM, Deal AM, Crockett SD, Reuland DS, Elston Lafata J
Exploring the Acceptability of Text Messages to Inform and Support Shared Decision-making for Colorectal Cancer Screening: Online Panel Survey
JMIR Cancer 2023;9:e40917
URL: https://cancer.jmir.org/2023/1/e40917
doi:10.2196/40917
PMID:37145859

Original Paper

Navigating the Cancer Journey Using Web-Based Information: Grounded Theory Emerging From the Lived Experience of Cancer Patients and Informal Caregivers With Implications for Web-Based Content Design

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Abstract

Background: The internet is an important source of information for many informal caregivers and patients living with cancer. A better understanding of how individuals use the internet to meet their informational needs is important for guiding intervention development.

Objective: The objectives of this study were to develop a theory describing why individuals living with cancer use the internet to find information, characterize the challenges faced with existing web-based content, and provide recommendations for web-based content design.

Methods: Adults (≥18 years) with a history of being patients with cancer or informal caregivers were recruited from Alberta, Canada. After providing informed consent, participants were engaged through digitally recorded one-on-one semistructured interviews, focus groups, a web-based discussion board, and emails. Classic grounded theory guided the study procedures.

Results: A total of 21 participants took part in 23 one-on-one interviews and 5 focus groups. The mean age was 53 (SD 15.3) years. Breast, gynecological, and hematological cancers were the most common cancer types (4/21, 19% each). In total, 67% (14/21) of patients, 29% (6/21) of informal caregivers, and 5% (1/21) of individuals reporting both roles participated. Participants experienced many new challenges in their cancer journey and used the internet to become better oriented to them. For each challenge, internet searching attempted to address one or more of 3 key orientation questions: why the challenge was happening, what to expect, and options for managing it. Better orientation resulted in improved physical and psychosocial well-being. Content that was well laid out, concise, free of distractions, and that addressed the key orientation questions was identified as the most helpful in assisting with orientation. Creators of web-based content are encouraged to 1) clearly identify the cancer challenge and population the content is addressing, as well as the presence of any potentially distressing information; 2) provide versions of the content in different formats, including printer-friendly, audio, video, and alternative languages; 3) state who created the content, including the individuals, organizations, and processes involved; 4) place hyperlinks after the key orientation questions have been addressed; and 5) ensure that the content is optimized for discovery by search engines (ie, Google).

Conclusions: Web-based content plays an essential role for many living with cancer. Clinicians are encouraged to take active steps to help patients and informal caregivers find web-based content that meets their informational needs. Content creators also have a responsibility to ensure that the content they create assists and does not hinder those navigating the cancer journey. Research is needed to better understand the many challenges that individuals living with cancer face, including how they are temporally related. In addition, how to optimize web-based content for specific cancer challenges and populations should be considered an important area for future research.

(JMIR Cancer 2023;9:e41740) doi:10.2196/41740

KEYWORDS

health information behavior; neoplasm; theory; internet; information needs; adults

Introduction

Background

An information need is an individual’s recognition that their knowledge is inadequate to satisfy their goals [1]. Most of those living with cancer experience unmet information needs at some point [2-6]. In the curative intent setting, information needs have been identified as the most commonly unmet supportive care need [7], with a prevalence exceeding 50% [8]. In the noncurative intent setting, similar findings have been identified, with information needs consistently being one of the most common and important unmet supportive care needs [9]. For informal caregivers, including friends and family supporting a patient, information needs are just as important and likely to go unmet [10]. These findings are not limited to a few studies as the importance of information and the high prevalence of unmet information needs in the populations affected by cancer have been well characterized in many studies, including across different cancer types [11] and points in the cancer journey [3,12,13]. Importantly, the range of information needs experienced during the cancer journey is vast. A recent review identified that the number of distinct information needs characterized in the literature totaled 1709 [5]. The authors were able to organize these needs into 17 distinct categories and 119 subcategories ranging from treatment-related to financial and legal information [5].

Addressing the information needs of those living with cancer, including patients and informal caregivers, should be prioritized by both clinicians and health care systems. From a health care system perspective, a systematic review explored the impact of decisional support for health care interventions on the costs of care [14]. A total of 7 studies were included, with decisional support being provided primarily through information sharing interventions delivered via DVDs, booklets, web-based content, videotapes, and coaching. The review identified that the information interventions were associated with decreased costs of health care delivery, including reduced treatment use rates [14]. Despite not including studies in the cancer context, these findings can be extrapolated. For instance, a systematic review of shared decision-making in the lung cancer context demonstrated that shared decision-making resulted in decreased emergency room visits and a reduction in the amount of chemotherapy received [15], presumably resulting in decreased health care resource use and costs.

In terms of clinical consequences, unmet information needs have been shown to be associated with negative outcomes in the short and long term. A systematic review explored the link between information and physical and psychosocial outcomes in patients with cancer [16]. This study found that information provision, quality of information, and satisfaction with the information provided were positively associated with health-related quality of life and physical well-being and negatively associated with anxiety and depression [16]. Similar findings were identified in another systematic review focusing on the unmet care needs of both patients and informal caregivers in the advanced cancer setting [10]. For patients, unmet needs related to information provision, including communication with health care providers and specific information needs, were identified to be associated with increased symptom burden and distress [17]. For informal caregivers, the review did not specifically explore how information needs and provision were associated with physical or psychosocial well-being. However, a study included in the review identified that increased caregiver information needs were associated with increased fatigue (P=.005) [18].

The relationship between information and the physical and emotional well-being of patients and caregivers is, at least to some extent, causal. Support for this comes from both the theoretical and empirical literature. From a theoretical perspective, information plays a key role in coping with stress [19,20]. According to stress and coping theory [20], individuals engage in 2 types of coping when confronted with a new challenge: problem-based and emotional-based coping. Information can assist with both as it can help individuals decrease uncertainty about what is to come, resulting in decreased anxiety, and help individuals plan what action to take to promote an outcome that is in line with their personal goals. Through this theoretical lens [19-21], the published literature demonstrating a statistically correlated relationship between unmet information needs and higher levels of depression, anxiety, and increased psychosocial complaints [10,16,22] supports the important role that information plays in assisting with emotional coping.

The literature also provides support for information as a key part of problem-based coping. For instance, a quasi-experimental study [23] evaluated the impact of an educational intervention on the side effects of chemotherapy. Compared with usual care, participants in the experimental group received 3 personalized educational sessions focusing on the self-management of chemotherapy side effects. Participants in the experimental group experienced significantly less (ie, P<.05) nausea, constipation, pain, mouth sores, weight change, fatigue, and difficulty sleeping [23]. Information has also been shown to help individuals navigate the impact of the cancer journey on the aspects of their lives outside of being patients or informal caregivers by supporting them in coordinating their non–cancer-related social roles (eg, being employees, parents, and friends) around the demands of the cancer journey [24,25].

The Internet and the Cancer Journey

Multiple studies have demonstrated that the internet is a key resource for those living with cancer. In a Swedish survey study of patients with cancer (N=282), 76.2% of the respondents reported using the internet to find cancer-related information after their diagnosis [26]. Another survey of patients with advanced breast cancer reported that 83% of the respondents used the internet to find information related to their diagnosis and to assist with navigating the cancer journey on a daily basis [27]. Other studies have identified that high rates of internet use are likely related to the fact that, unlike health care providers, the internet is accessible around the clock, does not require an appointment or travel to the physician's office, and affords the individual anonymity [28].

Although the internet plays an important role for many living with cancer, it is by no means a perfect source of information. An internet connection and appropriate device are required, and individuals may not be aware of or feel comfortable accessing web-based information [28]. For those who can access the internet, the content may be inaccurate, misleading, or a source of confusion and distress [17,29,30]. A recent review of web-based content from 48 websites for patients with cancer about depression used a validated tool to evaluate the quality of the content [31]. This review identified issues with accountability in 63% of the websites and readability in 54% and found that only 38% of the websites had been updated in the last 2 years, raising concerns about content accuracy. Another study found that the information patients need and what is available on the web are not always well aligned [32].

A Gap in the Literature

Developing web-based content to assist individuals living with cancer is a complex challenge where theory, rigorously grounded in empirical data from the cancer context, has an important role to play. Theory facilitates the identification of important factors and variables for planning how interventions are deployed, predicting expected outcomes, and informing what should be measured to assess efficacy [33]. In addition, theory can evolve over time, being revised as newly discovered scientific findings emerge to better reflect the phenomena in question [34,35]. Finally, theory provides common conceptual ground, promoting collaboration among researchers and institutions and across disciplines [36]. In the context of evolving how those living with cancer are cared for, the importance of structuring the development and evaluation of any novel intervention on a robust theory grounded in the cancer context cannot be overstated.

Several theoretical conceptualizations addressing how individuals living with cancer have their informational needs met exist. Those by Freimuth et al [37] and Longo [38] are important to mention as they both describe the information-seeking behavior of those living with cancer and were developed from data collected in the cancer context. The health information acquisition model by Freimuth et al [37] was developed using data collected from the Cancer Information Service, a telephone-based information service developed by the National Cancer Institute in the United States [37]. Longo developed a theory of health of information behavior beginning with initial work involving interviews with patients with breast cancer [38]. Notably, although not cancer-specific, Wilson [21] incorporated the work of both Longo [38] and Freimuth et al [37] as well as many other theorists and researchers across a number of disciplines and synthesized a comprehensive multidisciplinary theory of information-seeking behavior.

The work of Wilson [21], Freimuth et al [37], and Longo [39] provides important insight into how individuals living with cancer seek information. Importantly, the representative models from Freimuth et al [37] and Wilson [21] identify that important cyclical feedback mechanisms exist between stimuli, or perceived information needs, and information seeking [40]. Both models incorporate a cost-benefit (or risk-reward) analysis performed by the information seeker to determine whether the potential benefits of searching for more information outweigh the anticipated costs [21,40], such as time, energy, and potential emotional distress [25]. An important question that follows from these models relates to how web-based content can be created to optimize the benefit for the end user while minimizing costs.

To work toward addressing this important question, a rigorously developed theory grounded in the cancer experience is needed. This theory needs to conceptualize the challenges that individuals face when they turn to the internet and what makes internet content useful for addressing these challenges. Such a theory would be useful for guiding content creators in creating web-based content to better meet the needs of those living with cancer.

Study Objectives

This study was conducted to understand how to better support those living with cancer through web-based information. The objectives of this study were to develop theoretical conceptualizations of (1) the goals that individuals living with cancer are trying to achieve [41] when they use the internet to find information, (2) the challenges they face with existing content, and (3) web-based content design elements that would assist them in meeting their informational needs.

Methods

Recruitment

Research participants were recruited from emailing lists maintained by Alberta Health Services, including individuals living with cancer, as well as a cancer support clinic network. Recruitment posters were placed in clinical areas accessible to ambulatory patients at a major health center in Calgary, Alberta. Participants did not have a previous relationship with the researcher (MT). They were informed of the researcher's professional practice as a medical oncologist in Manitoba, Canada, and that the research project was being conducted in conjunction with the researcher's doctoral thesis work.

Data Collection

After providing informed consent, participants completed a short intake survey (Multimedia Appendix 1) capturing demographics and characterizing their cancer journey (ie, cancer type, treatment intent, and role as patient or informal caregiver) and their interest in participating in one-on-one interviews and focus groups. They then received a study-specific username and password to facilitate anonymous participation in the study's web-based discussion forum as well as email correspondence with the study lead (MT). Study activities included digitally recorded one-on-one semistructured interviews (via telephone or Zoom; Zoom Video Communications), focus groups (via Zoom), email correspondence, and participation in a private password-protected web-based discussion forum.

An initial interview guide (Multimedia Appendix 2) was developed by the authors that was modified as the study progressed in keeping with classic grounded theory methodology [35]. One-on-one interviews and focus groups were conducted with individuals selected to ensure that all emerging concepts reached saturation. This involved identifying individuals for study activities based on their responses to the intake questionnaire, availability, and what was known about them from their responses in earlier study activities (ie, from previous interviews, focus groups, emails, and web-based forum responses). As concepts emerged, in addition to being explored through interviews and focus groups, questions were posed to all participants through the private online discussion forum as well as through emails.

Data Analysis

The data collected included field notes (generated by the researcher during the interviews and focus groups), transcripts generated from audio recordings of the interviews and focus groups, email correspondence, and posts from the web-based forum. Data analysis involved open, selective, and theoretical coding as well as the generation and subsequent analysis of memos. Coding was conducted manually using NVivo Plus (version 12; QSR International). Data collection and analysis continued until theoretical saturation was achieved and a theory had emerged describing a core concept, a number of related concepts, and how these concepts interact [42]. Study procedures were performed by MT and were in keeping with classic grounded theory as outlined by Glaser and Strauss [35], Glaser [42], and Holton and Walsh [43]. A summary of methods of rigor used, as outlined by Chiovitti and Piran [44], is presented in Multimedia Appendix 3 [44]. The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist [45] was used to guide the development of this report and can be found completed in Multimedia Appendix 4 [45].

Ethics Approval and Informed Consent

Ethics board approval for this study was obtained through the Alberta Health Research Ethics Board (HREBA.CC-20-0429) before the initiation of study recruitment. Informed consent was obtained from all participants before study enrollment. The informed consent process included a discussion between potential participants and the researcher (MT) about the study objectives, methods, risks and benefits, and the option of study withdrawal at any point. These details were also outlined in the consent form. Participants were required to sign the consent form and return it to the researcher (MT) before study enrollment. All data collected were deidentified before analysis using a separate master list. Study data were only accessible to members of the research team. Participants did not receive compensation for taking part in the study.

Results

Participant and Study Activity Characteristics

Between August 2021 and June 2022, a total of 21 participants took part in 23 one-on-one interviews, 5 focus groups, and 26 web-based forum posts and sent the lead investigator a total of 10 emails responding directly to the study questions. In total, 38% (8/21) of the participants took part in a single interview or focus group, whereas 62% (13/21) participated in more than one interview or focus group. The average duration of the one-on-one interviews was 52 minutes and 30 seconds. The average duration of the focus groups was 57 minutes and 48 seconds. The demographic characteristics of the study participants are reported in Table 1.

Table 1. Participant demographics and cancer journey characteristics (N=21[a]).

Characteristics	Values
Sex, n (%)	
Female	16 (76)
Male	5 (24)
Age (years), mean (SD; range)	53 (15.3; 19-80)
Marital status, n (%)	
Single	5 (24)
Married	11 (52)
Widowed	1 (5)
Divorced	4 (19)
Cancer type[b], n (%)	
Breast	4 (19)
Gynecological	4 (19)
Hematological	4 (19)
Lung	3 (14)
Gastric	2 (10)
Colon	2 (10)
CNS[c]	2 (10)
Prostate	1 (5)
Sarcoma	1 (5)
Thyroid	1 (5)
Reported treatment intent[b], n (%)	
Curative	11 (52)
Noncurative	8 (38)
Unsure	3 (14)
Reported role, n (%)	
Patient	14 (67)
Informal caregiver	6 (29)
Both	1 (5)

[a] 22 individuals consented to participate in the study, but 1 was unable to take part in any study activities because of reoccurring scheduling issues.

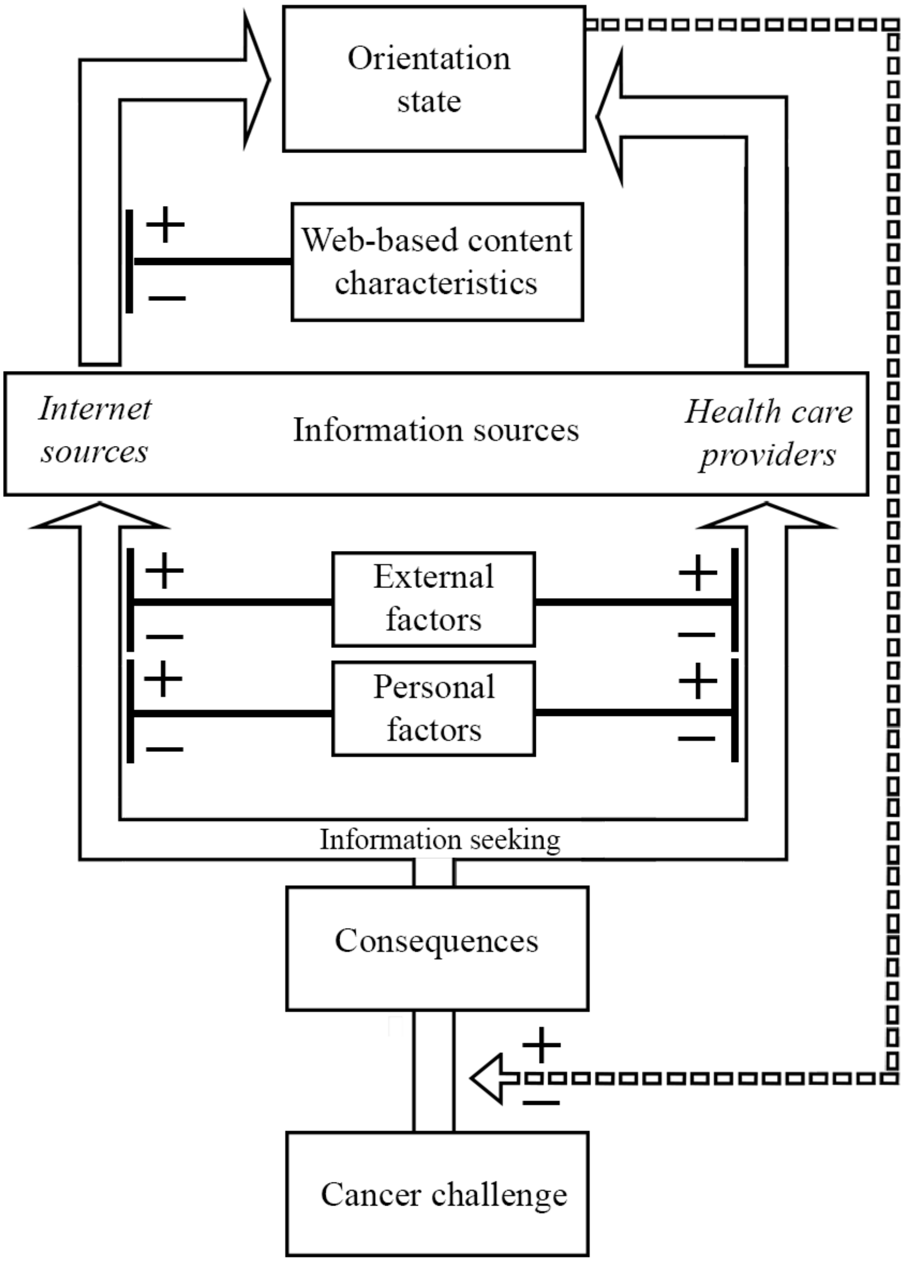
[b] Some participants reported multiple cancer experiences with more than one cancer type and treatment intent.

[c] CNS: central nervous system.

Theory Summary

The theory that emerged consists of 6 interconnected concepts: (1) cancer challenges, (2) orientation, (3) cancer challenge consequences, (4) information sources, (5) personal and external factors, and (6) internet content design characteristics. Cancer challenges describe the challenges that individuals face resulting from a cancer diagnosis. Orientation, the core concept, describes the awareness individuals have of why a challenge is happening, what to expect, and the options that exist for dealing with the challenge. Cancer challenge consequences, or simply consequences, describe the impact that the cancer challenge has on an individual's life and are ameliorated by how oriented the individual is to the challenge. Information sources are where individuals seek information from to become oriented, not limited to health care providers, television, the internet, family, and friends. Factors intrinsic to the individual (ie, personal factors) and external factors influence the individual's preferences for accessing different information sources. Health care providers and the internet were identified as primary sources of information. Characteristics of accessed internet content affect how effective it is in helping the individual become oriented. The theory that emerged is subsequently referred to as orientation theory. A graphical model of orientation theory is presented in Figure 1. The following sections describe the properties and relationships of these concepts.

Figure 1. Model of orientation theory. Individuals seek information in response to facing challenges on the cancer journey. The internet and health care providers are both important information sources. Individuals may prefer to use the internet for information for a number of reasons including but not limited to ease of access, preference for anonymity, or lack of trust in their health care providers. The design of web-based content influences how well individuals are able to use it to become oriented. The state of orientation, in turn, influences the consequences of the cancer challenge being faced, including whether additional information seeking is necessary.



Cancer Challenge

A cancer challenge describes the issues that are introduced into an individual’s life because of a malignancy. Participants described a wide range of challenges, ranging from planning travel to the cancer center and managing their day-to-day lives around the cancer diagnosis to dealing with uncertainty and existential issues regarding end of life:

> *...like how do we manage to get to these appointments and still maintain an income in the family and juggle all of these medical appointments and needs?* [Participant 24]

> *There were important questions about how quickly can you die from lung cancer...I think we became more acquainted in the death conversations as the journey became more clear.* [Participant 5]

Cancer challenges can be divided into 2 broad categories: direct and secondary. Direct challenges are related to the physical consequences of malignancy and participating in the receipt of health care. Examples include dealing with symptoms related to the malignancy, side effects of treatments, and navigating the health care system to get to appointments and treatments. Secondary challenges are those that arise as a result of direct challenges. They describe the collateral challenges of the malignancy diagnosis in the participants’ lives in their roles as employees, parents, spouses, and friends. The following 2 quotes illustrate examples of direct (ie, managing a cancer-related medical complication) and secondary (ie, maintaining a household income) challenges:

> *...the blood clot that I got in my leg which was actually the sign that we have to do some looking into what's going on—so the blood clot came out of the blue and I [had] absolutely no idea that cancer and blood clots were related.* [Participant 12]
>
> *And I think that was probably one of the biggest challenges was managing on one income and I'm self-employed, so how do I work around getting to all of these appointments?* [Participant 24]

Participants described dealing with many cancer challenges throughout their cancer journey. Data analysis identified that certain cancer challenges more commonly occurred or became more prominent at typical times in the cancer journey. For instance, some of the common challenges participants described facing at the time of initial diagnosis included understanding why the cancer occurred, prognosis, figuring out which health care providers were going to be helpful, and planning their lives around the receipt of health care. Importantly, a common challenge participants experienced was finding information resources to help them navigate the cancer journey. This was especially true in the initial weeks to months between receiving the diagnosis and being connected with the cancer specialists who would be managing their care:

> *I [had] questions and so I didn't have anyone, not my family doctor, not the specialist, not the surgeon, I didn't have anyone that I could connect with and say: "hey I have questions." "This is what I am concerned about." "This is how I am feeling right now."* [Participant 10]

Table 2 provides illustrative examples of the cancer challenges identified in this study, including their categorization as either direct or indirect and when they were observed to occur in the participants' lives. Multimedia Appendix 5 contains an illustrative list of the cancer challenges identified through the coding and data analysis process but should not be considered a comprehensive list of cancer challenges that individuals experience.

Table 2. Categories, types, and timing of examples of cancer challenges.

Challenge categories and types	Observed timing[a]
Direct	
Understanding what the diagnosis means	Beginning
Making treatment decisions	Throughout active treatment
Starting new treatments	Throughout active treatment
Identifying which health care provider to see for which problem	Beginning and during active treatment
Sharing diagnosis with friends and family	Beginning
Managing new treatment side effects	Reoccurring with each new treatment
Fear of reoccurrence	After active treatment
Traveling to cancer care centers (eg, driving, parking, and lodging)	Beginning and active treatment
Finding helpful sources of information to help navigate cancer challenges	Throughout the cancer journey
Secondary	
Maintaining control of personal schedule	Diagnosis and active treatment
Maintaining commitments outside of those related to receiving cancer care	Diagnosis and active treatment
Performing in roles outside of being a patient with cancer or assisting a patient with cancer in receiving care	During active treatment and palliation

[a] Timing reflects general trends of when the challenge is common or most substantial; phases considered include beginning (includes diagnosis and initial treatment decision-making), active treatment (includes treatments that contain one or more types or multiple treatments in sequence), surveillance (occurs following active treatment with the intent of more anticancer treatment in the setting of reoccurrence or progression), and palliation (includes best supportive care and symptom management with no additional anti-malignancy–directed treatment).

Orientation

Orientation describes the relative state of knowledge a person has regarding each individual challenge they face in their cancer journey. Broadly, the state of orientation an individual is in with respect to a given challenge can be described as oriented or unoriented. Individuals progress from a state of being unoriented to being oriented by developing the knowledge needed to address the questions they have regarding the cancer challenge. The questions participants described could be categorized into three groups of representative key orientation questions: (1) *Why is this happening?* (2) *What can I expect?* and (3) *What are my options for dealing with this?*

The first category of orientation questions relates to the nature of the challenge, including why something is happening or has happened. Examples include questions about why certain treatments are being recommended, why symptoms are occurring, and what has caused the cancer diagnosis. For instance, a participant described their experience of becoming oriented to why they developed lung cancer:

> *I [googled] why did I get it?...Like I am a non-smoker. I have never smoked in my life...Was I exposed to any of those chemicals [at work] and you know the answer was "no" I was just an office guy for all those years...I've got great genes—my mom died at 100 and my dad at 93...It's just luck of the draw and I—I guess I was hoping for something a little more concrete.* [Participant 12]

The second category of questions (ie, *what can I expect?*) reflects the participants' concerns about planning for the future and anticipating what kind of challenges they will face. Examples include questions about life expectancy, what the side effects of treatments will be, and the timing of appointments. For instance, a participant who was an informal caregiver of older parents who had passed away shared the following:

> *I remember needing to find out the prognosis...especially for my dad, [for my] mom it was just three weeks [after the diagnosis] and she was dead. For my dad it was five years and so for him, periodically, I would check in like, has the research changed?* [Participant 5]

The third category (ie, *what are my options?*) reflects the participants' search for answers regarding what can be done to optimize or improve the outcome of the cancer challenge they are facing. Participants described looking for answers regarding treatment options (including conventional biomedical treatments and alternative and complementary options), exercise, nutrition, and other strategies to manage the many different types of challenges. For instance, a participant described searching for options to minimize chemotherapy toxicity:

> *I did ask [in the information session], I said "is there anything else I could do or any supplements I can take that would help to boost or build my immune system?" because there is no mention of it whatsoever in any of the [information that was provided].* [Participant 10]

Consequences

The relative state of orientation has important consequences for the well-being of the individual facing the challenge. Participants described more negative consequences of managing cancer challenges when in an unoriented state compared with an oriented state. An unoriented state was associated with increased uncertainty about what to expect and what action to take and a negative impact on the time, emotional and physical energy, and financial resources they had available to use for other aspects of their lives. For instance, a participant described the impact of being unoriented regarding how to manage a common side effect of chemotherapy and how information from a health care provider helped them become oriented and avoid the problem in the future:

> *I had a problem after the IV infusion that I would feel like my throat had closed off and I could not breathe—very scary as I thought I was going to pass out. I could not find anything about this side effect. My oncologist was able to tell me some of his understanding of the side effect and how to avoid future problems. [Participant 21]*

Another participant, an informal caregiver, shared their experience working with a health care provider to manage their partner's seizure medications and how becoming better oriented to the limitations of the health care provider's scope of practice and the resources available improved their cancer experience:

> *[The specific health care provider] only prescribes and knows a couple of very common [seizure medications]...because the first medication...wasn't working, [they] added a benzodiazepine, and then just kept on upping it, and so [the patient] was having pretty detrimental side effects from the benzos entirely, and they also weren't working for seizure control...[it] took months [to find a neurologist]...the next time that we needed adjustments to medication...we just straight up, just went back [to the specific health care provider] and said, "We wanna see [the neurologist]."* [Participant 9]

Importantly, just as cancer challenges were identified as occurring concurrently throughout the cancer journey, the consequences of cancer challenges did not occur in isolation. Participants described being overwhelmed, experiencing intense emotions, and being essentially unable to function at times when they faced many challenges at once—especially if they were unoriented to several of the challenges they were facing. A participant, an informal caregiver, shared their experience following the diagnosis of their partner:

> *Yeah, honestly, I think at the time, I don't know if I was feeling much for emotion [I] was just totally overwhelmed. We went from a diagnosis of, "Yes, we believe this is lymphoma," [to] starting chemo because it was stage four [two weeks later]. So it was very fast and very overwhelming and...Yeah, I mean the dread, the fear, the unknown, it was really so challenging...The financial aspect was terrifying, what are we gonna do? My partner had no health insurance and no backup savings or anything like that, and so that was really challenging. And yeah, so feeling very helpless, very alone in trying to navigate things.* [Participant 24]

Textbox 1 provides a summary of the consequences described by participants as they faced cancer challenges from different states of relative orientation.

Textbox 1. Consequences of managing cancer challenges from different orientation states.

Unoriented

- Being unsure of how to act and increased chances of making a regrettable choice
- Not knowing what to expect
- Not being able to provide others with accurate information
- Increased fear, anxiety, stress, and pessimism
- Increased requirements of time, energy, and money to deal with challenge
- Less effective in participating in management of health issues

Oriented

- Awareness of right choice of action
- Knowing what to expect
- Able to help orient others
- Reassurance and hope
- More efficient use of personal resources, including for finding information
- More effective role in managing health issues

Information Sources

Obtaining the information needed to become oriented to a cancer challenge occurs in many ways. Participants described receiving information from multiple sources, including friends and family, television, and books or audiobooks. Personal experience was also an important source of information, particularly for addressing the key orientation question of *what can I expect?* A participant shared their experience with treatment and how they came to learn that their reaction to treatment was unique:

> *...so you know the treatment has not really affected me I see people come in and they are very [emaciated] and they have no hair and they are very sluggish...[I find] that half way [through treatment] I have a nap, at the first of the treatment and then I'm like ready to tear apart the place I am just so full of energy...it's been just the opposite for me I guess than it has been for a lot of people.* [Participant 13]

Of all the potential sources of information, participants consistently identified health care providers as an important source of information. With few exceptions, participants described that they trusted the information that health care professionals provided the most compared with other sources. However, the internet was also consistently described by participants as an equally essential source of information.

Personal and External Factors Influencing Information Source

Participants described several factors influencing their choice to use internet content for information as opposed to health care providers. These can be divided into the categories of personal and external factors. Preference for exploring content related to cancer challenges anonymously, respect for the health care providers' time, or being in an overwhelmed state at the time of the health care provider visit were some of the personal factors described. A participant described their experience obtaining information from their health care provider:

> *It wasn't Pollyanna because at that time [of the oncologist visit] you are absolutely on overload already...I wouldn't have found [more information] useful because you are already up to your shoulders and you just keeping your head above water to help you exist.* [Participant 3]

External factors such as the characteristics of the health care system (ie, clinic location and operational hours) as well as the attitudes and language used by health care providers were important in determining the participants' choice to use the internet as a potential source. Among these factors, accessibility of health care providers in terms of geographic location, appointment availability and duration, and general convenience were commonly identified as factors that influenced internet use:

> *Yah, basically I think as a patient, if I could like email my [health care team] I think there would be a lot less random googling, you know?* [Participant 15]

Importantly, internet content was not only accessed when participants were unable to use information from health care providers because of personal or external factors. Even when health care providers had given participants potentially useful information for helping them address a cancer challenge, the internet still played an important role for many in becoming oriented. A common practice described by the participants was to use the Google search engine to verify the information they received from health care providers, non–health care providers, and elsewhere on the internet. This practice involved looking for additional sources to compare whether the information was consistent. Participants described that, when the information was consistent between sources, they considered the information accurate and the sources credible. In contrast, inconsistent patterns raised questions of doubt. For instance, an informal caregiver described their experience with a health care provider whom they ultimately determined was not credible:

> *...I was looking for other sources of information to see if I could validate or discredit what [the oncologist] was telling [the patient]. And then when I found things online then I went to my [family physician] and asked more questions because that was someone that I trusted, and I didn't trust [the patient's oncologist] and it's a good thing we didn't.* [Participant 2]

Situations where internet searching was preferred to obtaining information from health care providers could be divided into 6 categories, summarized in Table 3.

Table 3. The 6 situations where participants preferred web-based information sources to health care providers.

Categories	Descriptions	Supporting participant quotes
Accessing routine health services	Looking up things to assist with accessing health care services (ie, directions, phone numbers, hours of operation, parking, and lodging)	"Sometimes it just basic as getting peoples' phone numbers, so, I might have commented already on that in the blog. But you cannot find palliative care's phone number online anywhere." [Participant 5]
Accessing additional services outside of what the health care team routinely provides	Looking up how to access health care services not provided through consultation or referral from a health care provider in the public health care system (eg, massage therapy, self-referral physiotherapy, naturopathy, and medical assistance in dying)	"Why else did I go to the internet? Sometimes just practical stuff like for a lot of the homecare needs, you know where do you find, you know, a wheelchair and how does that process work? Just the practical details of all of the associated equipment and supplies that were needed because that is not in one place, and it is hard to find." [Participant 5]
Cannot access health care providers	Addressing questions that arise in between or after appointments	"You know you leave the oncologist's office and it's like 'oh shit I should have asked [them] about this' and so I go home and do that kind of searching." [Participant 12]
Questions on which a health care provider likely will not be helpful or may be hurtful or where there is a preference for anonymity	Questions are out of the provider's scope or not relevant to the specific clinical interaction, or responses are not expected to be helpful.	"I had an issue with the eating...as a big [person], I am programmed not to eat stuff different things...I wouldn't talk about it anymore with the doctor for sure...they are going to be like 'what is wrong with you?' you know it is just going to make me feel bad and life is too short now." [Participant 10]
Validate or fact-check information from health care providers or other sources	These questions are related to confirming information received from health care providers, other individuals, or other sources—such as the internet.	"...so trying to sort out and match what was being told to us by physicians with what the literature was saying out there and seeing if it matched. So a little bit of triangulating, like trying to figure out you know what my parents were saying, what the doctors were saying when I was able to sit in on appointments with either of them and then what I was able to read on the internet." [Participant 5]
Questions not directly related to the care of the individual living with cancer or the care of a loved one	These questions might include those related to opportunities for public advocacy or improving cancer care for the future.	"I am also part of a support group here in Calgary for Lung Cancer patients, and there are triggers that could come out of that. Somebody will say something about 'oh there is this new brigatinib drug' which is like the next level up for me, 'oh maybe I should look that up.'" [Participant 14]

Internet Use Patterns

Internet Use Timing

In contrast to information accessed through health care providers, internet resources are generally accessible around the clock and without travel. Internet information gathering commonly occurs in between other activities that either cannot be rescheduled or are of higher priority. However, participants also described rearranging their schedules and setting aside time to facilitate web-based information gathering to address orientation questions that they considered to be high priority. As an example, an informal caregiver described transitioning from searching in between other tasks while "on break" (participant 5) at work to scheduling time to sit down to find specific information. This occurred when the individual was struggling to address the key orientation questions of *what to expect?* and *what are my options for dealing with this?* after having a disappointing experience with health care locally:

> *So that became a lot more specific in terms of setting aside half an hour to sit down and figure out "who am I going to call at this [out of country] clinic? What information do they need before I call? What do I need to have next to me?"* [Participant 9]

Sources and Strategies for Finding Web-Based Information

In general, participants identified that internet information gathering included using search engines, browsing familiar sites, scrolling through social media feeds and discussion boards, and accessing web-based patient portals. Participants described different sources as being useful for identifying different types of information. Social media sources were helpful for connecting with people who had experienced similar cancer journeys, especially in the setting of rare malignancy types, for peer support, including first-person accounts of what to expect and direction to helpful resources:

> *So Facebook I find to be helpful, Twitter, Instagram, TikTok. TikTok is the one when I go on and talk about what I live with and stuff and I blog as well and I do YouTube.* [Participant 19]

However, some participants felt that social media and discussion forum content were untrustworthy and avoided them. As a participant stated, "...not TikTok or whatever. I refuse to believe anything that's on there" (participant 14).

A few participants identified that recommendations for internet sites were provided directly by health care providers or indirectly through pamphlets and handouts provided through health care system facilities. However, Google searching was identified consistently by participants as the primary approach for finding web-based information. Participants described using the Google search engine to conduct searches using several keywords related to the cancer challenges they were facing and then browsing search results and selecting those that were assumed to be helpful based on previous experiences with the site, familiarity with the website domain name, or previous recommendations from health care providers.

Web-Based Cancer Content Design: Challenges Experienced With Web Page Content

Rabbit Holing

Participants described that, when they began searching for information about a cancer challenge, they would come across unfamiliar terms and concepts. They would then redirect their internet searches to further explore these new concepts. This process involved clicking on links discovered on websites or conducting new searches related to the unfamiliar terms. Inevitably, they would end up not addressing the information need related to the initial search. The process, described by the participants as "rabbit holing," was eventually terminated when the individual was interrupted by another task or became emotionally exhausted. Going down the rabbit hole was identified as a distracting and undesirable event. A participant described their experience as follows:

> *...you get in that rabbit hole, you click...And then you click, and you click, and you click, and you click, and I've done that before myself. And all of a sudden I'm like, "Oh, I actually came here to look up whatever, and an hour and a half later, I'm on some other random site that I've just gone down this rabbit hole."* [Participant 24]

Lack of End User–Oriented Design

On multiple occasions, participants described accessing web-based content intended to provide a comprehensive overview of a topic but finding the content presented in a way that was problematic. Common issues were too much content, nonintuitive organization and layout, or lack of details specific enough to help the individuals address the key orientation questions. A participant described their experience with a website from a prominent Canadian health center:

> *...you go looking for a certain type of information it does not bring you to what the next logical step is. It is like you have to go really deep into the [website] to find the one piece of the information you are looking for and it shouldn't be like that.* [Participant 9]

Participants also described that, without warning, they came across information that was distressing or that they were actively trying to avoid, such as information on prognosis. In addition, content irrelevant to the cancer journey of the individual was often presented on websites from well-regarded cancer centers, including targeted advertisements on web pages designed for people living with cancer. This was identified as a source of distraction that was upsetting to some participants.

Discussion

Principal Findings

The cancer journey presents patients and informal caregivers with many new and unfamiliar challenges. The challenges are numerous and varied and include those directly related to engaging with the health care system as patients and informal caregivers and those related to navigating roles as parents, spouses, friends, and employees outside the cancer context [25]. How well an individual is oriented to these challenges while navigating them has important consequences for the individual's well-being and overall cancer experience [10,16-18]. Although health care providers are an important source of information, the internet may be a preferred source depending on the challenge the individual is working to become oriented to, as well as the characteristics of the individual, their health care providers, and health care system.

The characteristics of web-based content affect how useful it is for helping individuals become oriented to the cancer challenges they face. The presence of distracting links, unfamiliar terms, and distressing content; the lack of intuitive design; and the absence of information addressing all or any of the key orientation questions are characteristics expected to make web-based content less useful. On the basis of the findings of this study, five recommendations for creating web-based content that supports orientation are as follows: (1) clearly identify the cancer challenge and population the content is addressing as well as the presence of any potentially distressing information; (2) provide versions of the content in different formats (eg, printer-friendly, audio, video, and alternative languages); (3) state who created the content, including the individuals, organizations, and processes involved; (4) place hyperlinks after the 3 key orientation questions have been systematically addressed; and (5) ensure that content is optimized for discovery by search engines, especially Google.

An infographic outlining these recommendations can be found in Multimedia Appendix 6. A detailed discussion of how these recommendations were informed by orientation theory is included in Multimedia Appendix 7 [46-54]. Multimedia Appendix 8 [55,56] includes sample web-based content developed through the course of the study with the participants, along with an explanation of how it reflects the principles of orientation theory and the 5 recommendations for web-based content design.

Building on Existing Theories

Orientation theory is a substantive middle-range theory addressing information-seeking behavior in the cancer context with implications for guiding web-based content design [1] that complements existing theoretical work, including that of Wilson [21] and Longo [38]. Both Wilson [21] and Longo [38] connect information-seeking behavior and information needs with important consequences. Wilson [21] describes that information seeking and information behavior in general are an important part of effectively dealing with stresses. Longo [38] links addressed information needs with themes of empowerment, satisfaction, increased participation in activities of daily living, and improved health outcomes. Similarly, the consequences of orientation (Textbox 1) include empowerment through the ability to participate actively in care (including self-management); enhanced emotional well-being; and improved participation in the roles and relationships existing outside of health care receipt, such as those with friends, family, and the workplace.

Both Wilson [21] and Longo [38] identify that individuals obtain information from a number of different sources, but neither of these theories detail why individuals living with cancer use the internet. Orientation theory adds to these works by both identifying the importance of information from health care providers and characterizing the internet as a uniquely important source of information in the cancer context that is preferred in some instances (Table 3). In addition, orientation theory highlights the important process that individuals engage in to validate information by cross-checking the information they receive from sources, including health care providers, with content on the internet. These findings underscore that internet-sourced content is not just complementary but is an essential source of information for many individuals living with cancer.

Clinical Implications

Orientation theory describes health care providers as both a source of information and an influencing factor on information source preferences. This places clinicians in a position to both provide information and influence which sources are accessed by individuals. Therefore, clinicians should consider providing direction to useful, credible websites and facilitating access to specialized staff such as nurse educators as part of routine practice. In addition, the provision of educational content that assists patients and informal caregivers in becoming better skilled at evaluating the quality of web-based content may be a welcome addition for many individuals experiencing cancer as this will likely go a long way toward helping them navigate the many challenges not brought to the attention of their care providers. In particular, web-based resources that individuals living with cancer may find helpful include *Health On the Net* [57], which provides a search engine restricted to certified high-quality web-based health information, and *DISCERN* [58], which provides a tool and instructions developed to help health care consumers evaluate the quality of written health information.

Finally, orientation theory states that individuals may have varying levels of comfort with health care providers and prefer to explore some topics anonymously or outside the clinic. As a result, clinicians should not assume that just because a patient or informal caregiver does not ask about a topic, they do not have unanswered questions about it. Orientation theory suggests that clinicians should consider voluntarily providing information, including written material or direction to web content, that can be reviewed outside the clinical setting. This is especially true for cancer challenge topics of a sensitive nature that may have a major impact on both the patient and informal caregiver, such as end of life [59] and the impact of cancer and cancer treatment on sexuality [60].

Research Implications and Future Directions

Identifying that orientation has multiple consequences and involves finding answers to multiple questions raises concerns about appropriate study measures for evaluating the effectiveness of informational interventions. A scoping review examining existing validated information needs assessment tools developed in the cancer context will hopefully provide some insight into which questionnaires best reflect the concepts outlined by orientation theory [61]. However, additional work is needed to explore how the identified consequences of orientation are reflected in existing instruments.

On a larger scale, how to address information needs in a way that results in a meaningful improvement in the cancer experience remains an important question. This study provides an important theoretical starting point [33] by describing the concept of "cancer challenges" and the process and consequences of orientation. However, it does not attempt to provide an exhaustive list of the cancer challenges that an individual is likely to face in their cancer journey. This study identified that cancer challenges occur concurrently and that they may be able to be grouped by their stereotypical temporal relationships. Therefore, it is likely that the most impactful interventions will be designed to support orientation to multiple cancer challenges at once. To accomplish this, research is needed to systematically map out the cancer challenges that individuals face in their journey, including when they are likely to arise, to inform subsequent intervention development.

Finally, an important consideration relevant to both coping with cancer and information-seeking behavior is the distinction between high and low monitors (ie, blunters) [62]. The literature supports that individuals can be dichotomized into 1 of these 2 coping styles, with each having important implications for how an individual navigates health concerns. High monitors have been characterized by being more likely to seek out information about their illness, whereas low monitors typically avoid seeking information [62]. There is some evidence suggesting that these coping styles may be, at least in part, situational [63], with individuals exhibiting blunting behavior in response to some stressors and high monitoring behavior in response to others. Given the considerable number of cancer challenges that the participants in this study identified, it is certainly possible that there are specific challenges that an individual may preferentially seek out information for at any given time while ignoring others. However, this was not explored in any detail in this study. Exploring the relationship between cancer challenges and coping styles in future research is important as it may have implications for both evolving orientation theory and informing how to best develop and deliver informational interventions.

Limitations

Glaser and Strauss [35] identify that theory produced using the classic grounded theory approach is robust and valid as it emerges from data obtained directly from the field of interest. However, there are a number of important considerations in terms of interpreting and applying the findings of this study. First, the data used in this study were collected from participants who had internet access in a geographic region where health care is administered through 1 body (ie, Alberta Health Services). In addition, strategies guiding participant selection for data collection were driven primarily by age, role as either patient or informal caregiver, cancer type, and curative versus noncurative intent. The role of factors such as ethnicity, sex, and gender was not explored. Given the similarities between orientation theory and other preexisting theoretical work [20,21,38,40], it is likely that the identified concepts and their relationships are relevant across a wide range of populations. However, the concepts described in this paper, such as the consequences of orientation, likely manifest differently in different contexts. Therefore, some caution should be exercised when applying the concepts of orientation theory to develop content or guide other interventions as the concepts may not be universally applicable. For this reason, including individuals from the target audience in content or intervention development is likely key to ensuring that the content is both applicable and appropriate [64].

Finally, internet use in orientation theory was primarily focused on web page content. This was because web pages discovered through Google searches were identified as the primary source of web-based content for the participants, with other sources playing a lesser and more inconsistent role. As a result, these other sources of internet content were not explored after the conclusion of open coding [35]. Therefore, although it is certainly possible that the insights gained in this study are relevant across other media, such as social media, patient portals, discussion boards, and paper-based content, content creators should exercise caution when applying them outside web page design.

Conclusions

Through the lens of orientation theory, the cancer journey can be viewed as one that involves navigating many unfamiliar and often unwanted challenges, often simultaneously. How informed individuals are of why each challenge is occurring, what to expect, and the options for managing it has important implications for the individual's well-being and cancer experience [5,10,18,65]. The high prevalence of unmet information needs of both patients and informal caregivers suggests that there is considerable opportunity for transforming the cancer experience by improving information provision [8-10]. The internet has the potential to be a source of low-cost, high-quality, and easily accessible information capable of improving the journey of many individuals living with cancer. However, to create robust and effective web-based informational interventions, further work is needed to fully understand the cancer journey, the many challenges faced, and how to assess the consequences of orientation. In the meantime, cancer clinicians and creators of web-based cancer content must recognize the power of information to transform the cancer journey and their responsibility to share information in a way that does no harm.

Acknowledgments

The authors wish to thank the research participants for the time, energy, and commitment they gifted to this project. This project was supported by scholarship funding awarded to MT from the University of Calgary Department of Graduate Studies, Faculty of Nursing, and from the Dobson Family. This project was completed as part of doctoral work at the University of Calgary, Faculty of Nursing, by MT. Financial support for publication fees was provided by the CancerCare Manitoba Foundation.

Data Availability

The data sets generated during this study are not publicly available as they contain sensitive information that may make it possible to identify study participants despite careful steps being taken to remove identifying details. Data may be made available upon reasonable request from the corresponding author with ethics board consultation.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Intake survey.
[DOCX File , 23 KB - cancer_v9i1e41740_app1.docx]

Multimedia Appendix 2
Initial interview guide.
[DOCX File , 15 KB - cancer_v9i1e41740_app2.docx]

Multimedia Appendix 3
Rigor statement.
[DOCX File , 17 KB - cancer_v9i1e41740_app3.docx]

Multimedia Appendix 4
Completed Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist.
[PDF File (Adobe PDF File), 481 KB - cancer_v9i1e41740_app4.pdf]

Multimedia Appendix 5
Cancer challenge example list.
[DOCX File , 14 KB - cancer_v9i1e41740_app5.docx]

Multimedia Appendix 6
Infographic for better web-based content.
[PNG File , 796 KB - cancer_v9i1e41740_app6.png]

Multimedia Appendix 7
Theory-based discussion of the 5 recommendations for better web-based content.
[DOCX File , 39 KB - cancer_v9i1e41740_app7.docx]

Multimedia Appendix 8
Theory-based explanation of generated sample content.
[DOCX File , 439 KB - cancer_v9i1e41740_app8.docx]

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Abbreviations

COREQ: Consolidated Criteria for Reporting Qualitative Research

Edited by A Mavragani; submitted 06.08.22; peer-reviewed by M van Eenbergen, K Scott, W Demark-Wahnefried; comments to author 03.01.23; revised version received 21.01.23; accepted 15.03.23; published 17.05.23.

Please cite as:
Thiessen M, Raffin Bouchal S, Tang PA, Sinclair S
Navigating the Cancer Journey Using Web-Based Information: Grounded Theory Emerging From the Lived Experience of Cancer Patients and Informal Caregivers With Implications for Web-Based Content Design
JMIR Cancer 2023;9:e41740
URL: https://cancer.jmir.org/2023/1/e41740
doi:10.2196/41740
PMID:37195760

Original Paper

Association of the Extent of Internet Use by Patients With Cancer With Social Support Among Patients and Change in Patient-Reported Treatment Outcomes During Inpatient Rehabilitation: Cross-sectional and Longitudinal Study

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Abstract

Background: Given the increasing number of cancer survivors and their rising survival rates, rehabilitation plays an increasingly important role. Social support among patients is an essential element of inpatient and day care rehabilitation. The internet can empower patients with cancer to become more active health care consumers and facilitate information and supportive care needs. By contrast, therapists suspect that high internet use during rehabilitation may severely limit social interactions between patients, thus interfering with the patients' rehabilitation program and jeopardizing treatment success.

Objective: We hypothesized that the extent of internet use would be negatively related to social support among patients with cancer during their clinical stay as well as fewer improvements in patient-reported treatment outcomes from the first to the last day of their clinical stay.

Methods: Patients with cancer participated during their inpatient rehabilitation. Cross-sectional data, such as the extent of participants' internet use and perceived social support among patients, were collected during the last week of their clinic stay. The treatment outcomes, that is, participants' levels of distress, fatigue, and pain, were collected on the first and last day of the clinic stay. We used multiple linear regression analysis to study the association between the extent of internet use and social support among patients with cancer. We used linear mixed model analyses to study the association between the extent of internet use by patients with cancer and the change in patient-reported treatment outcomes.

Results: Of the 323 participants, 279 (86.4%) participants reported that they used the internet. The extent of the internet use (t_{315}=0.78; P=.43) was not significantly associated with the perceived social support among the participants during their clinical stay. In addition, the extent of participants' internet use during their clinical stay was not associated with changes in participants' levels of distress ($F_{1,299}$=0.12; P=.73), fatigue ($F_{1,299}$=0.19; P=.67), and pain ($F_{1,303}$=0.92; P=.34) from the first to the last day of their clinical stay.

Conclusions: The extent of internet use does not seem to be negatively associated with the perceived social support among patients with cancer or with the change in patients' levels of distress, fatigue, or pain from the first to the last day of their clinical stay.

(JMIR Cancer 2023;9:e39246) doi:10.2196/39246

KEYWORDS

internet; internet use; social support; perceived social support; inpatients; patient-reported outcome measures; cancer; rehabilitation; distress; fatigue; pain

Introduction

Background

Cancer survivors can experience long-term physical and psychological consequences of cancer and its treatment [1-3]. Fatigue, pain, and distress are among the most frequently reported symptoms during and after primary cancer treatment [4-9]. Given the increasing number of cancer survivors and rising survival rates resulting from progress in early detection, treatment, and cancer management [10,11], rehabilitation is playing an increasingly important role.

Different rehabilitation approaches are being used for patients with cancer worldwide. On the basis of the biopsychosocial model of the World Health Organization, these programs are based on a similar multidisciplinary understanding of cancer rehabilitation [12-14]. In Germany, after primary treatment, every patient with cancer is legally entitled to participate in a 3-week combined multidisciplinary treatment program consisting of physical therapy, patient education, relaxation training, functional training, psycho-oncological treatment, nutrition counseling, and occupational counseling, depending on the patient’s functioning and needs as assessed at the beginning of the rehabilitation [12,15]. A special feature is that in Germany, cancer rehabilitation is mainly performed in inpatient clinics [12]. Uncontrolled before-and-after studies showed that patients undergoing cancer rehabilitation can improve their somatic status, psychosocial status, and quality of life and reduce their anxiety, depression, and distress from the beginning to the end of inpatient rehabilitation [16-18].

The 2 essential elements of inpatient and day care rehabilitation are social support from other patients in cancer rehabilitation and physical activity [12]. Social support has been recognized as an important factor in overall well-being [19,20] and has been positively associated with both improvement in cancer-related stress [21] and posttraumatic growth in patients with cancer [22]. In inpatient and day care, patients in cancer rehabilitation receive social support from other patients undergoing rehabilitation with a cancer diagnosis (peer support) during therapist-guided group treatment sessions and unguided peer support during leisure-time activities. The three main attributes of peer support are (1) emotional support by discussing personal difficulties, (2) informational support by providing knowledge relevant to problem-solving, and (3) appraisal support such as encouragement to persist in problem-solving and reassurance that efforts will lead to positive outcomes [23]. Previous research found gender and age differences in seeking and providing social support. Women seem to provide more emotional support to both men and women, and they seem to receive more help in return [24]. Older people (aged ≥60) are less likely to explicitly ask for emotional support compared with younger people [25]. Systematic reviews that explored the benefits of one-on-one and group peer support interventions for patients with cancer, conducted analog and on the web, showed mixed results. Peer support interventions increased perceived distress, quality of life, and treatment-related compliance of patients with breast cancer [26], as well as the emotional health, quality of life, coping and psychosocial functioning [27,28], and empowerment of patients with cancer [29]. However, unmoderated and unstructured group peer support interventions conducted on the web without peer training had no effect or even adverse effects on quality of life, distress, and depression [26,30]. In the absence of moderation or group structure, expressions of anger and fear increased, as did discussions about death and dying [30,31]. Furthermore, initial cross-sectional studies indicated that high informational support may be associated with lower cancer-related fatigue [32].

eHealth applications and the internet can empower patients with cancer to become more active health care consumers and facilitate information and supportive care needs [33-36]. First, patients with cancer can search the internet for health- or cancer-related information or solicit medical advice from their physicians via email. Intensive searches revealed that there are no publications on the prevalence of cancer-related internet searches during inpatient or day care rehabilitation. However, the prevalence of patients with cancer in a Dutch sample, 2 American samples, and a Swedish sample who used the internet ranged from 60.2% to 79.8% [34,37-39]. In advanced economies, 87% of the population uses the internet at least occasionally [40]. The internet can help patients with cancer fulfill their needs for information regarding their diagnosis, prognosis, or treatment options [37,41,42]. Patients with cancer who search the internet for cancer-related information are younger and more highly educated than those who do not search the internet [37-39]. Second, patients with cancer can use web-based communication and web-based communities for social support. Patients with cancer can access the internet anytime and from almost anywhere [43], anonymously if desired, and even patients with rare cancer types can find other patients with the same cancer type to share experiences [44]. Web-based peer support programs used in a study setting can have a positive influence on the psychosocial well-being of patients with cancer, including quality of life and distress [26,45]. Third, eHealth programs are used as independent treatment measures or to improve or assist health care services in various phases of cancer treatment [46-49]. eHealth cancer rehabilitation and aftercare programs address logistically challenged populations and commonly use elements such as education, self-monitoring, self-management training, personalized exercise programs, communication with health care providers, and communication with fellow patients [48,49].

The starting point of this study was the observations by health care professionals of the cooperating oncological rehabilitation clinic that a high level of internet use between and after rehabilitation sessions reduced social interactions between patients during their clinic stay and high levels of internet use interfered with the patients’ rehabilitation program. This observation was somewhat related to the social displacement hypothesis. The social displacement hypothesis suggests that despite increased communication opportunities, internet use is largely a nonsocial activity that competes with face-to-face interaction and is, therefore, associated with lower social involvement and psychological well-being, as indicated by the initial results from longitudinal studies [50,51]. However, the results of subsequent studies have contradicted these claims [52-54], and a meta-analysis found only a small cross-sectional association between internet use and well-being [55]. Displacement theory has also been studied more recently with social media use instead of general internet use. The results of a study using a national probability sample could not support the social displacement hypothesis for social media use [56]. Instead, study results suggest that social media use displaces time spent using other media [57]. Results of a meta-analysis of cross-sectional studies [58] and results of longitudinal studies [59,60] indicate that the association between internet or social media use and well-being varies by the type of internet and social media use. Positive associations were found for media use directed at a specific person through which emotional information can be conveyed, such as phone calls or texting with emojis [58-60]. Furthermore, while the use of social media in general had a small negative association with well-being, interactive aspects of social media use were positively correlated with well-being [58-60]. The associations found might also be linked to the individuals' personality or social skills. For extraverts, internet use seems to be associated with an increase in social engagement and self-esteem and a decrease in loneliness [52]. Individuals with high levels of neuroticism who use the internet frequently to seek information seem to perceive lower levels of support [53]. However, the causal direction of these associations remains unclear [53,57].

Objective

Health care professionals at the cooperating oncological rehabilitation clinic observed that a high level of internet use between and after rehabilitation sessions reduced social interactions between patients during their clinic stay and high levels of internet use interfered with the patients' rehabilitation program. These observations are inconsistent with previous study results on the associations between the extent of internet use, social support, and changes in well-being. However, compared with participants of previous studies on the associations between internet or social media use, social support, and well-being, patients with cancer in inpatient rehabilitation are in a different setting. During their 3 weeks of inpatient treatment, they have no or limited face-to-face contact with their friends and family, as rehabilitation clinics are often located in rural areas distant from the patients' homes, making personal visits difficult. Although previous research has suggested that internet use does not affect social interactions, primarily with friends and family [52,54], we believe that it might be possible for internet use to affect social interactions with relative strangers in the rehabilitation setting. In addition, the psychological and mental health of patients with cancer at the beginning of rehabilitation is significantly worse than that of the general population [17], which makes comparison difficult.

We formulated the following explorative research questions: (1) is the extent of internet use negatively associated with the perceived social support among patients with cancer during their clinical stay? (2) is the extent of internet use by patients with cancer during their clinical stay negatively associated with changes in distress, fatigue, and pain scores from the beginning to the end of inpatient cancer rehabilitation, with distress being the primary outcome? In addition, we aimed to describe the extent and purpose of internet use by patients with cancer during their clinical stay and at home.

Methods

Study Design

In the cross-sectional part of the study, we obtained data using a paper-pen questionnaire to gain insight into the extent and purpose of rehabilitant internet use, their preferences for future use of eHealth or web-based programs, their perceived social support from other patients, and their physical activity during the clinic stay. For the longitudinal part of the study, medical data and 3 patient-reported outcome measures (PROMs) were collected on the first day and the last day of the clinic stay.

This study followed the recommendations of the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement. The STROBE statement contains 18 items that are common to cohort, cross-sectional, and case-control studies. Four checklist items (items 6, 12, 14, and 15) have specific variations according to the study design [61] (Multimedia Appendix 1).

The protocol for this study is freely available at the Open Science Framework [62] and was published before the recruitment of the first participant.

Setting, Recruitment, and Participants

The participants were recruited during the third week of their 3-week inpatient cancer rehabilitation stay at a German rehabilitation clinic. Potential participants were approached during the patient consultation. Patients in rehabilitation were recruited between September, 2018, and February, 2020. Recruitment occurred in random time samples. During the random time samples, all eligible patients were asked to participate. Patients were included if they had been diagnosed with any type of cancer, were aged 18 years, and had sufficient oral and written proficiency in German language. Participants were informed that their medical data would be included in the evaluation of the study. Medical data were routinely collected on the first day and last day of the clinic stay. Afterward, the medical director distributed the pen-and-paper questionnaire to the participants, which the participants completed and handed to their treating physician the next day.

Measures and Data Source

Cross-sectional Questionnaire

Sociodemographic and Medical Characteristics

The questionnaire during the last week of the clinic stay included multiple choice items designed to describe the sociodemographic (age, gender, years of schooling, professional situation, and current living situation) and medical characteristics (type of cancer) of the participants.

The Extent and Purpose of Patients' Internet Use

We used an adapted version of the questionnaire used by Drewes et al [63] to measure the internet use of patients during their clinic stay and at home as well as their interest in future interactions with new media. First, the participants reported whether they used the internet. Participants who indicated not using the internet were instructed to skip all questions about the extent and purpose of internet use.

The frequency of internet use at home and during the clinic stay was self-reported by responses on a 4-point response scale from "never" to "daily." Two items about the daily time spent on the web during the clinic stay and at home were answered on a 5-point response scale from "none" to "more than 120 minutes." Furthermore, participants were asked which device they used to access the internet at home and during their clinic stay. To indicate the most common web-based activities during the clinic stay and at home, participants could select one or more of the 10 options of predefined activities and could enter an activity themselves.

Preferences for Future Use of eHealth or Web-Based Programs

Participants' interests in future interactions with new media or web-based services in health care were determined by rating 6 statements on a 4-point Likert scale from "I strongly disagree" to "I strongly agree."

Patients' Views on Internet Use During Clinic Stay

Participants rated the following statements on a 4-point Likert scale from "I strongly disagree" to "I strongly agree": "The availability of Wireless LAN (WLAN) in the rehabilitation clinic is very important to me," "I would like to receive online support during treatment," "I feel distracted from rehabilitation by using the internet during rehabilitation," "I can fulfill my information needs by using the internet during my rehabilitation stay," and "I was absent from the clinic's leisure-time activities because I spent the time on the internet."

Perceived Social Support Between Patients During Clinic Stay

To measure the perceived social support between patients during the clinic stay, the questionnaire on social support between patients (F-SozU-P) was used [64]. The F-SozU-P is an adaptation of the German self-report questionnaire for the assessment of social support (F-SozU) [65], which is the long version of the brief form for assessing social support (F-SozU K-6) [64]. Both the order and the sentence structure of the F-SozU items were retained in the F-SozU-P. However, words such as "people," "relatives," and "family" in the F-SozU were replaced by "fellow patients" or "patients" in the F-SozU-P. All 54 items were scored on a 5-point Likert scale ranging from 1="not true" to 5="exactly true." In the validation study, the global scale wahrgenommene soziale Unterstutzung–Patienten (perceived social support-patients; WasU-P) had high values for internal consistency (α=.93) [64].

Physical Activity During Clinic Stay

Physical activity during the clinic stay was measured using the German version of the Godin-Shephard Leisure-Time Physical Activity Questionnaire (GSLTPAQ) [66]. The GSLTPAQ is commonly used for classification purposes in oncology [67]. Participants reported how often and how long (in minutes) they engaged in low-, moderate-, and high-intensity physical activity in the past week. The frequency at each intensity was multiplied by 3, 5, and 9 metabolic equivalents and then multiplied by the duration divided by 60 and summed. Scores derived from the GSLTPAQ represent the time of physical activity during the clinic stay in the form of metabolic equivalents hours within the last week [67].

Longitudinal Questionnaire

The longitudinal questionnaire included 3 validated PROMs. First, the German version of the Distress Thermometer [68] consists of a single-item scale ranging from 0=no distress to 10=extreme distress, indicating how much stress the participant experienced in the last week, including the day of assessment. A score of 5 is internationally recommended as an indicator that a patient is distressed and may need support [68]. Second, the German version of the numeric rating scale (NRS) for pain [69] is an 11-point numeric scale (NRS 11) ranging from 0=no pain to 10=worst pain imaginable [69]. This instrument is commonly used to measure pain in patients with cancer [7]. Third, participants completed the German version of the Brief Fatigue Inventory [70]. The Brief Fatigue Inventory is used for the specific assessment of fatigue in patients with oncological diseases. The questionnaire contains 10 items. Three items ask patients to rate the severity of their fatigue on average, at its worst, and right now, with 0=no fatigue and 10=fatigue as bad as you can imagine. In addition, 6 items measure the extent to which patients' fatigue interferes with general activity, mood, walking, work, relationships with others, and enjoyment of life. These items are rated on a scale of 0=does not interfere to 10=completely interferes [70]. A score between 3 and 4 points indicates medium-severity fatigue in patients with tumors.

Pilot Testing

We pilot-tested the complete set of items in March 2018 in 6 patients undergoing rehabilitation. The pilot participants were recruited from the same German rehabilitation clinic as the respondents in the following study. The inclusion criteria for participation in the pilot test were identical to those of the main study. Participants were instructed to think aloud while completing the questionnaires to identify how they interpreted items, whether instructions were easy to understand, whether problems occurred, and whether they understood the items in the way they were intended [71]. The pilot study showed satisfactory results and revealed that participants generally understood the set of items well. The completion of the questionnaire took between 25 and 50 minutes.

Data Analysis

We used SPSS Statistics (version 25; IBM SPSS Inc) for the statistical analyses. The participants' sociodemographic and medical characteristics, the extent and purpose of rehabilitant internet use, and their preferences for future use of eHealth or web-based programs were summarized descriptively (ie, means, SDs, frequencies, and percentages).

For further analysis, we excluded cases with >30% of missing F-SozU-P items [72]. We used multiple linear regression analysis to determine the association between the extent of participants' internet use (independent variable) and perceived social support among patients during their clinic stay (dependent variable; research question 1). To identify whether participants who used the internet for interactive activities, such as “communication with relatives” and “writing emails,” reported more social support among them than patients who did not, a dummy-coded variable was included as an independent variable. To control for potential confounding variables, we included physical activity during the clinical stay (GSLTPAQ score), age, education (>10 years of school education vs ≤10 years), and sex as additional independent variables. Categorical variables were dummy coded. The variable extent of internet use was the product of 2 factors: the time spent on the web and the frequency of internet use during the clinic stay. To identify the extent of multicollinearity, the variance inflation factor (VIF) of all independent variables were reported. If the VIF is >10, there is reason for concern [73]. Missing values of the F-SozU-P and the independent variables, namely, the extent of internet use during rehabilitation, GSLTPAQ, age, and education were imputed using the expectation-maximization algorithm [74].

We used 3 linear mixed models with random intercepts to determine the association between the extent of participants’ internet use during inpatient rehabilitation (independent variable) and the change in distress as the primary outcome as well as the secondary outcomes, namely, fatigue and pain (dependent variables) from the beginning to the end of inpatient rehabilitation (research question 2). The dependent variables in each model were calculated as the difference between the outcomes on the first day and the last day of the clinic stay. To answer the research question, we tested the main effects of the extent of internet use (fixed factor). Furthermore, we included the fixed factors of social support among patients and the interaction between internet use and social support to test whether social support moderated the association between the extent of participants’ internet use and changes in the 3 PROMs. The variables of social support among patients and internet use were mean centered to avoid multicollinearity problems [75,76]. To identify the extent of multicollinearity, the VIFs of all fixed factors were reported using the R package “performance” (version 0.10.2; R Foundation for Statistical Computing) [77]. If the VIF is >10, there is reason for concern [73]. To control for differences in the baseline values and regression to the mean, baseline PROMs values were included as fixed factors [78,79]. The overall fit of the models was evaluated by the −2 log likelihood. We used the restricted maximum likelihood method to estimate the parameters in all 3 models [80].

Furthermore, we conducted a sensitivity analysis using the described 3 linear models before including the interaction term.

For the planned multiple regression analyses, we conducted an a priori power calculation by using G*Power [81]. On the basis of this analysis, we concluded that study data from 352 patients would be needed to sufficiently demonstrate a correlation with a small to medium effect size of R=0.20 (corresponding to an f-square=0.0417), with 80% power and a level of significance set at α=.05 in a multiple linear regression analysis with 7 predictor variables.

Ethics Approval

The study was conducted in accordance with the Code of Ethics of the Declaration of Helsinki and was surveyed by the Ethics Committee of the local Medical Association (Schleswig-Holstein, Germany; study ID 042/18 II). Participants had to sign an informed consent form before they could participate in the study. The form included information about the study goal, potential risks and benefits of study participation, the voluntary nature of participation, and the type and duration of data storage.

Results

Cross-sectional Results

Participants Sociodemographic and Medical Characteristics

A total of 900 patients undergoing rehabilitation participated in this study; of them, 323 patients were asked to participate, which resulted in a response rate of 35.9% (323/900). The participants’ ages ranged from 29 to 88 years (Table 1). More female (172/323, 53.3%) than male patients participated in the study. Approximately one-third of the participants (111/323, 34.4%) had >10 years of school education. Almost half of the participants (146/323, 48.3%) were retired. Furthermore, 69.9% (226/323) of the participants were married or lived in a committed relationship. Colon (69/323, 17.5%), breast (66/323, 16.7%), and prostate (49/323, 12.4%) cancers were the most common types of cancer among the participants.

Table 1. Medical and sociodemographic characteristics of participants (N=323).

Participant characteristics	Values
Age (years), mean (SD, range)	62.3 (11.1, 29-88)
Sex, n (%)	
Female	172 (53.3)
Male	150 (46.4)
Missing values	1 (0.3)
Highest educational achievement, n (%)	
13 years of school education	111 (34.4)
10 years of school education	110 (34.1)
9 years of school education	93 (28.8)
No degree	2 (0.6)
Other	3 (0.9)
Missing values	4 (1.2)
Professional situation, n (%)[a]	
Retired	144 (44.6)
Working full time	97 (30)
Working part time	48 (14.7)
Unemployed	11 (3.4)
Housewife or househusband	18 (5.6)
Other	20 (6.2)
Missing values	0 (0)
Current living situation, n (%)	
Living with partner or living with partner and children	222 (68.7)
Living alone	83 (25.7)
Living alone with kids	11 (3.4)
Other	3 (0.9)
Missing values	4 (1.2)
Cancer type, n (%)[a]	
Colon	68 (21.1)
Breast	65 (20.1)
Prostate	49 (15.2)
Lung	27 (8.4)
Non-Hodgkin	24 (7.4)
Kidney	18 (5.6)
Mouth, throat, and esophagus	15 (4.6)
Pancreatic	14 (4.3)
Other	83 (25.7)
Missing values	0 (0)

[a] Multiple selection; percentages of respondents.

The Extent and Purpose of Patients' Use of the Internet During Their Clinic Stay and at Home

Of the 323 participants, 279 (86.4%) reported using the internet. These participants are referred to as "internet users" in the following section. During their clinical stay, 70.9% (198/279) of the internet users used the internet daily. At home, 84.9% (237/279) of the internet users used the internet daily (Table 2). Overall, 30 of the 279 (10.8%) internet users never used the internet during their clinic stay. During their clinic stay, 27 of the 279 (9.8%) internet users used the internet for more than 1 hour per day, compared with 84 of the 277 (30.3%) participants at home. Smartphones were the most frequently used device for internet access during the clinic stay (219/279, 78.4%) and at home (215/279, 77.1%). During the clinic stay and at home, social media use (192/279, 68.9%; 208/279, 74.6%) and emailing (143/279, 51.3%; 228/279, 81.7%) were among the 3 most frequently reported web-based activities.

Table 2. The extent and purpose of patients' use of the internet during their clinical stay and at home (N=279).

Participant characteristics	Setting, n (%)	
	During clinic stay	At home
Frequency of internet use		
Daily	198 (71)	237 (84.9)
>Once a week	16 (5.7)	22 (7.9)
>Once a month	0 (0)	5 (1.8)
Rarely	23 (8.2)	11 (3.9)
Never	30 (10.8)	2 (0.7)
Missing values	12 (4.3)	2 (0.7)
Daily time spent on the web in minutes		
>120	7 (2.5)	28 (10)
60-120	20 (7.2)	56 (20)
30-60	84 (30.1)	118 (36.5)
0-30	119 (44.4)	71 (42.3)
None	38 (13.6)	3 (1.1)
Missing values	11 (3.9)	3 (1.1)
Devices used to access the internet[a]		
Smartphone	219 (78.5)	215 (77.1)
Tablet	69 (24.7)	118 (42.2)
Laptop	62 (22.2)	152 (54.5)
PC	4 (1.4)	130 (46.6)
None	26 (9.3)	4 (1.4)
Other	7 (1.4)	5 (1.8)
Missing values	4 (1.4)	1 (0.3)
Web-based activities[a]		
Using social media	192 (68.9)	208 (74.6)
Communication with relatives	148 (53)	154 (55.2)
Writing emails	143 (51.3)	228 (81.7)
Other (news, web-based games, shopping on eBay or Amazon, erotic, etc)	106 (38)	205 (73.5)
Searching for health-related information	68 (24)	173 (62)
Reading	54 (19.4)	92 (33)
Working	14 (5.0)	74 (26.5)
Learning or studying	12 (4.3)	88 (31.5)
Looking for treatment support	11 (3.9)	22 (7.9)
Participation in web-based courses for private education and qualification	3 (1.1)	22 (7.9)
Other	12 (4.3)	25 (9)
Missing values	7 (2.5)	2 (0.7)

[a] Multiple selection; percentages of respondents.

Internet Users' Views on Internet Use During the Clinic Stay and Patients' Interest in Future Interaction With New Media or Web-Based Service in Health Care

About 9.3% (26/279) of internet users did feel distracted from rehabilitation by using the internet during their clinical stay, and 1.8% (5/279) reported having missed their clinic's leisure-time activities because they spent time on the internet (Multimedia Appendix 2). The results concerning patients' interest in future interactions with new media or web-based services in health care are displayed in Multimedia Appendix 3.

Association Between the Extent of Internet Use and Social Support Among Rehabilitants During Rehabilitation

A total of 2.2% (7/323) of cases were excluded from the multiple regression analysis because >30% of F-SozU-P items were missing. The mean perceived social support between patients during their clinic stay was 3.2 (SD 0.7).

The extent of internet use (t_{315}=0.78; *P*=.43) was not significantly negatively associated with the perceived social support among the participants during their clinic stays (Table 3). Participants who were younger (t_{315}=−6.01; *P*<.001) and female participants (t_{315}=2.02; *P*=.04) perceived significantly more social support from other patients with cancer during their clinic stay than older and male participants, controlling for all other predictors in the model. Seventeen percent (R^2=.17) of the variance in perceived social support among patients during rehabilitation was explained by the model. Participants who used the internet for communicative activities did not perceive more social support from other patients with cancer during their clinic stay (t_{315}=−0.03; *P*=.98) than the participants who did not use it for communicative activities. The VIFs of the predictors ranged from 1.04 to 1.41.

Table 3. Parameters of the multiple regression analysis with perceived social support as the dependent variable (n=316).

Variables	b (SE)	2-tailed *t* test	*P* value	95% CI	VIF[a]
Intercept	4.31 (0.30)	14.17	<.001	3.71 to 4.90	—[b]
Extent of internet use during clinic stay	0.01 (0.01)	0.72	.43	−0.01 to 0.03	1.73
Age	−0.02 (0.00)	−5.95	<.001	−0.03 to −0.02	1.46
Sex (male vs female)	0.14 (0.07)	2.00	.04	0.00 to 0.28	1.09
GSLTPAQ[c]	0.00 (0.00)	0.81	.42	−0.00 to 0.01	1.05
Education (>10 years vs ≤10 years of school education)	−0.04 (0.07)	−0.57	.58	−0.18 to 0.10	1.05
Interactive internet use (users vs nonusers)	−0.00 (0.08)	−0.03	.98	−0.16 to 0.16	1.41

[a] VIF: variance inflation factor.

[b] Not available.

[c] GSLTPAQ: Godin-Shephard Leisure-Time Physical Activity Questionnaire.

Longitudinal Results

Descriptive Overview for Both Measurement Points

Participants' mean level of distress decreased from 5.2 (SD 2.4) to 2.7 (SD 2.1) from the beginning to the end of rehabilitation (Table 4). The mean fatigue decreased from 3.2 (SD 1.9) to 2.1 (SD 1.6) from the beginning to the end of rehabilitation. The mean pain decreased from 2.4 (SD 2.8) to 1.2 (SD 1.9) from the beginning to the end of rehabilitation.

Table 4. Descriptive data for outcomes for both measurement points (N=323).

Questionnaire	First measurement point		Second measurement point	
	Value, n (%)	Value, mean (SD)	Value, n (%)	Value, mean (SD)
DT[a]	315 (97.5)	5.2 (2.4)	311 (96.3)	2.7 (2.1)
BFI[b]	315 (97.5)	3.2 (1.9)	311 (96.3)	2.1 (1.6)
NRS[c] for pain	316 (97.8)	2.4 (2.8)	315 (97.5)	1.2 (1.9)

[a] DT: Distress Thermometer.

[b] BFI: Brief Fatigue Inventory.

[c] NRS: numeric rating scale.

Association Between the Extent of Internet Use and Changes in Distress From the First to the Last Day of the Clinic Stay (Primary Outcome)

The extent of participants' internet use during their clinic stay ($F_{1,299}$=0.12; *P*=.73) and the perceived social support among patients ($F_{1,299}$=2.69; *P*=.10) were not significantly associated with changes in participants' distress levels (Multimedia Appendix 4). The interaction between the extent of participants' internet use during their clinic stay and perceived social support among patients ($F_{1,299}$=0.31; *P*=.58) was not significantly associated with changes in the participants' distress levels. Higher baseline distress levels were significantly ($F_{1,299}$=168.87; *P*≤.001) associated with greater changes in the participants' distress levels. The VIFs of the fixed factors ranged from 1.01 to 1.07.

Association Between the Extent of Internet Use and Changes in Fatigue and in Pain From the First to the Last Day of the Clinic Stay (Secondary Outcomes)

The extent of participants' internet use during their clinic stay ($F_{1,299}$=0.19; *P*=.67) and the perceived social support among patients ($F_{1,299}$=1.68; *P*=.20) were not significantly associated with changes in participants' fatigue levels (Multimedia Appendix 5). The interaction between the extent of participants' internet use during their clinic stay and perceived social support among patients ($F_{1,299}$=0.12; *P*=.73) was not significantly associated with changes in the participants' fatigue levels. Higher baseline fatigue levels were significantly ($F_{1,299}$=143.10; *P*<.001) associated with greater changes in the participants' fatigue levels. The VIFs of the fixed factors ranged from 1.01 to 1.07.

The extent of participants' internet use during their clinic stay ($F_{1,303}$=0.92; *P*=.34) and the perceived social support among participants ($F_{1,303}$=0.35; *P*=.55) were not significantly negatively associated with changes in their pain levels (Multimedia Appendix 6). The interaction between the extent of participants' internet use during their clinic stay and perceived social support among patients ($F_{1,303}$=0.52; *P*=.47) was not significantly associated with changes in the participants' pain levels. Higher baseline pain levels were significantly ($F_{1,303}$=363.76; *P*≤.001) associated with greater changes in the participants' pain levels. The VIFs of the fixed factors ranged from 1.01 to 1.07.

Sensitivity Analyses

Multimedia Appendix 7 summarizes the results of the 3 linear mixed models before including the interaction effects. The main effects for social support between patients and the extent of internet use did not change when the interaction term between the 2 variables was included.

Discussion

Principal Findings

The study results do not support the observations of health care professionals. The extent of internet use was not negatively associated with the perceived social support among patients with cancer during their stay at the oncological rehabilitation clinic. In addition, the extent of participants' internet use during their clinic stay was not negatively associated with the change in the 3 PROMs, namely, distress (primary outcome), pain, and fatigue from the first day to the last day of the clinical stay. The results of this study represent the first examination of the associations between the extent of internet use, social support, and changes in rehabilitation outcomes in an inpatient rehabilitation setting.

Furthermore, the results of the multiple linear regression analysis indicate that younger and female participants perceived significantly more social support from other patients with cancer during their clinic stay than older and male participants.

The descriptive study results indicate that more than four-fifths of the patients with cancer were internet users. During clinic stay, 70.9% (198/279) of internet users used the internet daily. 10.8% (30/279) of the internet users never used the internet during their clinic stay.

Comparison With Previous Work

The assumption before the start of the study was that a high level of internet use during rehabilitation could reduce social interaction between patients and, therefore, the perceived social support among patients with cancer during their clinic stay. This assumption was based on the observations of health care professionals and related to the social displacement hypothesis [50,52]. However, finding no association between the extent of participants' internet use and perceived social support is consistent with the results of cross-sectional and longitudinal studies that examined internet use in healthy individuals [52-54] and in patients with spinal cord injuries [82]. Furthermore, only 1.8% (5/279) of internet users reported missing clinic leisure-time activities because they spent time on the internet. Finding female sex to be associated with more perceived social support from other patients in the clinic fits the results of the validation study of the F-SozU-P, in which female psychosomatic patients in inpatient rehabilitation perceived more social support than male patients [64]. Women seem to provide more emotional support to both men and women, and they seem to receive more help in return [24]. A positive association between younger age and higher perceived social support for patients with cancer may be partially explained by the findings of a previous study that reported that older adults reported seeking less explicit social support but reported using a similar amount of implicit social support, seeking to cope with their stressors [21]. In an unfamiliar environment with initially unfamiliar fellow patients, explicitly asking for emotional support seems to be associated with higher perceived social support.

The finding of no association between the extent of participants' internet use and the change in participants' levels of distress, pain, and fatigue from the first day to the last day of their clinic stay is inconsistent with the health care professionals' observations and assumptions but is consistent with participants' perceptions of the relationship between internet use and rehabilitation activities and partially consistent with previous study results [55,58-60]. Health care professionals observed that high levels of internet use interfered with the patients' rehabilitation program and competed with social interaction between patients during their clinic stay. However, only 9.3% (26/279) and 1.8% (5/279) of internet users, respectively, reported that they felt distracted from the rehabilitation program and that they missed recreational activities at the clinic because they spent time on the internet. Previous study results indicated that the overall extent of internet or social media use is not, or only marginally, associated with well-being [55] or changes in well-being [59], which is consistent with the results of our study. However, previous studies also indicated that the association between internet or social media use and well-being depends on the type of internet or social media use [58-60]. Our study results indicate that the participants who used the internet for communicative activities did not perceive more social support from other patients with cancer during their clinic stay than the participants who did not use it for communicative activities. However, we did not measure the extent of different types of internet activities. Measuring the extent of different types of internet activities might have led to positive associations, for example, between interactive internet or social media use and friends and family, social support, and well-being [52,53,58,59]. Further studies should be conducted to investigate the causal direction of these associations. These studies should also include personality and social skills of the participants [52].

Finding no association between social support and the change in participants' levels of distress from the first day to the last day of their clinic stay is inconsistent with the results of systematic reviews examining peer support interventions for patients with cancer [27] and breast cancer [26]. The results of systematic reviews show that peer support interventions increase perceived distress, quality of life, emotional well-being, and psychosocial functioning of patients with cancer [26,27,83]. We have 2 possible explanations for the lack of association between social support and changes in participants' distress. First, social support during the clinic stay predominantly occurs between treatment sessions, at meals, and during leisure-time activities. This type of social interaction is unmoderated and unstructured, which could have no or even adverse effects on quality of life and distress [26,30]. In the absence of moderation, or group structure, expressions of anger and fear, as well as discussions about death and dying can increase [30,31]. Second, emotional support is highly desired by patients with cancer and has positive influence on the patients' well-being. It may be that emotional needs are best met by close friends and relatives of patients with cancer rather than by relative strangers in peer groups [83,84].

Health care professionals' observations and assumptions and the social displacement hypothesis share the implicit mediation hypothesis that social support mediates the effect of the extent of internet use on change in well-being. Because we found no association between the extent of internet use and the mediator social support in the multiple regression analysis, we assumed that the probability of finding a mediation was too low and therefore decided not to apply the mediation analysis [85]. In addition, social support did not moderate the association between the extent of participants' internet use and changes in the 3 PROMs. Further studies should be conducted to examine the causal direction of these associations outside residential treatment.

This study is the first to present data on the extent and purpose of patients' internet use during inpatient cancer rehabilitation. The prevalence of internet use among participants (279/323, 86.4%) was higher than that in previous studies with patients with cancer (60.2%-79.8%) [34,37,38] and very similar to the prevalence (87%) in the population of advanced economies [40]. The higher prevalence compared with previous studies with patients with cancer may be explained by the samples in the earlier studies being recruited in 2005 [34], 2007 [37], and 2015 [38] and the increasing internet access and use among patients with cancer [86].

Limitations

The first limitation concerns the somewhat low participation rate, which could be an indicator that our sample had a nonresponse bias [87]. However, the scores of the study participants who experienced fatigue differed only slightly from the scores of all patients with cancer (n=1204) treated at the analyzed oncological rehabilitation clinic in 2019, indicating that our sample might be representative of patients in the rehabilitation clinic. Second, we were unable to find comprehensively validated instruments to measure perceived social support between patients, the extent and purpose of rehabilitating patients' use of the internet, and patients' interest in future interactions with web-based services. The F-SozU-P was validated as part of a dissertation project and showed good values for internal consistency and convergent and discriminant validity [64]. The items that we used to measure the extent and purpose of rehabilitating patients' use of the internet and patients' interest in future interactions with web-based services were obtained or adapted from a previous study by Drewes et al [63]. We pilot-tested all instruments of the questionnaire to assess the experiences of patients with cancer, while they were completing the instruments. The results of the pilot study showed that the participants generally understood the questions well, and no adjustments to the questionnaire had to be made. Third, 7.7% (25/323) to 12.1% (39/323) of the values for the items measuring patients' interest in future interaction with web-based services were missing. The missing values can be partially explained by the fact that participants who reported not using the internet were instructed to skip all questions about the extent and purpose of internet use. Overall, of 44 noninternet users, 9 (20%) additionally skipped the last 6 questions of the questionnaire about their interest in future interactions with web-based services.

Conclusions

The extent of internet use by patients with cancer during their clinic stay does not seem to be associated with the perceived social support among patients with cancer or with the change in their level of distress, fatigue, or pain from the first day to the last day of their clinic stay. Therefore, we recommend that clinics offer their patients free, easily accessible, and fast wireless local-area network connection.

Acknowledgments

This study was financed by our own funds.

Data Availability

Our data are available on the Open Science Framework [88].

Conflicts of Interest

None declared.

Multimedia Appendix 1
The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement.
[DOCX File , 33 KB - cancer_v9i1e39246_app1.docx]

Multimedia Appendix 2
Internet users' views on internet use during their clinic stay.
[DOCX File , 15 KB - cancer_v9i1e39246_app2.docx]

Multimedia Appendix 3
Participants' interests in future interactions with new media or web-based services in health care.
[DOCX File , 15 KB - cancer_v9i1e39246_app3.docx]

Multimedia Appendix 4
Parameters of the linear mixed model analysis with distress as the dependent variable.
[DOCX File , 14 KB - cancer_v9i1e39246_app4.docx]

Multimedia Appendix 5
Parameters of the linear mixed model analysis with fatigue as the dependent variable.
[DOCX File , 14 KB - cancer_v9i1e39246_app5.docx]

Multimedia Appendix 6
Parameters of the linear mixed model analysis with pain as the dependent variable.
[DOCX File , 14 KB - cancer_v9i1e39246_app6.docx]

Multimedia Appendix 7
Parameters of the sensitivity analyses.
[DOCX File , 16 KB - cancer_v9i1e39246_app7.docx]

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Abbreviations

F-SozU-P: questionnaire on social support between patients
GSLTPAQ: Godin-Shephard Leisure-Time Physical Activity Questionnaire
NRS: numeric rating scale
PROM: patient-reported outcome measure
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology
VIF: variance inflation factor
WasU-P: wahrgenommene soziale Unterstutzung–Patienten (perceived social support-patients)

Edited by A Mavragani; submitted 04.05.22; peer-reviewed by R Kraut, A AL-Asadi; comments to author 10.01.23; revised version received 15.02.23; accepted 14.03.23; published 17.05.23.

Please cite as:
Lange-Drenth L, Schulz H, Endsin G, Bleich C
Association of the Extent of Internet Use by Patients With Cancer With Social Support Among Patients and Change in Patient-Reported Treatment Outcomes During Inpatient Rehabilitation: Cross-sectional and Longitudinal Study
JMIR Cancer 2023;9:e39246
URL: https://cancer.jmir.org/2023/1/e39246
doi:10.2196/39246
PMID:37195742

Original Paper

Therapist Feedback and Implications on Adoption of an Artificial Intelligence–Based Co-Facilitator for Online Cancer Support Groups: Mixed Methods Single-Arm Usability Study

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Abstract

Background: The recent onset of the COVID-19 pandemic and the social distancing requirement have created an increased demand for virtual support programs. Advances in artificial intelligence (AI) may offer novel solutions to management challenges such as the lack of emotional connections within virtual group interventions. Using typed text from online support groups, AI can help identify the potential risk of mental health concerns, alert group facilitator(s), and automatically recommend tailored resources while monitoring patient outcomes.

Objective: The aim of this mixed methods, single-arm study was to evaluate the feasibility, acceptability, validity, and reliability of an AI-based co-facilitator (AICF) among CancerChatCanada therapists and participants to monitor online support group participants' distress through a real-time analysis of texts posted during the support group sessions. Specifically, AICF (1) generated participant profiles with discussion topic summaries and emotion trajectories for each session, (2) identified participant(s) at risk for increased emotional distress and alerted the therapist for follow-up, and (3) automatically suggested tailored recommendations based on participant needs. Online support group participants consisted of patients with various types of cancer, and the therapists were clinically trained social workers.

Methods: Our study reports on the mixed methods evaluation of AICF, including therapists' opinions as well as quantitative measures. AICF's ability to detect distress was evaluated by the patient's real-time emoji check-in, the Linguistic Inquiry and Word Count software, and the Impact of Event Scale-Revised.

Results: Although quantitative results showed only some validity of AICF's ability in detecting distress, the qualitative results showed that AICF was able to detect real-time issues that are amenable to treatment, thus allowing therapists to be more proactive in supporting every group member on an individual basis. However, therapists are concerned about the ethical liability of AICF's distress detection function.

Conclusions: Future works will look into wearable sensors and facial cues by using videoconferencing to overcome the barriers associated with text-based online support groups.

International Registered Report Identifier (IRRID): RR2-10.2196/21453

(JMIR Cancer 2023;9:e40113) doi:10.2196/40113

KEYWORDS

cancer; recommender system; natural language processing; LIWC; natural language processing; emotion analysis; therapist adoption; therapist attitudes; legal implications of AI; therapist liability

Introduction

Half of all Canadians will be diagnosed with cancer in their lifetime, and the illness is often associated with psychological distress. Canadians living in remote areas have limited access to supportive services, and many experience difficulties in accessing services due to physical disabilities. The recent onset of the COVID-19 pandemic and the social distancing requirement have created a further demand for virtual support programs [1].

Emerging evidence supports the effectiveness of online support groups to reduce access barriers [2]. CancerChatCanada offers therapist-led, text-based online support groups to address patients' cancer-related distress and has demonstrated positive results. CancerChatCanada, offered by de Souza Institute, consists of a series of synchronized, therapist-led, text-based online support groups for patients with cancer and their caregivers. CancerChatCanada is a national program operated in collaboration with 6 provincial cancer agencies in Canada. The online support groups vary in theme and therapeutic model, with all groups being manual-based and consisting of 8-10 sessions [3]. During the group sessions, the facilitators aim to support and process discussions based on session themes and related concerns while also acknowledging and attending to the members' emotional needs individually. Each online support group is led by 1 or 2 licensed counselors/therapists and is composed of 6-10 participants, meeting weekly for 8 weeks in a web-based synchronous chatroom. However, therapists leading text-based online support groups often find it challenging to address individual group members' simultaneous responses around their distress/needs in the absence of visual communicative cues. Recent advances in artificial intelligence (AI) may offer novel solutions. Using typed texts from online support groups, AI can monitor therapy sessions, help identify the potential risk of mental health concerns, alert group facilitator(s), and automatically recommend tailored resources while monitoring group emotions. In particular, 1 study has developed an AI system to analyze therapy session transcripts to provide a cognitive behavioral therapy session fidelity score for therapists [4].

We developed and evaluated an AI-based co-facilitator (AICF) to track and monitor online support group participants' distress through a real-time analysis of texts posted during online support group sessions. Specifically, AICF was designed for the following functions: (1) profiling, that is, generate participant profiles with discussion topic summaries and emotion trajectories for each session in a dashboard (Figures 1-3), (2) distress warning, that is, identify participant(s) at risk for increased emotional distress and alert the therapist for follow-up (Figure 4), and (3) resource recommendation, that is, automatically suggest tailored resources based on participant needs (Figure 5). AICF allows real-time detection of issues (eg, disengagement, feeling unsupported) that were amenable to treatment, allowing therapists to be more proactive in supporting group members on an individual basis during the group sessions. A full protocol of the AICF algorithm development and preliminary findings has been published previously [3,5]. The AICF development details are shown in Multimedia Appendix 1 [6-25].

The objectives of this study were to present the results of therapist user testing and their experiences by using focus group methodology. The detailed training and testing results of each AICF functionality will be published in detail in a separate paper.

Figure 1. Dashboard of the group and individual emotion analysis. Agg: aggregate.

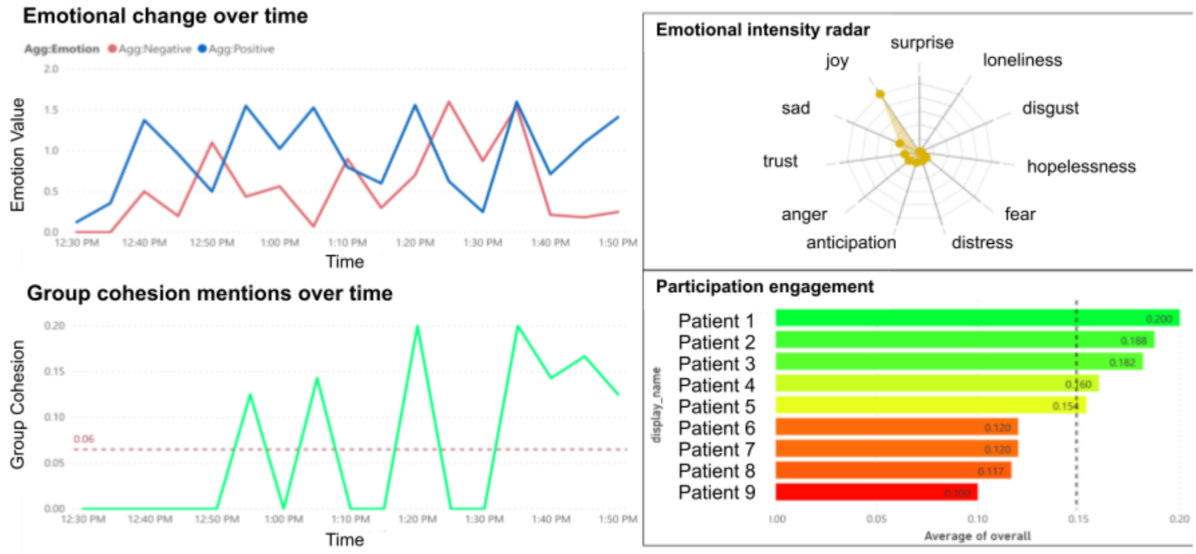


Figure 2. Breakdown of the emotion analysis of individuals.

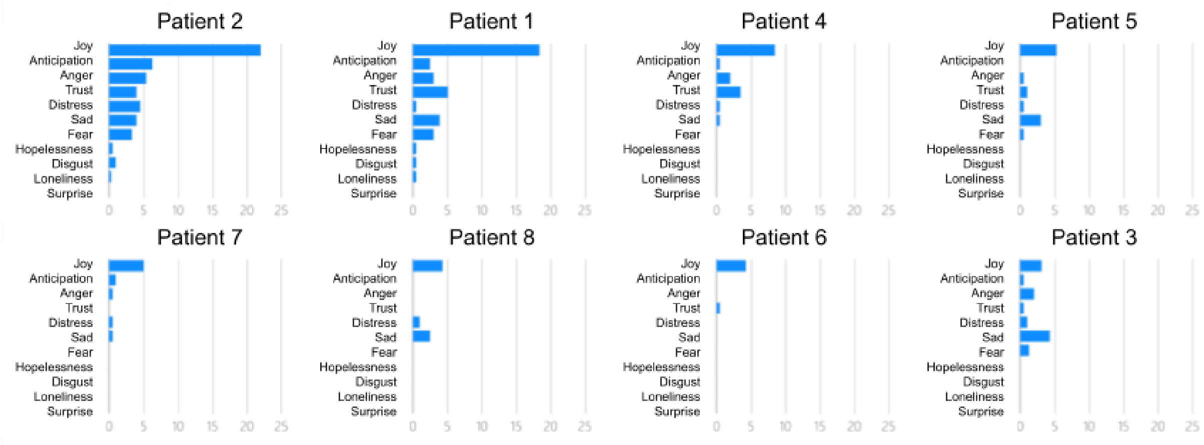


Figure 3. Positive and negative emotion analyses of individuals. Agg: aggregate.

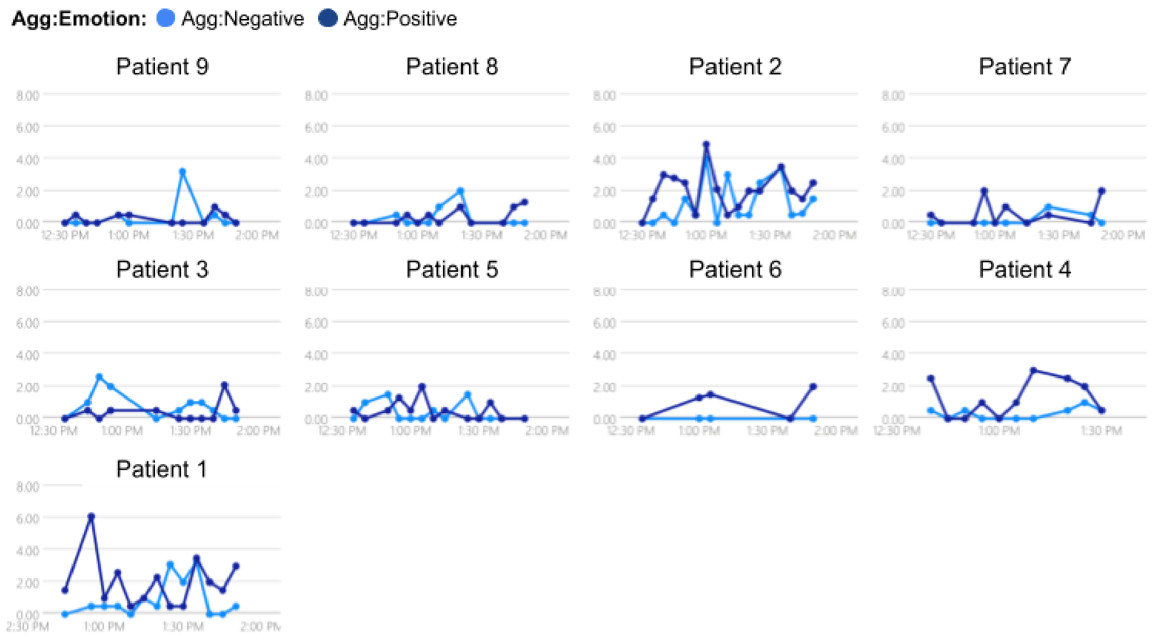
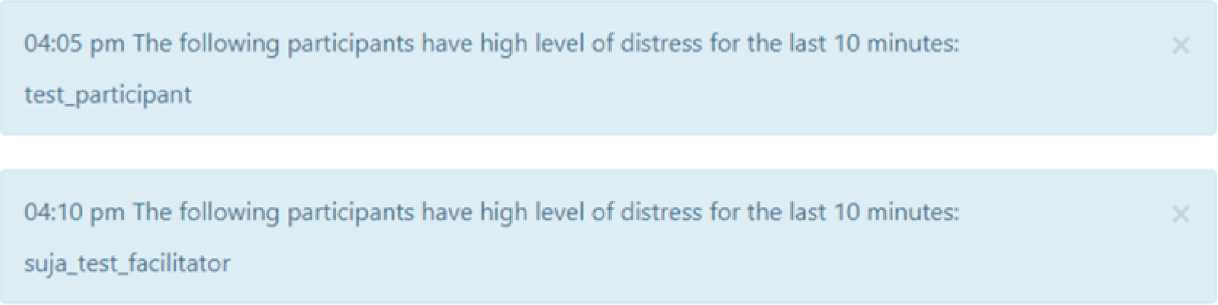


Figure 4. Distress warnings for therapists.



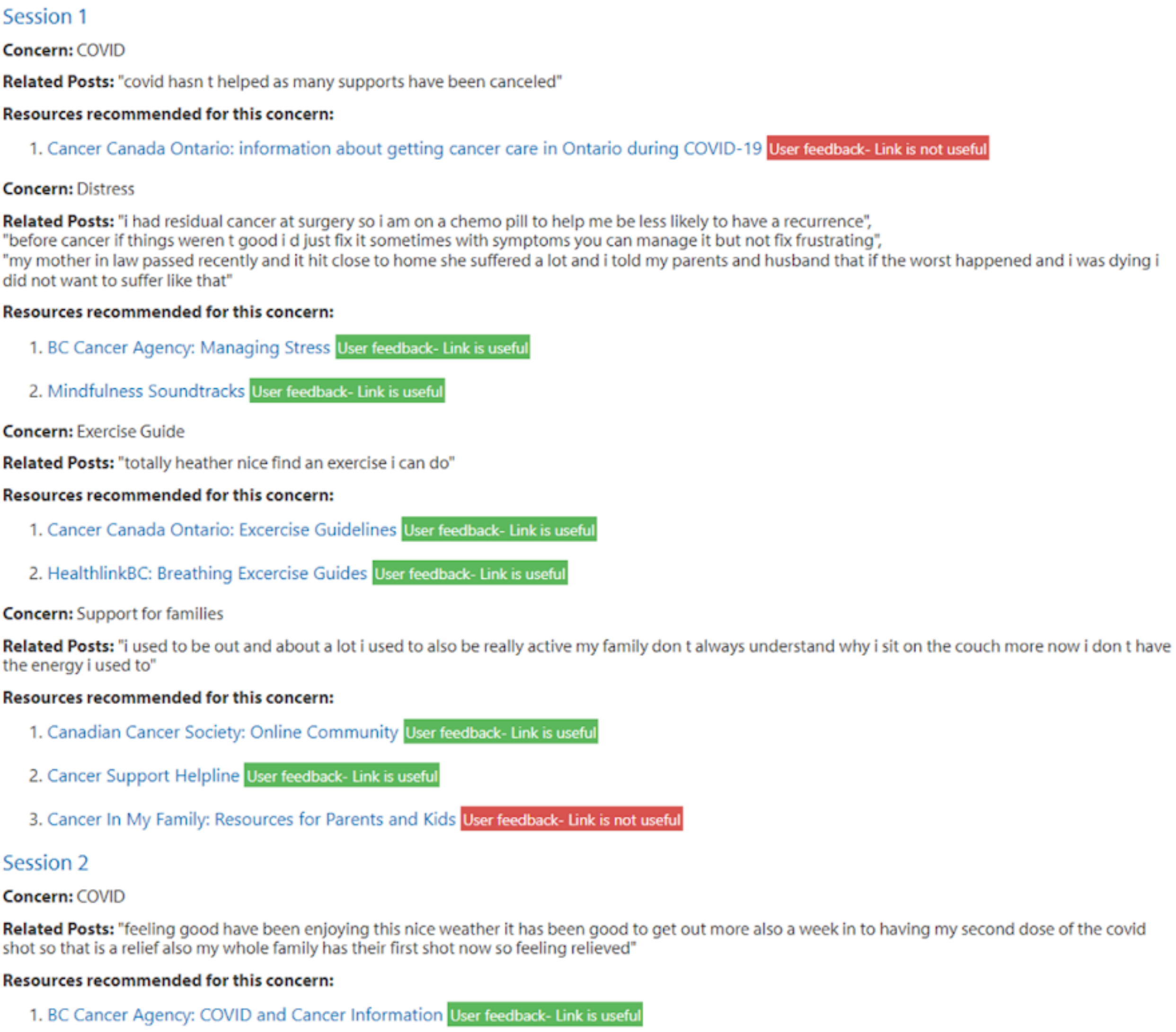
04:05 pm The following participants have high level of distress for the last 10 minutes:

test_participant

04:10 pm The following participants have high level of distress for the last 10 minutes:

suja_test_facilitator

Figure 5. Participant conversation summary and resource recommender.



Session 1

Concern: COVID

Related Posts: "covid hasn t helped as many supports have been canceled"

Resources recommended for this concern:

1. Cancer Canada Ontario: information about getting cancer care in Ontario during COVID-19 User feedback- Link is not useful

Concern: Distress

Related Posts: "i had residual cancer at surgery so i am on a chemo pill to help me be less likely to have a recurrence",
"before cancer if things weren t good i d just fix it sometimes with symptoms you can manage it but not fix frustrating",
"my mother in law passed recently and it hit close to home she suffered a lot and i told my parents and husband that if the worst happened and i was dying i did not want to suffer like that"

Resources recommended for this concern:

1. BC Cancer Agency: Managing Stress User feedback- Link is useful
2. Mindfulness Soundtracks User feedback- Link is useful

Concern: Exercise Guide

Related Posts: "totally heather nice find an exercise i can do"

Resources recommended for this concern:

1. Cancer Canada Ontario: Excercise Guidelines User feedback- Link is useful
2. HealthlinkBC: Breathing Excercise Guides User feedback- Link is useful

Concern: Support for families

Related Posts: "i used to be out and about a lot i used to also be really active my family don t always understand why i sit on the couch more now i don t have the energy i used to"

Resources recommended for this concern:

1. Canadian Cancer Society: Online Community User feedback- Link is useful
2. Cancer Support Helpline User feedback- Link is useful
3. Cancer In My Family: Resources for Parents and Kids User feedback- Link is not useful

Session 2

Concern: COVID

Related Posts: "feeling good have been enjoying this nice weather it has been good to get out more also a week in to having my second dose of the covid shot so that is a relief also my whole family has their first shot now so feeling relieved"

Resources recommended for this concern:

1. BC Cancer Agency: COVID and Cancer Information User feedback- Link is useful

Methods

Study Participants

Eleven therapists and 156 participants in the online support group were recruited through CancerChatCanada as well as through the web page and social media accounts (Facebook and Twitter) of de Souza Institute. Patients with a cancer diagnosis were included in this study. Distressed patients who needed immediate psychological care were excluded. The therapists were mainly social workers, with 1 registered clinical psychologist and 1 registered clinical counsellor. There were no exclusion criteria for the therapists.

Ethics Approval

This study was approved by the University Health Network research ethics board (18-5354).

Study Design

This is a mixed methods, single-arm study that evaluated AICF's feasibility, acceptability, validity, and reliability among CancerChatCanada therapists and participants. The feasibility and acceptability of AICF were assessed by a focus group composed of therapists with a designed interview guide (Multimedia Appendix 2). The validity and reliability of AICF were assessed using correlation statistics. This study was conducted from July 1, 2019, to August 31, 2021.

Procedure

AICF was deployed and tested in the back end (out-of-the therapists' view) in 3 online support groups and with beta testing in 10 groups. The AICF system developed in phase I of our research provided outputs that included 8 basic emotions (sadness, anger, fear, joy, trust, surprise, anticipation, disgust) and their intensities, group cohesion, engagement, and emotional profiling features [3]. In our quantitative evaluation, we hypothesized that AICF would have high correlations with standard measures of distress, high performance of distress threshold (area under the curve>70%), and predictive values for distress. Upon completing user testing, 3 therapists were interviewed in a focus group, which involved 4 parts of a discussion: (1) review the study purposes and design specifications, (2) distress and other emotions, (3) recommendations for specific functionalities, and (4) overall impression of AICF.

Measures

A standardized measure called the Impact of Event Scale-Revised (IES-R) was used to validate AICF's ability in detecting the distress of online support group participants. The IES-R [26] was used to measure cancer-related distress and deployed before and after the online support group program and is a 22-item measure rated on a 5-point Likert scale, yielding a total score ranging from 0 to 88. The IES-R has 8 items on the subscale for intrusion (Cronbach α=.87-.94), 8 items for avoidance (Cronbach α=.84-.87), and 6 items on hyperarousal (Cronbach α=.79-.91).

Analysis

Quantitative Analysis

We defined distress as aggregating all the negative emotions (sadness, anger, fear, disgust) detected by AICF. To test the validity of AICF in detecting distress, we designed a real-time emoji check-in to gain insights from the participants directly during group sessions. Nine common emojis (neutral, happy, feeling supported, relaxed, anger, bored, overwhelmed, sad, or worried) would pop up on the participant screen every 30 minutes during the 1.5-hour online support group session. The Linguistic Inquiry and Word Count (LIWC) software [27] was applied to all textual data to obtain a reference score for positive and negative emotions. LIWC scanned each line of the conversation for positive and negative emotions. We hypothesized that correlations between LIWC and AICF outputs would be strong (≥0.7).

To validate AICF by the close to real-time participant emotional states, we grouped the 9 emojis into positive and negative states, with the neutral emoji excluded. The remaining 8 emojis were grouped into positive (happy, feeling supported, relaxed) and negative (anger, bored, overwhelmed, sad, worried) emotions. The number of positive and negative emojis for each participant was counted, and their averages were calculated for each 30-minute interval. For example, if the participant chose happy, feeling supported, worried, or sad, their positive emotion count would be 2/3 and negative count would be 2/5. A Spearman ρ correlation test was conducted on the average positive and negative emoji counts against positive and negative scores produced by LIWC and AICF. The fourth session was selected for the analysis, as the group would have developed a reasonable level of rapport and trust among the members and the facilitator by then. Construct (convergent) validity of AICF-detected distress was compared against the self-reported standardized measure (IES-R). We hypothesized that AICF-extracted negative emotions in the fourth session were positively correlated with the distress level after the program, as assessed by IES-R.

Qualitative Analysis

The focus group qualitative data were analyzed by content analysis [28] completed by 2 members of the research team (SN and YL). The questions were designed to ask about the opinion of each functionality of AICF. We extracted key themes from each question discussion and categorized them into pros and cons of each functionality of AICF and created a table to display the extracted themes with therapist quotes. When there were disagreements between the 2 members, a third person (LD) would resolve the conflicts by revising the wordings upon which all parties agreed. The results were ordered from high to low frequency of mentions.

Results

Participant Characteristics

Table 1 shows the characteristics of the participants in the CancerChatCanada online support groups; 156 participants consented and completed the pre–group surveys, while 91 participants participated in the fourth session and 77 participated in the last session. Five groups (active treatment, COVID anxiety, advanced cancer, active treatment, active cancer support) were removed, as the AICF algorithm was being tested and updated (n=57).

The F1-scores for distress detection, group cohesion, and resource recommendation were 0.71, 0.80, and 0.88, respectively. AICF-detected distress showed consistent but weak correlations with patient-selected negative emojis in the first 30 minutes (Table 2) and during 30-60 minutes of the session (r=0.29, P=.004; r=0.21, P=.004, respectively). There were moderate correlations between AICF distress and LIWC negative emotions (r=0.39, P<.001; r=0.51, P<.001) in the second (Table 3) and last 30 minutes of the session (Table 4). There were no relationships between AICF distress in the fourth session and the standardized measure of distress (IES-R) in the pre–group survey (P=.35).

Table 1. Characteristics of the participants (N=156).

Characteristic	Values, n (%)
Age group (years)	
25-34	9 (5.8)
35-44	21 (13.5)
45-54	39 (25)
55-64	59 (37.8)
≥65	28 (18)
Province	
Alberta	17 (10.9)
British Columbia	59 (37.8)
Ontario	62 (39.7)
Other	18 (11.5)
Cancer type	
Breast	76 (48.7)
Colorectal	11 (7.1)
Gastrointestinal	5 (3.2)
Gynecological	8 (5.1)
Non-Hodgkin lymphoma	10 (6.4)
Other	46 (29.5)
Support group	
Active treatment	35 (22.4)
Advanced cancer	19 (12.2)
Caregivers	23 (14.7)
Expressive arts	7 (4.5)
Fear of cancer recurrence	18 (11.5)
Posttreatment	15 (9.6)
Restoring body image and sexual health after cancer	24 (15.4)
COVID-related anxiety	15 (9.6)

Table 2. The Spearman ρ correlations among artificial intelligence–based co-facilitator, Linguistic Inquiry and Word Count, and emoji scale during the first 30 minutes of session 4.

Variable	Positive emotion (Human)	Negative emotion (Human)	Positive emotion (AICF[a])	Negative emotion (AICF)	Positive emotion (LIWC[b])	Negative emotion (LIWC)
Positive emotion (Human)						
r	1	–0.449	0.264	–0.154	–0.112	–0.052
P value	—[c]	<.001	.009	.13	.27	.61
Negative emotion (Human)						
r	–0.449	1	0.043	0.293	0.015	0.141
P value	<.001	—	.67	.004	.88	.17
Positive emotion (AICF)						
r	0.264	0.043	1	0.299	0.063	0.037
P value	.009	.67	—	.003	.54	.72
Negative emotion (AICF)						
r	–0.154	0.293	0.299	1	–0.061	0.17
P value	.13	.004	.003	—	.55	.10
Positive emotion (LIWC)						
r	–0.112	0.015	0.063	–0.061	1	0.480
P value	.27	.88	.54	.55	—	<.001
Negative emotion (LIWC)						
r	–0.052	0.141	0.037	0.17	0.480	1
P value	.61	.17	.72	.10	<.001	—

[a] AICF: artificial intelligence–based co-facilitator.

[b] LIWC: Linguistic Inquiry and Word Count.

[c] Not applicable.

Table 3. The Spearman ρ correlations among artificial intelligence–based co-facilitator, Linguistic Inquiry and Word Count, and emoji scale during the second 30 minutes of session 4.

Variable	Positive emotion (Human)	Negative emotion (Human)	Positive emotion (AICF[a])	Negative emotion (AICF)	Positive emotion (LIWC[b])	Negative emotion (LIWC)
Positive emotion (Human)						
r	1	–0.643	0.075	–0.153	–0.012	–0.191
P value	—[c]	<.001	.48	.14	.91	.07
Negative emotion (Human)						
r	–0.643	1	–0.077	0.205	–0.057	0.186
P value	<.001	—	.46	.048	.59	.07
Positive emotion (AICF)						
r	0.075	–0.077	1	0.212	0.193	0.075
P value	.48	.46	—	.04	.06	.47
Negative emotion (AICF)						
r	–0.153	0.205	0.212	1	0.146	0.390
P value	.14	.048	.04	—	.16	<.001
Positive emotion (LIWC)						
r	–0.012	–0.057	0.193	0.146	1	0.403
P value	.91	.59	.06	.16	—	<.001
Negative emotion (LIWC)						
r	–0.191	0.186	0.075	0.390	0.403	1
P value	.07	.07	.47	<.001	<.001	—

[a] AICF: artificial intelligence–based co-facilitator.

[b] LIWC: Linguistic Inquiry and Word Count.

[c] Not applicable.

Table 4. The Spearman ρ correlations among artificial intelligence–based co-facilitator, Linguistic Inquiry and Word Count, and emoji scale during the last 30 minutes of session 4.

Variable		Positive emotion (Human)	Negative emotion (Human)	Positive emotion (AICF[a])	Negative emotion (AICF)	Positive emotion (LIWC[b])	Negative emotion (LIWC)
Positive emotion (Human)							
	r	1	–0.564	–0.004	–0.079	0.015	–0.182
	P value	—[c]	<.001	.97	.45	.89	.08
Negative emotion (Human)							
	r	–0.564	1	0.021	0.167	–0.099	0.122
	P value	<.001	—	.84	.11	.34	.24
Positive emotion (AICF)							
	r	–0.004	0.021	1	0.093	0.064	0.067
	P value	.97	.84	—	.37	.54	.52
Negative emotion (AICF)							
	r	–0.079	0.167	0.093	1	0.032	0.505
	P value	.45	.11	.37	—	.76	<.001
Positive emotion (LIWC)							
	r	0.015	–0.099	0.064	0.032	1	0.481
	P value	.89	.34	.54	.76	—	<.001
Negative emotion (LIWC)							
	r	–0.182	0.122	0.067	0.505	0.481	1
	P value	.08	.24	.52	<.001	<.001	—

[a] AICF: artificial intelligence–based co-facilitator.

[b] LIWC: Linguistic Inquiry and Word Count.

[c] Not applicable.

Focus Group Participants

Four female therapists from CancerChatCanada participated in our focus group. Each therapist had more than 2 years of facilitating online text-based support groups. In addition, all therapists had a social work background. The therapists conducted online support groups using AICF. Table 5 shows the focus group findings summarized by the functions of AICF and their pros and cons: emoji check-in, engagement score, distress warning, cohesion score, resource recommender, and dashboard. Each of these functions are detailed below.

Table 5. Focus group result summary.

AICF[a] function	Representable pros	Representable cons	Therapist quotes for pros	Therapist quotes for cons
Emoji check-in	• Emoji check-in provided facilitators sufficient feedback on participant emotions to address the absence of visual cues. • Emoji check-in produced less invasive but critical information than a distress warning. • Emoji check-in helped bridge the gap between the postsession report and clinical outcomes such as engagement and distress.	• Emoji check-in results were not shown in the session in real time, limiting facilitators' situational awareness. • Facilitators did not have control over the deployment of emoji check-in when needed.	*…The emojis help address the lack of non-verbal feedback.* [Therapist 3] *…The emoji check-in helped provide more granular information regarding distress compared to distress warnings.* [Therapist 3] *…Sometimes the post-session reports don't line up with the red bar or other analyses, however, emojis help address this gap.* [Therapist 1]	*…Facilitators can't see the emojis during the session, so participants might feel ignored if their concerns aren't being taken seriously.* [Therapist 3] *…It would be beneficial if we could deploy the emoji check-in when we believe it is appropriate.* [Therapist 3]
Engagement score	Engagement score was helpful in identifying inactive participants.	• The system could not show the typing of participants as an engagement indicator. • If a participant left early, they would be flagged as low engagement. • Text might be insufficient to show engagement as participants were thinking or feeling beyond what they could express in text. Other indicators such as heart rate might be complementary to the text-based analysis.	*…The engagement score is really helpful to see who is actually inactive.* [Therapist 1]	*…I would love to see the participant typing.* [Therapist 2] *…Is there a way the system knows if the person has left early and is not just disengaged?* [Therapist 1] *…Engagement isn't always shown through text. What someone is thinking or feeling beyond what text messages they are sending.* [Therapist 1]
Distress warning	• Facilitator felt they could provide more support to participants with distress warnings during the session. • Distress warnings provided a reminder for the facilitator to follow up with the distressed patient.	• Distress warnings could not help therapists to distinguish between healthy and unhealthy positivity, which refers to participants who refused to acknowledge their negative emotions. • The distress warning score needed fine-tuning as most participants were usually above average. • The distress graph needs to be simplified.	*…I had a patient with a distress warning, so I directed the group to provide more support. I was really happy for the group support.* [Therapist 1] *…If I see the distress warning, it reminds me to follow up with them after the session.* [Therapist 1]	*…When a participant was showing toxic positivity, their messages were still read as "positive."* [Therapist 1] *…The system needs improvement on setting an average, since most participants were above the red bar.* [Therapist 1] *…Make the distress graph easier to read.* [Therapist 2]
Group cohesion score	The group cohesion score was helpful and is relative to other participants.	There were some discrepancies between the cohesion score and facilitator's judgement or experience concerning group cohesion.	*…It is helpful that the group cohesion scores are relative to other participants.* [Therapist 1]	*…A recent session I facilitated had a red cohesion score, however, this feedback does not fit with my experience with the group.* [Therapist 1]
Resources recommender	• The recommender system could standardize the distribution of reference materials to participants to maintain group cohesion and fluidity. • The recommender system was helpful to track participants' progress on the reference materials and their ratings on the usefulness.	Facilitators preferred to read and add additional materials into the automated email content before sending to patients.	*…I want everyone to read the same material, it can help improve group cohesion and fluidity.* [Therapist 3] *…It's really handy to see if participants have opened and clicked on the material and I can see whether or not it's useful.* [Therapist 2]	*…Sometimes there are resources I want to add, but I don't want to send them another email on top of the automated email.* [Therapist 2]

AICF[a] function	Representable pros	Representable cons	Therapist quotes for pros	Therapist quotes for cons
Dashboard	The conversation summary on the dashboard effectively summarized patient emotions and concerns.	• The distress graph was visually overwhelming as it showed the status of all participants. It was recommended that only abnormal distress levels be shown during the session. • Facilitators suggested the need for a more succinct summary with the most critical information.	*…The conversation summary was useful to look at patients' feelings and concerns during the session.* [Therapist 1]	*…It's [distress graph] visually busy. Unless there is someone whose fluctuating out of the usual boundary leaves it out maybe, when in range it's not too important to know.* [Therapist 2] *…The summary should only present the most important information and put the other details somewhere else.* [Therapist 2]

[a] AICF: artificial intelligence–based co-facilitator.

Focus Group Findings

Emoji Check-in

When participants were asked about their preferences of AICF, the majority of the comments positively addressed the emoji check-in as nonverbal feedback from the group participants. The emoji check-in was in fact a non-AI function implemented to give researchers the reference point for AICF's real-time emotional tracking. Emojis supplemented the nonverbal clues absent from web-based settings by providing information on each participant's emotions in a simple manner, indicating when participants needed additional support. The therapists generally preferred emoji check-in over distress warnings, as "the distress warning makes you feel that you have missed something." They regarded distress warnings as possibly increasing pressure and cognitive load on the therapist while facilitating the group session. The emoji check-in function also received many suggestions for further refinement. For example, the dashboard could include emoji check-in results and statistics for instant review. Some therapists expressed that the patient's emoji status could be shown in real time on the therapist screen to allow for a better understanding of the emotional status of each participant. Others expressed that adding an emoji check-in only at the end of each session could help assess the patient's satisfaction. Lastly, several therapists wished that they had the ability to deploy emoji check-ins whenever they wanted.

Engagement Score

Several comments from the focus group positively addressed the engagement score function. One therapist shared that the function helped indicate which patients were inactive, as the absence of visual cues made it difficult to judge participant engagement during sessions where the group members are receiving multiple texts. Therapists also appreciated the non-AI function of the engagement alert that flagged those patients who were inactive for over 10 minutes; therapists could immediately attend to the inactive patient. The engagement score provided after the session also provided an important indicator for facilitators to gauge patient engagement. For improvement, 1 therapist respondent proposed that the group facilitator should be able to chat with participants privately during the group session in order to increase engagement. Another recommended introducing an additional alert to the group facilitator when participants dropped out of the session. Some therapists felt that evaluating the engagement by using textual data could be insufficient, as participants may be thinking or feeling something beyond what they could text. To overcome this issue, it was recommended that patients wear a sensor to monitor biometric signs such as heart rate during the session, which may produce a more accurate engagement score. Lastly, some advised that the chatroom could include read receipts and typing-in-real-time indicators as a measurement of engagement.

Distress Warning

Therapists positively evaluated the distress warning function. They shared that the warning drew their attention to distressed patients, and they were able to provide proper support to the patients during the session in a timely fashion. They also appreciated that patient distress recorded in the session summary assisted them in accurately evaluating their group participants for necessary follow-up.

A therapist suggested that the distress graph could be represented in a more succinct manner—flagging only those who displayed extremely high levels of distress that warranted clinical actions. One therapist worried about the legality issues, for example, if the distress warning could be held as evidence against the therapists for potential negligence if something terrible happened to the patient. As distress was common in online support groups, these warnings could add extra pressure to the therapists. Therefore, therapists suggested including a disclaimer to protect them from being accused of malpractice. Similar to other clinical settings, online support groups are a nonemergency service where clinicians are not expected to respond to or to rule out every possible self-harm warning sign. Future studies should explore ways to reduce the ethical liability for therapists when using AI-generated distress warnings.

Group Cohesion Score

The therapists described the cohesion score as being helpful to demonstrate how well patients felt being connected with each other in the group. They expressed that a high cohesion score was a true indication that patients were more active and attentive during the session, increasing overall patient satisfaction, better experience, and greater support group effectiveness.

One therapist mentioned that there was some inconsistency between the group cohesion score and her own observations. Another therapist suggested designing an option to filter out absent participants when calculating the group cohesion score. Others also recommended that the facilitator should have the ability to rate group cohesion as a way to validate and calibrate the AICF-generated cohesion score. Another found that the positivity detected by AI was indistinguishable from toxic positivity, which refers to the inability to express negative emotional expressions encouraged by the therapist [29]. Indeed, they commented that toxic positivity could adversely impede group cohesion development, as participants would refrain from expressing their negative emotions if the overall tone was highly positive.

Resource Recommender

The therapists uniformly acknowledged that the resource recommender detected issues mentioned by the participants in a timely manner and therefore reduced their workload by providing relevant resources tailored for patients at the end of each session. One therapist suggested that all participants should have access to common materials aligned to a specific theme of each session to enhance group cohesion and fluidity. Several therapists also suggested that the host should be able to add additional web-based resources to the recommender system and edit the AICF-generated email containing the recommendation prior to sending to patients.

Dashboard

The therapists overall liked the AICF summary of concerns for each patient provided in the dashboard. However, there were some additional suggestions for improvement of the dashboard. One therapist expressed that the information on the dashboard could be more succinct. Other therapists commented that the dashboard should prioritize information and display more essential items first, for example, the group cohesion score. In addition, another therapist suggested that a graphical display of individual distress data across the sessions and flagging only the extremely distressed individual would facilitate clinical responses.

Videoconferencing

Many therapists in the focus group suggested that a videoconferencing function could address the absence of visual cues of text-based online support groups.

Discussion

AICF is a novel textual analysis system that tracks emotions in the texts expressed by online support group participants. To date, there is no similar AI system of this kind in the literature. Our study objectives were to investigate whether AICF added value to virtual care and to inform best virtual clinical practices by using real-time analytics, leading to greater ease and effectiveness for virtual support group management. When AICF functions are complemented by the basic functions of the chatroom platform, such as emoji check-ins and engagement alerts, our therapists found that AICF provided a new level of detail in tracking patient emotions and their engagement levels. Surprisingly, therapists prefer the emoji check-in, a non-AI item originally designed for researchers to provide a point of reference for real-time patient emotional experiences, over the distress warning. They felt that the emoji check-in was incredibly useful and undistracting for the patients. The next step is designing the display of participant emojis for maximum efficiency and aesthetics to provide actionable insights for therapists.

The original idea and purpose of developing an AICF dashboard was to give therapists essential indicators when facilitating a text-based online support group. This aim may be particularly helpful when a group leader is acting as the sole facilitator and when it is not possible to track patients' bodily or facial cues. However, therapists suggest that there is a need to balance what type and amount of information is provided during group sessions. For example, therapists may find too much information (eg, for each group participant) overwhelming while conducting a group session. Distress warnings are viewed as helpful but can also be distracting, and for some, they may pose additional burden concerning legality issues. The literature suggests that health care providers may prefer positive feedback from an AI system instead of being warned about their potential mistakes [30]. The perception that there may be information that could be used legally may pose a barrier for mental health care providers in adopting AI technology in their clinical practice [31]. Our study found that therapists would like to maintain a high level of control over the AI functions, for example, discounting scores from the participants who dropped out of the session early and the content of the automated resource recommendations. Therefore, the AICF dashboard may require further refinement in order to provide ease of use and adaptability into practice. Recommendations included a dashboard that does not pose too much added burden or stress, is easy-to-understand, and that leads to or helps provide actionable insights. Specific suggestions include the placement of the essential graphics, developing a threshold to show extreme distress that signals clinical actions, and easy control over the automated functions.

A previous study [4] reported an AI system that automatically processes the transcripts of therapy sessions to generate a fidelity score for motivational interviewing. A focus group was conducted in that study with cognitive behavioral therapists regarding the system's acceptability, appropriateness, and feasibility after watching a demonstration video of the technology. The feedback was generally positive. Similar to the findings in our study, therapists questioned the ability of detecting nonverbal cues and group cohesion. Similar to the concerns regarding our distress warning, the therapists in that study were also concerned about receiving low scores and how this would affect their self-perceived competence. With respect to ethical liability, the therapists also wanted to have more transparency on how the fidelity scores were calculated based on the session content.

The recent public health restrictions due to the COVID-19 pandemic served as an impetus for digital transformation in addressing mental health needs virtually. Consequently, digital means have become the main mode of mental health service delivery [32]. Moreover, privacy and confidentiality concerns over web-based teleconference calls have greatly lessened for most patients. Although CancerChatCanada group offerings and attendance [33] suggest positive experiences and good uptake with text-based groups, the therapists in the focus groups suggested that their group patients often expressed preference for teleconferencing, for example, cloud-based videoconferencing meeting over a text-based platform. Future research could consider assessing how to process transcripts generated by videoconferencing software for real-time analytics. Research efforts should also include the analysis of videos to track emotional states and the level of engagement of online group participants. Although AICF can be further refined, our findings have implications on exploring real-time voice-to-text technology and facial expression emotion analysis technology in a videoconferencing software.

An interesting point raised by the therapists is that AICF should be able to detect healthy and unhealthy emotions. The pressure to feel a need to only express positive emotions can occur in a group, including text-based groups, and may inhibit the expression of negative emotions, including sadness. This pattern can occur in both text-based and in-person groups and influence group participants to feel the need to remain positive to mask their negative feelings [29,34]. This response can result in feelings of isolation and further unmet needs and prevent open and authentic expression of emotions [35]. Therefore, further research is required to improve training of the algorithm to identify individuals who display unusual levels of expression of positive emotion in the context of cancer support groups.

Although AICF only showed a weak correlation with the patient-selected emoji scales, LIWC did not show any significant relationships. The lack of significant or consistent correlations among AICF, LIWC, and self-report IES-R is similar to that reported in other studies. A recent study found that LIWC emotion scores were not significantly associated with self-reports of emotional experience in the general population [36]. In another study addressing patients with subclinical depression, no correlation was found between the self-reported survey and the LIWC negative emotion score [37]. Lastly, in a study where patients were asked to watch a sad video, their self-reported emotions and LIWC scores were not significantly associated [38]. These findings suggest that patients do not express their emotional state verbally, indicating that analyzing textual data for emotions may be insufficient. The findings also imply that a static measure of emotions is not a good representation of a patient's real-time emotional state. The Internet of Things appears promising for capturing relevant emotional and clinical outcomes of patients in real time. Wearable watches or sensors are gaining popularity to measure biometric and clinical outcomes such as heart rate variability, blood pressure, heart rate, skin temperature, galvanic skin responses, and goosebumps [39,40]. By leveraging the machine-learning signal processing algorithms and cloud-based computing services, we will be able to develop a novel way of detecting and tracking patient emotions and predicting clinical progress beyond analyzing textual data. Tracking emotions is an ethically complex subject; therefore, this type of study should strictly follow the informed consent process and comply with the protection of privacy and intimacy principle of data acquisition [41].

The functions of AICF, such as the text-based conversation summary, recommender system, engagement score, and group cohesion score, were helpful for tracking patient progress only if the information displayed in the dashboard was simple, undistracting, and free of possible legal liability. The basic emoji check-in seems to be the best way to track and show real-time reactions of the online group participants. Emotional analysis using facial cues during videoconferencing seems to be promising. Future studies will investigate the Internet of Things for clinical outcome evaluation and video analysis for emotion tracking.

Acknowledgments

This study was funded by the Ontario Institute for Cancer Research.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Artificial intelligence–based co-facilitator methodology.
[DOCX File , 259 KB - cancer_v9i1e40113_app1.docx]

Multimedia Appendix 2
Artificial intelligence–based co-facilitator therapist interview guide.
[PDF File (Adobe PDF File), 53 KB - cancer_v9i1e40113_app2.pdf]

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Abbreviations

AI: artificial intelligence
AICF: artificial intelligence–based co-facilitator
IES-R: Impact of Event Scale-Revised
LIWC: Linguistic Inquiry and Word Count

Edited by A Mavragani; submitted 10.06.22; peer-reviewed by G Crombez, AM Lunde Huseboe; comments to author 25.10.22; revised version received 19.12.22; accepted 28.02.23; published 09.06.23.

Please cite as:
Leung YW, Ng S, Duan L, Lam C, Chan K, Gancarz M, Rennie H, Trachtenberg L, Chan KP, Adikari A, Fang L, Gratzer D, Hirst G, Wong J, Esplen MJ
Therapist Feedback and Implications on Adoption of an Artificial Intelligence–Based Co-Facilitator for Online Cancer Support Groups: Mixed Methods Single-Arm Usability Study
JMIR Cancer 2023;9:e40113
URL: https://cancer.jmir.org/2023/1/e40113
doi:10.2196/40113
PMID:37294610

Original Paper

Development of Quality of Life in Adolescents and Young Adults With Cancer Using a Patient Support Smartphone App: Prepost Interventional Study

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Abstract

Background: Adolescents and young adults often experience existential concerns in addition to side effects during a cancer trajectory, which they often carry alone. Thus, cohesion with other adolescents and young adults with cancer is essential but difficult due to the relatively small, widely dispersed nationwide population. In cocreation, a smartphone app has been developed and includes an information bank, a symptom tracker, and a social community platform, aiming to improve the quality of life (QoL) in this patient group.

Objective: This nationwide, multicenter study aimed to investigate the QoL in adolescents and young adults undergoing a cancer trajectory as they used the app for 6 weeks.

Methods: Via youth support initiatives, participants were recruited from hospitals in all regions of Denmark. Inclusion criteria were patients with cancer aged 15-29 years who either initiated any cancer treatment or started follow-up after cancer treatment within 30 days. Participants used the adolescents and young adults cancer app for 6 weeks. Before and after the 6 weeks of app use, they completed the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30). The participants were divided into a treatment and a follow-up group for analysis. A high score for a functional scale or the global health or overall QoL represents a high or healthy level of functioning or high QoL, respectively; however, a high score for a symptom scale or item represents a high level of symptomatology.

Results: Overall, 81 participants were recruited. However, 4 participants did not answer the questionnaire and 6 participants did not use the app. In the treatment group (n=36), significant improvement was found in 2 domains: “Role functioning” (baseline median 33.33, IQR 16.67-83.33 vs 6 weeks median 66.67, IQR 33.33-83.33; *P*=.04) and “Pain” (baseline median 33.33, IQR 16.67-50.00 vs 6 weeks median 16.67, IQR 0.00-33.33; *P*=.04). The “Global health/Overall QoL” scale remained stable (baseline median 58.33, IQR 45.83-77.08 vs 6 weeks median 62.50, IQR 41.67-75.00; *P*=.25). In the follow-up group (n=35), significant improvement was found in 3 domains: “Physical functioning” (baseline median 79.23, IQR 73.33-93.33 vs 6 weeks median 82.86, IQR 73.33-100.00; *P*=.03), “Cognitive functioning” (baseline median 62.38, IQR 50.00-83.33 vs 6 weeks median 69.52, IQR 50.00-100.00; *P*=.02), and “Social functioning” (baseline median 76.19, IQR 50.00-100.00 vs 6 weeks median 85.71, IQR 83.33-100.00; *P*=.05), as well as in the “Global health/Overall QoL” scale (baseline median 57.14, IQR 83.33-100.00 vs 6 weeks median 75.0, IQR 62.91-85.73; *P*<.001).

Conclusions: In this study, we found an improvement in specific QoL scales for both participants in treatment and follow-up when using the app for 6 weeks. The global health or overall QoL score improved significantly in the follow-up group. In the treatment group, it remained stable.

International Registered Report Identifier (IRRID): RR2-10.2196/10098

(JMIR Cancer 2023;9:e49735) doi:10.2196/49735

KEYWORDS

adolescent; young adult; cancer; quality of life; eHealth; smartphone application; application; development; interventional study; youth; grief; symptom tracker; social community; Denmark; physical functioning; treatment; mobile phone

Introduction

Each year, 600 adolescents and young adults aged 15-29 years are diagnosed with cancer in Denmark. Further, an increase in young cancer survivors exists due to cancer detection improvement and advanced cancer therapy [1,2]. Adolescents and young adults with cancer and young cancer survivors represent a unique patient group undergoing identity development during the cancer trajectory [3]. They are, therefore, vulnerable to identity and existential concerns. The concerns can leave them anxious and loaded with grief, which they often carry alone. Cohesion with other adolescents and young adults is essential, for example, through modern technological solutions such as online networks [4-7]. It is known that adolescents and young adults in cancer treatment often experience a burdensome trajectory, accumulating several symptoms during treatment, and it is not uncommon that quality of life (QoL) decreases [8,9].

User involvement and patient-reported outcome (PRO) are new perspectives implemented in scientific projects in recent years, focusing on aspects from patients' points of view [10-13]. The Danish smartphone app, "Kræftværket," aimed at adolescents and young adults with cancer, was created based on user involvement and by request of the users [5,14]. The app was developed to improve the QoL across diagnosis, gender, and age subgroups among adolescents and young adults [14]. It was designed by and for adolescents and young adults with cancer in 2018 and was implemented nationally as part of a research project in 2019 with great success [15]. Currently, 650 adolescents and young adults are active on the adolescents and young adults cancer app platform. The users are a mix of adolescents and young adults in active cancer treatment and adolescents and young adults in follow-up. The platform includes a tracking module focusing on symptoms and activities, an information bank including both text and video material, and a social community platform that facilitates networking and sharing experiences. Tracking symptoms using PROs during cancer trajectories has been shown to improve QoL [16].

The feasibility of using the adolescents and young adults cancer app has previously been demonstrated [5]. Further, a pilot study assessing the QoL at baseline and after 6 weeks of use of the same app was conducted in a very small population unaligned to the start of the treatment [14]. Preliminary results from the single-center pilot study suggested a possible positive effect when using the adolescents and young adults cancer app during cancer treatment and follow-up [17]. Still, a confirmatory study in a larger, national population is needed.

The aim of this national, multicenter study was to investigate QoL in a more extensive and aligned population with adolescents and young adults in a cancer trajectory as they used the adolescents and young adults cancer app for 6 weeks.

Methods

Participants

Eligible patients were adolescents and young adults aged 15-29 years who, within 30 days, either were (1) diagnosed with cancer and starting any cancer treatment or (2) starting follow-up after cancer treatment.

Inclusion criteria were adolescents and young adults aged 15-29 years with access to smartphones and the internet, including cellular data or Wi-Fi. Exclusion criteria were participating in the cocreation process and inability to read and write in Danish.

Study Setting and Recruitment

The study is anchored at the Departments of Oncology, Haematology, and Paediatrics and Adolescent Medicine at the Copenhagen University Hospital, Rigshospitalet, in the youth support center, Kræftværket. The study is national, including all regions in Denmark. Recruitment took place at the Department of Oncology at Odense University Hospital; the Department of Blood Diseases at Aarhus University Hospital; the Departments of Haematology at Zealand University Hospital, Roskilde, and Aalborg University Hospital; and the Department of Oncology and Haematology at Copenhagen University Hospital, Rigshospitalet.

Before recruitment, the distribution of adolescents and young adults in the respective regions was calculated to secure equality. The estimated recruitment was calculated to: 35% (35/100) of patients from the Capital Region of Denmark (Copenhagen University Hospital, Rigshospitalet), 21% (21/100) of patients from the Region of Southern Denmark (Odense University Hospital), 21% (21/100) of patients in the Central Denmark Region (Aarhus University Hospital), 14% (14/100) of patients from the Region Zealand (Zealand University Hospital, Roskilde), and 9% (9/100) of patients from the North Denmark Region (Aalborg University Hospital).

Participants were recruited from September 14, 2020, through May 2022, and a convenience sampling method was adopted. Potentially 600 individuals were recruitable each year from these departments; however, no screening log was used in this study.

Nurse specialists and adolescents and young adults youth coordinators sought to invite all adolescents and young adults undergoing a cancer trajectory to one of the abovementioned departments. Recruitment strategies also included advertisement in closed groups on social media such as Facebook and at social events at the youth facility centers.

Verbal and written study information was provided to eligible patients within the hospitals by the adolescents and young adults youth coordinators. The youth coordinators help adolescents and young adults with cancer navigate the health care system through their cancer trajectory and manage social events and activities in the existing social support groups. The youth coordinators also obtained informed consent. Finally, they helped with app information and installation guides and were available if the participants had questions about the study or needed support for the app.

Intervention

The intervention in this study was a health app specially developed to improve the QoL in adolescents and young adults with cancer. The Kræftværket app has three primary features: (1) a symptom and activity diary, (2) a supportive communication network between app users, and (3) a "one-stop shop" information bank with practical information as well as links to patient organizations and other resources.

The intervention requires that adolescents and young adults use the app over the course of 6 weeks and complete a baseline and follow-up European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30) health-related QoL inventory. Further information on the app's features and modules has previously been published [14]. The 6-week app use period was decided based on a comparable study including Danish adolescents and young adults with diabetes showing that the number of young people using the eHealth tool decreased after 6 weeks [18]. Both Android and iPhone operating systems were compatible with the intervention app.

Questionnaires

The participants were asked to complete 2 questionnaires. The first was the validated QoL EORTC QLQ-C30 (version 3.0) questionnaire [19-21]. This was used to assess the QoL at baseline and after 6 weeks of use of the adolescents and young adults cancer app. The EORTC QLQ-C30 questionnaire consists of functional scales, a global health or overall QoL scale, and symptom scales. A high score for a functional scale or the global health or overall QoL represents a high or healthy level of functioning or high QoL, respectively. On the contrary, a high score for a symptom scale or item represents a high level of symptomatology. For statistical analysis, scoring the EORTC QLQ-C30 scales is necessary, and the *EORTC QLQ-C30 Scoring Manual* was used for this purpose [22].

The second questionnaire focused on the experience of the social community platform available in the app. The results on the experience of the social community platform are reported elsewhere [23].

Statistical Analysis

Our study was initially inspired by studies performed in populations with breast cancer for testing apps as interventions for improving QoL and well-being. These studies comprised 30 to 78 participants [24] and investigated an app in adolescents and young adults with diabetes [25,26].

Since the minimum important difference being clinically meaningful for EORTC QLQ-C30 in adolescents and young adults with cancer undergoing therapy and in follow-up was not known at the time of designing the study, the intended sample size of 100 was solely based on experience from other similar studies.

The raw data from the EORTC QLQ-C30 questionnaires were entered into an Excel file (Microsoft Office version 2018) and imported to the statistical software program R (version 1.4.1717; Lucent Technologies). Using the *PRO Score* package, the raw data was transformed into the global health or overall QoL scale, the functional scales, and the symptom scales [22].

We examined for normal distribution within each scale with histograms and quantile-quantile plots. Since no scales were normally distributed, we used the Wilcoxon signed rank exact test to determine potential differences from baseline and after 6 weeks. Data from the participants were divided into 2 groups: participants in cancer treatment and participants in follow-up. All participants were included in the descriptive statistical analysis and baseline analysis. Participants in both groups who did not fill out the questionnaire after 6 weeks or did not use the app during the study period were not included in the statistical analysis of the EORTC QLQ-C30 scores.

Ethical Considerations

As from May 26, 2021, ethical approval in intervention studies with smartphone apps using QoL-questionnaires as outcome were mandatory according to the Danish ethical committee [27]. However, the initiation of this study was prior to this date; thus, this study was exempt from ethical approval according to Danish law. Data approval from the Danish Data Protection Agency (P-2020-317) was achieved before recruitment. Written informed consent was obtained from all study participants. In cases where the participant was younger than 18 years, the caretaker's consent was obtained.

In this study, the data are anonymous. Participants did not receive compensation.

Results

Recruitment

In total, 85 participants were recruited for the study. Further, 2 participants were excluded, and another 2 participants withdrew their informed consent. We did not receive the EORTC QLQ-C30 questionnaire after 6 weeks from 4 participants: 2 from the treatment group and 2 from the follow-up group. The reasons for this were that 1 died, 1 had problems with the app, 1 was too ill, and 1 was unknown. Further, 6 participants did not use the app: 5 from the treatment group and 1 from the follow-up group. However, 4 of the 6 participants still answered the EORTC QLQ-C30 questionnaire at baseline and after 6 weeks. The reasons why the participants did not use the app were that some of the participants were too ill (n=3), were in shock over their cancer diagnosis (n=2), or did not need the app (n=1).

Participants who did not fill out the questionnaire after 6 weeks and those who did not use the app were excluded from the final comparison analysis. After exclusion, the participants were equally distributed, with 36 participants in the treatment group and 35 in the follow-up group (Figure 1). Recruitment was achieved by the distribution estimation (Table 1).

Figure 1. Flowchart showing recruitment of participants and reasons of exclusion. EORTC QLQ-C30: European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30.

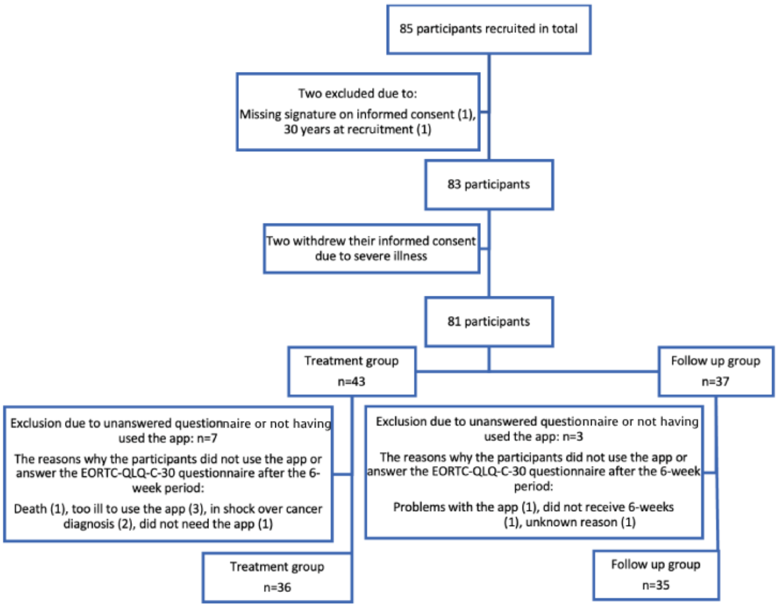


Table 1. Regional distribution of participants.

Recruitment region	Estimated participants (n=100), n (%)	Recruited participants (n=81), n (%)
The Capital Region of Denmark (Copenhagen University Hospital, Rigshospitalet)	35 (35)	34 (42)
Region Zealand (Zealand University Hospital, Roskilde)	14 (14)	10 (12)
Region of Southern Denmark (Odense University Hospital)	21 (21)	15 (18)
Central Denmark Region (Aarhus University Hospital)	21 (21)	13 (16)
North Denmark Region (Aalborg University Hospital)	9 (9)	9 (11)
Total	100 (100)	81 (100)

Characteristics in the Study Population

Demographic data showed equal distribution of gender, with a slightly overweight of women compared to men in both the treatment and the follow-up group. Additionally, age and age range were similar in both groups. Clinical data showed a representation of same cancer types in both groups except that gastrointestinal cancer (n=2), thyroid cancer (n=1), and uterus cancer (n=1) appeared in the treatment group only. In the follow-up group, central nervous system cancer (n=2), neuroendocrine tumor (n=1), and malign melanoma (n=1) appeared (Table 2).

Table 2. Demographic and clinical data of the participants.

Characteristics	Treatment group (n=36)	Follow-up group (n=35)
Gender, n (%)		
Men	16 (44)	16 (46)
Women	20 (56)	19 (54)
Age (y), median (range)	24 (18-29)	23 (18-29)
Cancer type, n (%)		
Lymphoma	15 (42)	11 (31)
Breast	1 (3)	2 (6)
Leukemia	5 (14)	5 (14)
Testicular	7 (19)	7 (20)
GI[a]	2 (6)	0 (0)
Thyroid	1 (3)	0 (0)
CNS[b]	0 (0)	2 (6)
NET[c]	0 (0)	1 (3)
Sarcoma	1 (3)	3 (9)
Ovarian	2 (6)	2 (6)
Cervix	1 (3)	1 (3)
Malignant melanoma	0 (0)	1 (3)
Uterus	1 (3)	0 (0)

[a] GI: gastrointestinal.

[b] CNS: central nervous system.

[c] NET: neuroendocrine tumor.

EORTC QLQ-C30 Scores

In the treatment group, significant change was found in 2 domains from baseline to after 6 weeks. Both in the domain “Role functioning” (baseline median 33.33, IQR 16.67-83.33 vs 6 weeks median 66.67, IQR 33.33-83.33; *P*=.04) and the domain “Pain” (baseline median 33.33, IQR 16.67-50.00 vs 6 weeks median 16.67, IQR 0.00-33.33; *P*=.04), the score was improved after 6 weeks (Table 3).

Table 3. EORTC QLQ-C30[a] scores in the treatment group.

Treatment group (n=36)	Baseline, median (IQR)	6 weeks, median (IQR)	Wilcoxon pseudo median (95% CI)	Wilcoxon *P* value (<.05)
Global health or overall QoL[b]	58.33 (45.83-77.08)	62.50 (41.67-75.00)	–4.49 (–13.08 to 4.00)	.25
Physical functioning	80.00 (60.00-93.33)	80.00 (73.33-88.33)	0.71 (–6.69 to 6.83)	.57
Role functioning	33.33 (16.67-83.33)	66.67 (33.33-83.33)	–15.34 (–25.67 to –0.63)	.04
Emotional functioning	70.83 (58.33-83.33)	66.67 (58.33-83.33)	0.61 (–5.12to 8.96)	.72
Cognitive functioning	83.33 (62.50-100.00)	83.33 (50.0-83.33)	2.56 (–1.88 to 10.18)	.29
Social functioning	66.67 (50.00-83.33)	66.67 (50.0-83.33)	0.63 (–8.02 to 9.12)	.70
Fatigue	55.56 (33.33-77.78)	55.56 (33.33-80.56)	0.33 (–10.80 to 11.23)	.81
Nausea or vomiting	16.67 (0.00-33.33)	0.00 (0.00-20.83)	7.43 (–0.28 to 15.18)	.09
Pain	33.33 (16.67-50.00)	16.67 (0.00-33.33)	16.66 (0.974 to 26.14)	.04
Dyspnea	16.67 (0.00-33.33)	0.00 (00.00-33.33)	1.54 (–2.44 to 15.10)	.32
Insomnia	33.33 (0.00-66.67)	33.33 (25-41.67)	–1.28 (–16.82 to 14.61)	.68
Appetite loss	33.33 (0.00-66.67)	00.00 (0.00-33.33)	13.32 (–3.30 to 31.75)	.32
Constipation	00.00 (0.00-33.33)	00.00 (0.00-33.33)	–1.29 (–17.40 to 14.54)	.68
Diarrhea	00.00 (0.00-33.33)	00.00 (0.0-33.33)	2.16 (–2.10 to 15.48)	.46
Financial difficulties	00.00 (0.00-33.33)	00.00 (0.00-33.33)	–0.35 (–4.032 to 2.79)	.77
QLQ-C30[c] summary score	71.71 (54.62-80.32)	74.17 (62.30-84.83)	–3.75 (–10.54 to 3.16)	.29

[a] EORTC QLQ-C30: European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30.

[b] QoL: quality of life.

[c] QLQ-C30: Quality of Life Questionnaire Core 30.

In the follow-up group, significant change was found in 3 functional domains from baseline and after 6 weeks. In all 3 domains, “Physical functioning” (baseline median 79.23, IQR 73.33-93.33 vs 6 weeks median 82.85, IQR 73.33-100.00; *P*=.03), “Cognitive functioning” (baseline median 62.38, IQR 50.00-83.33 vs 6 weeks median 69.52, IQR 50.00-100.00; *P*=.02), and “Social functioning” (baseline median 76.19, IQR 66.67-100.00 vs 6 weeks median 85.71, IQR 83.33-100.00; *P*=.046), the score was improved after 6 weeks. Further, the “Global health/overall QoL” scale enhanced over time (baseline median 57.14, IQR 41.67-66.67 vs 6 weeks median 75.0, IQR 54.17-83.33; *P*<.001). A significant change was also seen in the “QLQ-C30 summary score” (baseline median 74.95, IQR 62.91-85.73 vs 6 weeks median 79.41, IQR 62.91-85.73; *P*=.03; Table 4).

In the follow-up group, a significant change was found in the score “Global health/overall QoL.” In contrast, the insignificant score in the treatment group (Figure 2).

Table 4. EORTC QLQ-C30[a] scores in the follow-up group.

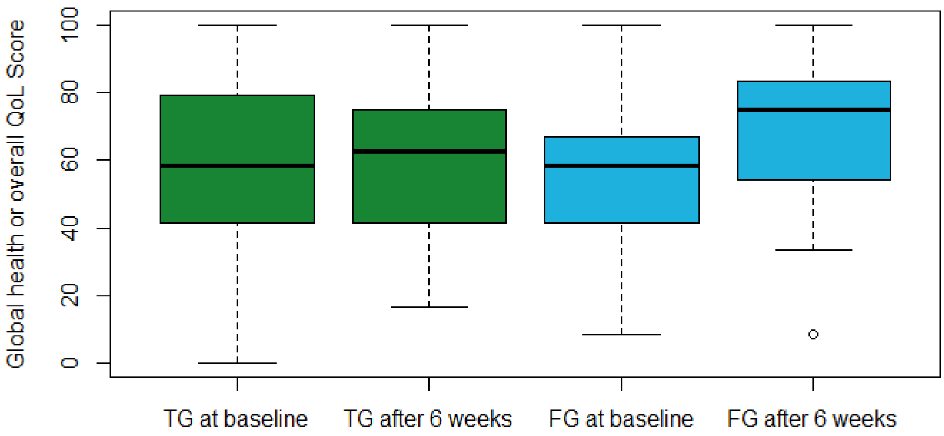
Follow-up group (n=35)	Baseline, median (IQR)	6 weeks, median (IQR)	Wilcoxon pseudo median (95% CI)	Wilcoxon *P* value (<.05)
Global health or overall QoL[b]	57.14 (41.67-66.67)	75.00 (54.17-83.33)	–8.99 (–16.56 to –4.66)	<.001
Physical functioning	79.24 (73.33-93.33)	82.86 (73.33-100.00)	–3.56 (–6.81 to –0.094)	.03
Role functioning	66.67 (50.00-91.67)	73.81 (58.33-100.00)	–5.54 (–17.42 to 6.02)	.27
Emotional functioning	65.47 (50.00-83.33)	72.38 (62.50-87.50)	–4.84 (–12.14 to 0.13)	.07
Cognitive functioning	62.38 (50.00-83.33)	69.52 (50.00-100.00)	–8.48 (–16.20 to –0.70)	.02
Social functioning	76.19 (66.67-100.00)	85.71 (83.33-100.00)	–8.25 (–17.12 to –0.06)	.046
Fatigue	46.03 (22.22-66.67)	39.05 (22.22-50.00)	6.49 (–0.027 to 14.60)	.05
Nausea or vomiting	12.38 (0.00-16.67)	10.00 (0.00-16.67)	0.69 (–0.72 to 2.23)	.22
Pain	21.90 (0.00-41.67)	19.05 (0.00-33.33)	1.39 (–2.35 to 10.44)	.37
Dyspnea	14.29 (0.00-33.33)	12.38 (0.00-33.33)	0.57 (–2.75 to 11.53)	.69
Insomnia	39.05 (16.67-66.67)	35.24 (0.00-66.67)	1.86 (–1.16 to 11.40)	.23
Appetite loss	20.95 (0.00-33.33)	17.14 (0.00-33.33)	–0.48 (–4.71 to 4.01)	.76
Constipation	13.33 (0.00-16.67)	9.52 (0.00-16.67)	0.56 (–2.16 to 3.55)	.67
Diarrhea	7.62 (0.00-16.66)	9.52 (0.00-16.67)	–1.07 (–3.38 to 0.82)	.23
FI: financial difficulties	16.19 (0.00-33.33)	17.14 (0.00-33.33)	–0.75 (–3.46 to 4.28)	.61
QLQ-C30[c] summary score	74.95 (62.91-85.73)	79.41 (71.65-90.38)	–3.47 (–7.08 to –0.37)	.03

[a] EORTC QLQ-C30: European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30.

[b] QoL: quality of life.

[c] QLQ-C30: Quality of Life Questionnaire Core 30.

Figure 2. Boxplot showing the global health or overall QoL score at baseline and after 6 weeks in the TG and in the FG. FG: follow-up group; QoL: quality of life; TG: treatment group.



Discussion

Principal Findings

In this study, we found an improvement in specific QoL scales for both adolescents and young adults in treatment and adolescents and young adults in follow-up when using the app for 6 weeks.

Significant improvement from baseline throughout the 6 weeks was found in the follow-up group related to the physical, cognitive, and social functions, as well as for role functioning and pain in the treatment group. In the follow-up group, the global health or overall QoL score improved significantly. In the treatment group, it remained stable.

These results support the findings from the more unstructured and smaller pilot study by Pappot et al [17], where QoL was first tested when using the same adolescents and young adults cancer app. As in this study, the pilot study found a significant increase in overall QoL after 6 weeks in the follow-up group. For the treatment group, the QoL remained stable throughout the 6 weeks. This initial finding could have been due to the single-center nature of the study. This study is strengthened by the fact that the app as an intervention was developed in a single institution and tested in a national, multicenter study. Participation in the cocreation process was an exclusion criterion for this study.

Adolescents and young adults in cancer treatment often experience a burdensome trajectory, accumulating several symptoms during treatment, and it is not uncommon that QoL decreases [8,9]. In this study, no decrease in QoL after 6 weeks is seen despite the expectation of increasing symptom burden during treatment. The stable level of the overall QoL among adolescents and young adults in treatment is therefore interpreted as a positive result.

In addition, patients with hematological diagnoses were overrepresented in the cancer treatment group compared to the follow-up group (20/36, 56% vs 16/35, 45%), which could influence the symptom frequency negatively due to severe symptoms during treatment among hematological patients [28]. Therefore, the significant improvement in the symptom domain “Pain” is interesting, since pain is often sustained during cancer treatment [8]. However, the improvement might be explained by adolescents and young adults cancer app use, as previously suggested, within patients with cancer and chronic pain [29-31].

Among adolescents and young adults in cancer treatment, results show significant improvement in the domain of “Role functioning.” This can be explained not by the effect of using the adolescents and young adults cancer app only but by the phenomenon of “Response shift,” where the meaning of an individual’s self-evaluation of their health status and QoL change over time [32]. Adolescents and young adults in cancer treatment are likely to transition from experiencing initial crisis and loss of control at diagnosis to accepting their diagnosis and situation. An increase in awareness and use of coping strategies supports this transition in this patient group [33].

Several others have demonstrated that QoL is reported to decrease compared to the background population, especially regarding the social, emotional, cognitive, role, and physical functions [34,35]. It is essential to notice that Husson et al [34] found no difference in QoL among short- and long-term lymphoma survivors. Furthermore, Geue et al [35] found that adolescents and young adults had reduced QoL in comparison with the general population even a long time after the treatment was completed, where female adolescents and young adults with cancer reported significantly lower QoL compared to male adolescents and young adults with cancer. This argues the need for great awareness of the risk of a long-term decrease in QoL among adolescents and young adults survivors after cancer and how to prevent this [7,36]. Significant increase in several functional domains were found for both the treatment and follow-up groups in our study, suggesting that adolescents and young adults cancer apps could benefit this patient group during cancer treatment and follow-up. The results in our study mirror the findings of others related to the association between smartphone app use and QoL in young patients with cancer. The pilot randomized clinical trial by El-Jawari et al [37] found that their psychological smartphone app for young, newly diagnosed patients with acute myeloid leukemia showed significant improvement in QoL (Functional Assessment of Cancer Therapy-Leukemia) and self-efficacy (Cancer Self-Efficacy Scale) and a decrease in symptom burden (Edmonton Symptom Assessment Scale) in patients using the smartphone app compared to the patients receiving standard care. Additionally, the meta-analysis by Siew et al [38] demonstrated that social media–based interventions significantly improved QoL and anxiety symptoms among patients with cancer.

A possible reason contributing to the significant increase in QoL in the follow-up group in our study could be that the smartphone app enabled a community with equals outside the hospital and beyond the cancer trajectory. The qualitative interviews conducted in our study population showed that some adolescents and young adults assessed the social forum as more valuable at diagnosis, while others experienced meaningful peer support after cancer [23]. Lea et al [39] also found in their qualitative study that adolescents and young adults with cancer were underprepared for and challenged by the unexpected, emotional, and physical consequences of ending cancer treatment. By providing an online community, the smartphone app could potentially bridge the transition from ending cancer treatment into the follow-up trajectory for adolescents and young adults with cancer.

Strengths and Limitations

A limitation of this study is that we do not have data linking time consumption at each of the 4 modules in the adolescents and young adults cancer app to each study participant. We can, therefore, not adjust for this in the analyses and come closer to whether changes in QoL are associated with the adolescents and young adults cancer app or other external factors. Especially in the treatment group, external factors such as medical oncological treatments with accompanying side effects, supportive care medication, and other health care interventions might interfere with QoL.

Further, if we had included a control group in the study, the impact of the app on QoL would have been better elucidated.

A bias might be that patients for the study were recruited and helped to download the adolescents and young adults cancer app by youth coordinators. The contact with these health care professionals might also have influenced QoL. Furthermore, results might have been different if the use was prompted by health care professionals throughout the cancer trajectory and integrated as part of the clinical care.

Originally, it was planned to include 100 patients [14]. Due to the global pandemic with COVID-19, recruitment was ended at 85 participants. However, the estimated geographical distribution was maintained.

Other limitations might be selection bias and missing data, which could influence the internal validity and generalizability of our findings.

A strength of this study is the nationwide design, including adolescents and young adults with cancer from all regions in Denmark with a broad variation in diagnosis and age distribution. The study is also strengthened because the adolescents and young adults cancer app was thoroughly developed in cocreation with adolescent and young adult patients aiming to improve QoL [5,14,15].

Further Implications

This study and previous findings [40] on the impact of this adolescents and young adults cancer app on adolescent and young adult patients' lives have led to the decision to implement the adolescents and young adults cancer app on a national level in Demark. However, the effect on self-empowerment and self-efficacy of using the app, as well as the impact on different functionalities of the app on QoL, remain to be investigated further. Furthermore, it must be acknowledged that apps are dynamic tools that need continuous development and adaptation to new challenges.

Conclusions

In this study, we found an improvement in specific QoL scales for both adolescents and young adults in treatment and adolescents and young adults in follow-up when using the app for 6 weeks.

The global health or overall QoL score improved significantly in the follow-up group. In the treatment group, it remained stable.

Acknowledgments

All departments mentioned were essential collaboration partners regarding recruitment and study conduction. Additionally, the participation of adolescents and young adults with cancer is highly appreciated. Finally, thanks to Julius Lund-Jacobsen, CEO at Viceron ApS, for support in the statistical program R during the statistical analysis phase. This study was financially supported by Tryg Fonden (grant 120451).

Data Availability

The data sets generated and analyzed during this study are not publicly available due to the Danish data protection rules but could be available from the corresponding author on reasonable request.

Authors' Contributions

Conceptualization of this research paper was done by LB, SH, and HP; methodology and formal analysis were performed by HP and LB; in writing the original draft preparation was by LB; review and editing was done by LB, SH, MH, MBB, MT, AB, CL, and HP; supervision was by SH and HP; HP did the project administration. All authors have read and agreed on the published version of this paper. No content generated by artificial intelligence was incorporated into this paper.

Conflicts of Interest

None declared

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Abbreviations

EORTC QLQ-C30: European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30
PRO: patient-reported outcome
QoL: quality of life

Edited by T de Azevedo Cardoso; submitted 09.06.23; peer-reviewed by P Hoogendoorn, S Amin; comments to author 14.08.23; revised version received 28.09.23; accepted 27.10.23; published 04.12.23.

Please cite as:
Bentsen L, Hanghøj S, Hjerming M, Bergmann MB, Thycosen M, Borup A, Larsen C, Pappot H
Development of Quality of Life in Adolescents and Young Adults With Cancer Using a Patient Support Smartphone App: Prepost Interventional Study
JMIR Cancer 2023;9:e49735
URL: https://cancer.jmir.org/2023/1/e49735
doi:10.2196/49735
PMID:38048144

Original Paper

An Actionable Expert-System Algorithm to Support Nurse-Led Cancer Survivorship Care: Algorithm Development Study

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Abstract

Background: Comprehensive models of survivorship care are necessary to improve access to and coordination of care. New models of care provide the opportunity to address the complexity of physical and psychosocial problems and long-term health needs experienced by patients following cancer treatment.

Objective: This paper presents our expert-informed, rules-based survivorship algorithm to build a nurse-led model of survivorship care to support men living with prostate cancer (PCa). The algorithm is called No Evidence of Disease (Ned) and supports timelier decision-making, enhanced safety, and continuity of care.

Methods: An initial rule set was developed and refined through working groups with clinical experts across Canada (eg, nurse experts, physician experts, and scientists; n=20), and patient partners (n=3). Algorithm priorities were defined through a multidisciplinary consensus meeting with clinical nurse specialists, nurse scientists, nurse practitioners, urologic oncologists, urologists, and radiation oncologists (n=17). The system was refined and validated using the nominal group technique.

Results: Four levels of alert classification were established, initiated by responses on the Expanded Prostate Cancer Index Composite for Clinical Practice survey, and mediated by changes in minimal clinically important different alert thresholds, alert history, and clinical urgency with patient autonomy influencing clinical acuity. Patient autonomy was supported through tailored education as a first line of response, and alert escalation depending on a patient-initiated request for a nurse consultation.

Conclusions: The Ned algorithm is positioned to facilitate PCa nurse-led care models with a high nurse-to-patient ratio. This novel expert-informed PCa survivorship care algorithm contains a defined escalation pathway for clinically urgent symptoms while honoring patient preference. Though further validation is required through a pragmatic trial, we anticipate the Ned algorithm will support timelier decision-making and enhance continuity of care through the automation of more frequent automated checkpoints, while empowering patients to self-manage their symptoms more effectively than standard care.

International Registered Report Identifier (IRRID): RR2-10.1136/bmjopen-2020-045806

(JMIR Cancer 2023;9:e44332) doi:10.2196/44332

KEYWORDS

prostate cancer; patient-reported outcomes; nurse-led model of care; expert system; artificial intelligence–powered decision support; digital health; nursing; algorithm development; cancer treatment; AI; survivorship; cancer

Introduction

Background

Comprehensive models of survivorship care are necessary to improve access to and coordination of care and to address the complexity of physical and psychosocial problems and long-term health needs experienced by patients following cancer treatment [1]. In Canada, for prostate cancer (PCa), follow-up treatment typically consists of specialist visits every 3 to 6 months for the first 5 years, and annually thereafter. During visits, the specialist routinely asks questions about treatment side effects in addition to blood work (ie, prostate-specific antigen [PSA] testing, testosterone). Sometimes imaging tests and or prostate biopsies are completed if PSA values rise [2]. With the increasing demand for posttreatment cancer follow-up care with oncologists at prespecified intervals, clinics are over capacity and lack the ability to prioritize complex patients or address emerging needs [1-3]. There is, therefore, a need for improved sharing of health information, supportive care between oncologist-led follow-up visits, and better care coordination [1,4]. In recent years, nurse-led cancer survivorship models have been widely adopted and accepted as an effective means to support patients at scale; nurse-led survivorship programs in the United States and the United Kingdom have demonstrated clinical effectiveness and cost-effectiveness while yielding high satisfaction among patients and supporting staff [1,5-7]. Systematic reviews suggest better integration of nursing roles in survivorship services will improve the quality of care, patient experience, and health outcomes, and will promote systems-wide cost savings by reducing the need for other health care services [8-11].

No Evidence of Disease (Ned) Model of Service

In accordance with these best practices, our group conceived the Ned (No Evidence of Disease) nurse-led virtual clinic to support men living with PCa in the posttreatment follow-up phase of their survivorship journey [12]. Patients who have completed treatment and are at low risk of cancer recurrence as determined by their specialist can enroll in Ned clinics. There are two arms of the Ned clinic: (1) baseline Ned Specialist and (2) Ned Nurse.

Ned Specialist contains the usual care touchpoints of the traditional specialist standard of care visits but is conducted asynchronously or with virtual calls when deemed appropriate by the specialist.

Ned Nurse works as an added layer of intervention with patient triaging and decision support guided by the Ned algorithm on top of Ned Specialist. What Ned Nurse and the Ned algorithm add to the Ned model of service is the ability to (1) more frequently monitor the quality of life–related aspects of survivorship care and (2) facilitate more holistic follow-up through the nurse-led service surrounding the algorithm. Within the broader Ned service, Ned nurse coordinators will leverage the embedded algorithm to triage follow-up care for enrolled patients via algorithm-driven tiered alerts that will support the Ned nurse with follow-up care prioritization. Ned Nurse will be embedded within the PCa clinic of each institution from which patients will be recruited. This will allow Ned nurses to liaise with patients' Ned specialists and follow up with general practitioners as necessary through institution-based processes for interdisciplinary communication. Additionally, the nurse-led model of care provides an opportunity for a high nurse-to-patient ratio, with the intent to support optimized survivorship care and the use of health system resources. Once enrolled, patients are remotely monitored by an advanced practice Ned nurse to identify any deterioration in the quality of life while continuing specialist follow-ups in parallel to assess for cancer recurrence. The assessment schedule is as follows: specialist visits continue to occur at regular intervals (eg, every 6 months, or annually). In preparation for this visit, patients complete a self-report tool like the validated Expanded Prostate Cancer Index Composite for Clinical Practice (EPIC-CP), which has been widely adopted for PCa survivorship symptom monitoring at major cancer centers across Canada [13] and can be completed as needed to monitor outcomes [14]. In between, there are monthly check-ins. The patient is prompted automatically through the system to complete the EPIC-CP. Both providers (specialist and Ned nurse) have shared access to the patient's medical history, lab results, and self-reported symptoms to maintain continuity of care. However, the Ned nurse is the patient's primary care provider to resolve their unmet health needs.

Research Aim and Purpose of the Ned Algorithm

While the application of algorithm-based decision support systems to guide PCa detection and treatment is not new [15-17], previous efforts have not focused on the survivorship context to optimize follow-up care. Therefore, there is an opportunity to develop an expert-informed PCa survivorship care algorithm to support decision-making for both patients and providers. Central to the implementation of the Ned clinics is the ability for nurses to manage the large roster of PCa survivors being followed up in Canada's largest cancer centers. Focusing these clinics on a stable patient population with "no evidence of disease" increases the feasibility of a high nurse-to-patient ratio to enable efficient and holistic care. The Ned algorithm provides decision support for Ned nurses by automatically triaging patient needs for follow-up (via their EPIC-CP score and change in score), and generates alerts for the nurses to oversee and follow up when necessary in the form of additional support and triaging to appropriate services as needed. Additionally, the Ned algorithm provides direct patient support so that patients may also benefit from tailored guidance to self-manage chronic symptoms [18].

The purpose of this study is to build a novel, rules-based, expert system—the Ned algorithm—for PCa survivors with Ned to support the nurse-led arm of Ned clinics in an ongoing trial [12]. The system consists of relevant survivorship indicators as inputs (EPIC-CP) and outputs actionable insights to a clinician dashboard and patient app. With the assistance of the algorithm, nurses can safely scale their services to remotely monitor patients in the Ned clinic. More importantly, they can perform data-driven and contextualized assessments of which patients require immediate intervention and provide timely care.

Methods

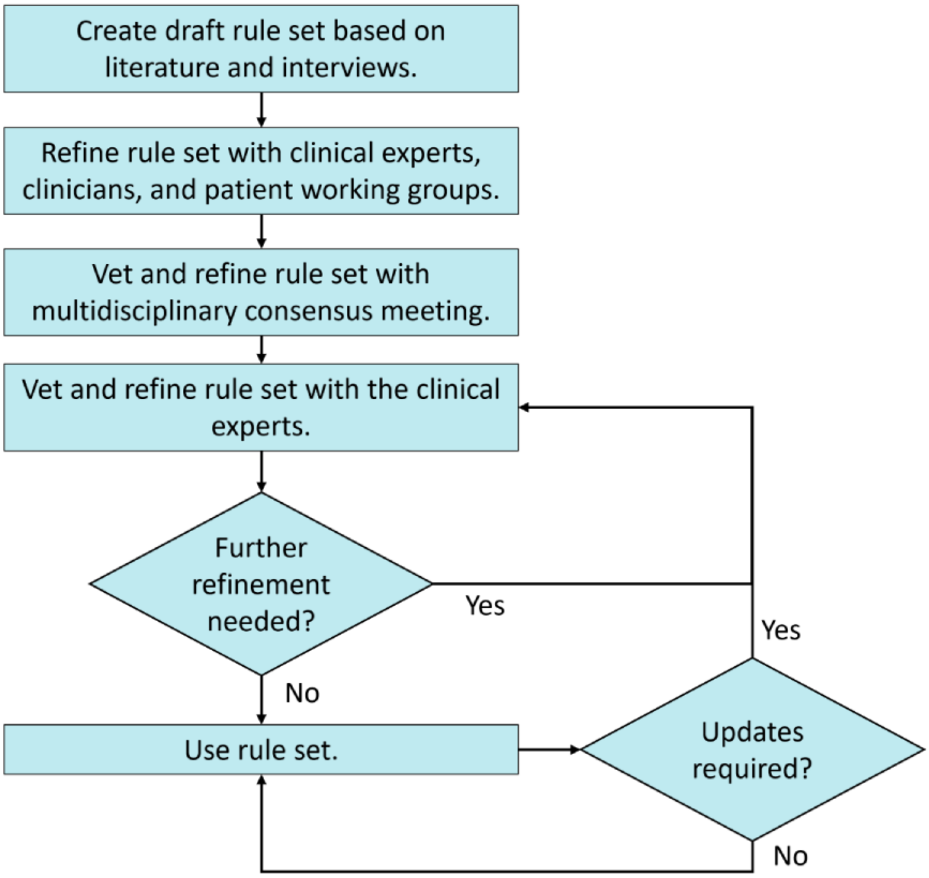
Ethics Approval

The process of developing the Ned algorithm was reviewed by the University Health Network (UHN) Quality Improvement Review Committee as part of a quality improvement initiative (QID 20-0114). This algorithm development was part of a larger project to develop and test the Ned platform for which approval was obtained through Clinical Trials Ontario (CTO) with the UHN Research Ethics Board as the board of record (Project ID 3238). This approval is a part of the larger CTO project portfolio, which maintains ethical oversight for all applicable activities associated with the Ned Nurse research program.

Development of the Ned Rule Set

An initial rule set was drafted using results from literature-informed ad-hoc subject matter expert interviews with our clinical champions to validate our foundational understanding of algorithm structure and notation (Figure 1). The draft rule set was then refined through 3 working groups of clinical experts across Canada (eg, nurse experts, physician experts, and scientists; n=20), and patient partners (n=3). The working group discussions were facilitated using the nominal group technique to develop consensus on important PCa survivorship inputs, appropriate care interventions, and system design requirements [19]. Our patient partners provided feedback on the initial lay design of the algorithm, particularly on how to position our survivorship algorithm to more strongly embed patient autonomy and empowerment. The rule set was further refined through a 1-day virtual consensus meeting to validate the proposed symptom inputs and alert outputs. The consensus meeting was recorded and meeting notes were taken for analysis.

Figure 1. Iterative user-centered process for rule development and validation.



Participants

A purposeful convenience sample was invited to participate in the consensus meeting as voting members based on their clinical and research expertise in oncology and cancer survivorship. Participants were recruited through participating sites for the trial (Ontario, Nova Scotia, and Alberta), as well as from subject matter experts on our investigator team. These participants had specialized expertise in cancer survivorship and PCa survivorship and represented major cancer care centers and research institutions across Canada. Working group participants consisted of clinical experts across Canada (eg, nurse experts, physician experts, and scientists; n=20), and nonvoting patient partners (n=3) to provide expertise on technology development and health service design. Algorithm priorities were defined through a multidisciplinary consensus meeting with clinical nurse specialists, nurse scientists, nurse practitioners, urologic oncologists, urologists, and radiation oncologists (n=17).

Preparation

We presented content and structure in accordance with a modified protocol from a previous algorithm consensus meeting to develop a heart failure telemonitoring system, which we adapted to meet the specific care needs of the PCa survivorship population [20]. An expert facilitator with experience in leading consensus meetings was recruited to lead the proceedings and support the overall voting process. Prior to the consensus meeting, a detailed package including PCa survivorship literature, a meeting agenda, and potential Ned algorithm inputs and outputs were disseminated to the consensus meeting participants.

System Refinement and Validation

The consensus meeting used the nominal group technique to develop the decision nodes and pathways of the Ned algorithm [19]. The nominal group technique allows for the pooling of judgment from a group of experts through 2 facilitated rounds of voting. Consensus was defined as at least 75% endorsement from votes. All votes were kept anonymous. In the first round of voting, assent and dissent regarding a particular component of the Ned algorithm (eg, inputs, alert states, and outputs) were assessed using a Zoom (Zoom Video Communications, Inc) poll. Members were asked whether they agreed or disagreed with a particular alert state. Participants who dissented were allocated 30 seconds to share their arguments and opinions with a 60-second response by our team. If consensus was not reached, a second round of voting was initiated. The algorithm alert states all passed the 75% consensus threshold necessary for validation.

Expert Input Responses and System Refinement

Following the consensus meeting, expert input and responses were used to refine the Ned algorithm and core components. Semistructured interviews (n=10) took place to refine and validate the prototype algorithm with clinical specialists and researchers based on their areas of expertise. Through these interviews, the vetted Ned algorithm, including core survivorship symptom inputs, rules for alert generation, and appropriate survivorship nursing interventions, was identified. Rules for escalation and clinically urgent symptoms were then translated into the algorithm.

Expert-Informed Validation of Alert State Classification

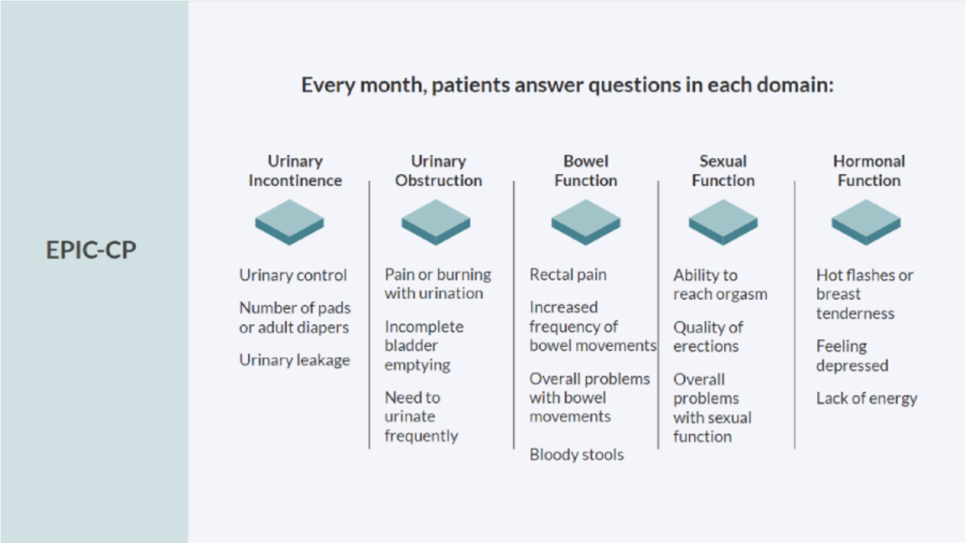
To validate the refined Ned algorithm, we prepared 2 rounds of fictitious case studies, each comprising 3 unique patients who presented with differing symptoms and needs. These case studies were designed to appraise the Ned algorithm's ability to discern the unique characteristics of each patient's reported symptoms, clinical context, the appropriate alert prioritization, and triaging of alerts. The case studies were assessed and analyzed by consensus meeting members (n=25), who were asked to review and prioritize alerts for both case studies and provide roundtable feedback.

Results

Algorithm Overview

The algorithm takes input from the patient self-report PCa composite index scale (ie, EPIC-CP), and flows to 2 levels of assessment (question and domain levels) to determine 1 of 4 possible triaged alerts (Figure 2). The alerts are green, yellow, orange, and red, where green means all domains have normal status and warmer colors represent higher levels of acuity, with red being the most acute.

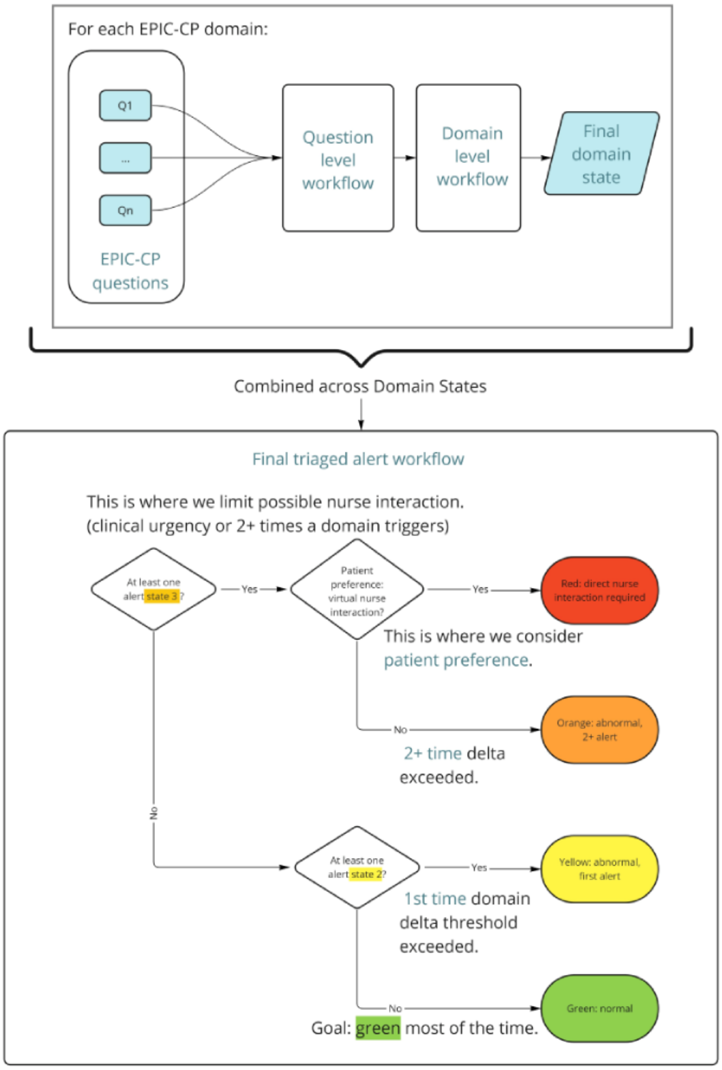
Figure 2. EPIC-CP's quality of life outcomes are central to the No Evidence of Disease (Ned) algorithm. EPIC-CP is comprised of a 1-page 16-item questionnaire covering questions relating to symptom domains of urinary incontinence (4 questions), urinary obstruction (1 question; 3 subquestions), bowel function (1 question; 3 subquestions), sexual function (3 questions), and hormonal function (1 question; 3 subquestions). Each question is scored categorically from 0, "no problem," to 4, "big problem," for a total domain score between 0 and 12 and a total overall prostate cancer quality of life score out of 60 [15]. Additional clinically important, nonscoring questions pertaining to hematuria and bloody stools were added. EPIC-CP: Expanded Prostate Cancer Index Composite for Clinical Practice.



Algorithm Inputs

The Ned algorithm ingests health-related quality-of-life outcomes monthly via the EPIC-CP [14]. The EPIC-CP covers 5 domains: urinary incontinence, urinary obstruction, bowel function, sexual function, and hormonal function (Figure 3). Each domain consists of 3 questions scored out of 4, with the domain scored out of 12 and a total score between 0 and 60; higher values mean worse symptoms [14].

Figure 3. Algorithm overview. Per domain, EPIC-CP questions (Wellness Survey on the patient-facing app) are input into a question-level workflow feeding forward into the domain-level workflow to yield a domain state. Domain states are then combined into a final triaged alert workflow considering clinical urgency, domain state history, domain changes over time (Δ), and patient preference to yield 1 of 4 global alerts: green, yellow, orange, and red. Nurse interaction is required for red alerts, with interaction at their discretion for orange alerts. EPIC-CP: Expanded Prostate Cancer Index Composite for Clinical Practice.



Algorithm Workflows

Question-Level Workflow

The question-level workflow is where the response to each EPIC-CP item is analyzed for whether it is a normal response or clinically urgent. Additional details on question-level workflow are available (Multimedia Appendix 1). We determined clinical urgency based on Cancer Care Ontario (CCO) guidelines [21] and consultations with clinical experts. Five clinically urgent items were unanimously validated for clinical appropriateness by our nurse and physician investigators where any patients presenting with these symptoms in the clinic would warrant further investigations. The 5 clinically urgent items are based on differential diagnoses, including (1) pain or burning with urination, (2) weak urine stream or incomplete emptying (urinary tract infection), (3) hematuria, (4) bloody stools (radiation-related side effects), and (5) depression, to determine whether specialized support like counseling, pharmacological treatment (eg, antidepressants), or both of these is warranted. Details of the normal and clinically urgent states are provided in Multimedia Appendix 2.

Domain-Level Workflow

The domain-level workflow determines the changes to domain scores over time. We defined 2 Δ (ie, change scores): (1) local Δ to capture changes to scores compared to the previous month and (2) baseline Δ to capture changes to scores compared to a refreshing baseline, where the baseline score gets refreshed every 6 months. To calculate the Δ, patients must have completed at least 2 surveys to calculate a change in score. Where a missing datapoint is present, the algorithm uses the most recent EPIC data compared to the previous month. If the date of completion is outside 3 weeks from the expected due date of the current follow-up month, then this automatically triggers (flagging for patient overdue) a message to the nurse to follow up. The baseline refresh is important to capture large shifts in patients' trending scores (eg, high score, followed by improvement with slow deterioration). By accounting for both types of Δ, the algorithm is sensitive to capturing rapid (ie, since the previous month) and gradual changes over time (eg, slow-creeping scores). Based on expert consultation with the original authors of the EPIC-CP, we codefined the threshold for both local and baseline Δ domain level states. These thresholds represent minimal clinically important differences (MCID) in scores and can be custom tailored and further informed by literature-defined minimally important differences (MIDs) for the EPIC-26 and EPIC-CP [22,23]. Specific domain thresholds were defined as Δ>0 (ie, urinary incontinence and hormonal function), and Δ>1 (ie, urinary obstruction, bowel function, and sexual function). Clinically urgent questions escalate the state as appropriate (ie, urinary irritation or obstruction, bowel function, and hormonal function). Pragmatically, these thresholds can be tunable based on clinician preference to provide more personalized thresholds that are either more or less sensitive for patients (Multimedia Appendix 1).

Two additional considerations inform the domain-level state. First, a domain-state history is used for pushing appropriate actionable patient-facing feedback to the patient that considers patient symptom chronicity (ie, that the unique “fingerprint” of symptoms for each patient remains fairly stable over time). Second is an escalation based on clinical urgency, which also considers domain-state history. The domain-state outputs are green for normal states and yellow or orange for abnormal states. Yellow is escalated to orange if a Δ threshold is exceeded for the second or more time, or if a clinically urgent symptom is present.

Algorithm Outputs

After the domain-level workflow, each domain’s state output is combined to provide a global alert in accordance with CCO guidelines and validated through a unanimous expert panel agreement. There are 4 possible alert states (Figure 3):

- Green (normal): This is the alert triggered if no domain state thresholds were met and no support is necessary.
- Yellow (abnormal): This alert is triggered for the first time alerting on a domain, which means the Δ threshold is exceeded for the first time. If this alert is triggered for any subsequent time (ie, second or more times), the alert is escalated to orange.
- Orange (abnormal+): This alert is triggered for the second+ time with elevated domain state (ie, Δ threshold exceeded for a second or more time) or due to a clinically urgent symptom being present. A push from the Ned platform (a mobile patient-facing app) is sent to the patient to ask their preference for a nurse consultation. If the patient indicates they would like a nurse consultation (ie, they accept the interaction), their alert state is updated to red.
- Red (direct nurse interaction required): This alert is triggered if the patient accepts a virtual nurse interaction when one or more orange domain states are present.

When the Ned algorithm outputs any alert, patient-facing actionable feedback is provided as the first line of the response with tailored care steps that outline prescriptive actions patients can enact to self-manage their alerting symptoms. The nurse on the web-based dashboard is shown the patients’ overall alert and summary of domain states and questions factoring into the alert.

Discussion

Anticipated Impact of Patient-Facing Actionable Feedback on Patient Self-Care

Given the chronicity of PCa survivorship symptoms, patients living with long-term symptoms may prefer not to receive clinical care despite reporting ongoing symptom experience, especially as symptoms often lack complete resolution [24]. When the Ned algorithm outputs an alert, patient-facing actionable feedback is the first line of response, in the form of domain-specific care steps. This process honors patient autonomy while facilitating a higher patient-to-clinician ratio by providing self-management strategies to minimize the number of required follow-ups. The goal is to provide patients with an arsenal of techniques to self-manage their symptoms as needed. This ensures patients who constantly receive alerts and demonstrate continuous or increasing symptom burden are provided the necessary care while being respectful of their decision to decline direct nursing intervention. To ground the algorithm outputs as a tractable example, a fictitious patient case study is outlined at baseline and 2 timepoints (Multimedia Appendix 3).

We anticipate the successful application of this survivorship algorithm will support the delivery of holistic nurse-led care and facilitate improved quality of life and survivorship experience with a high patient-to-nurse ratio. Our approach provides patient-facing actionable feedback on patient self-care to promote independent access to self-care education without necessarily having to see a care provider.

> *People who have been having prostate cancer treatment symptoms for a long time are familiar with how to manage it...they might not want medical advice because they know they can manage it and that there is no true solution.* [Patient A]

Overcoming Ned Algorithm Operationalization Barriers

Our intent was to incorporate the Ned algorithm into our Ned virtual clinics to improve efficiencies while enhancing the quality of care (eg, empower patients with the ability to self-manage symptoms and aspects of their cancer care). To operationalize the Ned algorithm there are 3 additional considerations. First, within the context of nurse-led care provision, the Ned algorithm must have a clearly defined scope in terms of eligibility and appropriate use. Second, robust provider education is required to ensure appropriate clinical application and utility. To this end, we engaged senior nurse experts in oncology care to inform the creation of a nursing curriculum that will position Ned nurses to understand both algorithm-related and non–algorithm-related core care intervention pathways. Third, a formal evaluation is warranted of care provider responses to algorithm alerts and Ned as clinical decision support.

Future Directions

The Challenge and Opportunity to Advance the Ned Algorithm With PSA

While it is difficult to obtain unanimous agreement on PSA and what constitutes recurrence, incorporating PSA may be the most obvious algorithm feature as a first screening step for future directions of the Ned algorithm. For example, based on a recent systematic review, most publications use a PSA of greater than 0.4 ng/mL [25] while the RTOG-ASTRO (Radiation Therapy Oncology Group–American Society for Therapeutic Radiology and Oncology) Phoenix Consensus Conference uses a definition of a PSA increase of more than 2 ng/mL regardless of the nadir value [26], and in Canada, it has been recommended to use a combination of testosterone and PSA levels (≤0.7 nmol/L and ≤2 ng/mL, respectively) [27]. Others have proposed age-specific thresholds [28] and the European Association of Urology (EAU) Prostate Cancer Guidelines Panel's recommendations state that "The indication for further treatments should not be based on meeting a threshold PSA recurrence as defined above alone, but should depend on an individualized risk for progression." [25]. Especially with these nuances, there exists an element of subjectivity for clinicians assigning a clinical stage with errors in the clinical stage assignment of greater than 35% [29]. We report here on a more conservative algorithm. As part of future work, we aim to marry these 2 approaches through a data-driven clinical support system to facilitate clinician trust while reducing data fatigue.

Refining Algorithm Thresholds for a More Flexible Response

The focus of this project was to develop the algorithm. Evaluation of the algorithm's pragmatic feasibility to support a high patient-to-nurse ratio, and further validation of algorithm output compared to a human assessor is part of ongoing work. While we based the thresholds on expert recommendations, practically, there may be more value in tailoring thresholds for each patient through an initial consultation with a Ned nurse. We also understand each patient will have their own unique "fingerprint" of side effects following treatment. Currently what will be trialed are the thresholds as defined in the manuscript. However, to address potential oversensitivity for each patient's unique baseline values, in consultation with our clinical partners, we discussed fine-tuning or updating the thresholds on a case-by-case basis to prevent alert fatigue both for patients and the Ned nurse. However careful consideration is necessary to mitigate the risk of potential maladaptation of the algorithm. Additionally, granularity beyond the first and subsequent alerts may be more effective to assist patients with self-resolving their symptoms. Continuing with the evaluation of this research will help refine and optimize both thresholds and patient-facing resources.

Limitations and Next Steps

Patient user feedback was obtained from members of our patient partner council, who are very active in their care and therefore may not represent patients who play a less active role in their care. Future directions should include additional input and perspectives from more diverse patient expertise to further corroborate these findings. In line with conventional user-centered design, a summative pragmatic pilot evaluation is needed to ensure the usability of the algorithm prior to mass deployment to ensure no issues could produce adverse events. As part of the next steps, we will evaluate the incorporation of the Ned algorithm's prescriptive patient-facing actionable feedback on the patient experience, perceptions of patient empowerment, clinical outcomes and clinical efficacy, degree of expected missing data, and missing-data mitigation strategies.

Conclusions

The Ned algorithm is positioned to facilitate PCa nurse-led care models with a high nurse-to-patient ratio. This novel expert-informed PCa survivorship care algorithm contains a defined escalation pathway for clinically urgent symptoms while honoring patient preference. Though further validation is required through a pragmatic trial, we anticipate the Ned algorithm will support a high patient-to-nurse ratio and enhanced efficiency with empowering patients to self-resolve their symptoms and improve their quality of life.

Acknowledgments

The study was funded by the Canadian Institutes for Health Research (CIHR) Canadian Cancer Society Survivorship Grant (CCS: 706713; CIHR: 168606). The funding agencies were not involved in the design or analysis of the study.

Data Availability

Data sharing is not applicable to this paper as no data sets were generated or analyzed during this study.

Authors' Contributions

The conceptualization and design of the algorithm were led by QP, KJP, EJ, RL, and DW. All authors were involved in the design, development, and evaluation of the No Evidence of Disease (Ned) prostate cancer survivorship platform described in the manuscript. Project administration and data collection were conducted by DN, RL, and DW. Manuscript preparation was led by KJP with support from SS. All authors reviewed and approved the manuscript.

Conflicts of Interest

AF and University Health Network jointly own intellectual property rights to the No Evidence of Disease (Ned) app. QP, AB, AF, and JAC own intellectual property rights to the Ned Clinic intervention and are entitled to personally benefit from any commercial use of the intellectual property.

Multimedia Appendix 1
Workflows and domain state history. This multimedia appendix provides supplementary information regarding the question and domain-level workflows and domain state history including in-depth algorithm workflow diagrams (Figures S1 and S2).
[DOCX File , 445 KB - cancer_v9i1e44332_app1.docx]

Multimedia Appendix 2
Considering clinical acuity. This multimedia appendix provides supplementary information regarding clinical acuity and how this is captured for standard and special domains. It includes in-depth algorithm workflow diagrams for urinary incontinence (Figure S3), bowel function (Figure S4), and hormonal function (Figure S5).
[DOCX File , 560 KB - cancer_v9i1e44332_app2.docx]

Multimedia Appendix 3
Fictitious case study. This multimedia appendix provides a fictitious patient case study to illustrate how the No Evidence of Disease (Ned) algorithm flows from scenario to output at baseline and two follow-up time points (Table S1).
[DOCX File , 26 KB - cancer_v9i1e44332_app3.docx]

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Abbreviations

ASTRO: American Society for Therapeutic Radiology and Oncology
CCO: Cancer Care Ontario
CTO: Clinical Trials Ontario
EAU: European Association of Urology
EPIC-CP: Expanded Prostate Cancer Index Composite for Clinical Practice
MCID: minimal clinically important differences
MID: minimally important difference
Ned: no evidence of disease

PCa: prostate cancer
PSA: prostate-specific antigen
RTOG: Radiation Therapy Oncology Group
UHN: University Health Network

Edited by T de Azevedo Cardoso; submitted 21.11.22; peer-reviewed by J Luo, J Lehmann, K Le Du; comments to author 12.07.23; revised version received 25.07.23; accepted 14.08.23; published 04.10.23.

Please cite as:
Pfisterer KJ, Lohani R, Janes E, Ng D, Wang D, Bryant-Lukosius D, Rendon R, Berlin A, Bender J, Brown I, Feifer A, Gotto G, Saha S, Cafazzo JA, Pham Q
An Actionable Expert-System Algorithm to Support Nurse-Led Cancer Survivorship Care: Algorithm Development Study
JMIR Cancer 2023;9:e44332
URL: https://cancer.jmir.org/2023/1/e44332
doi:10.2196/44332
PMID:37792435

Original Paper

Exploring Online Crowdfunding for Cancer-Related Costs Among LGBTQ+ (Lesbian, Gay, Bisexual, Transgender, Queer, Plus) Cancer Survivors: Integration of Community-Engaged and Technology-Based Methodologies

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Abstract

Background: Cancer survivors frequently experience cancer-related financial burdens. The extent to which Lesbian, Gay, Bisexual, Transgender, Queer, Plus (LGBTQ+) populations experience cancer-related cost-coping behaviors such as crowdfunding is largely unknown, owing to a lack of sexual orientation and gender identity data collection and social stigma. Web-scraping has previously been used to evaluate inequities in online crowdfunding, but these methods alone do not adequately engage populations facing inequities.

Objective: We describe the methodological process of integrating technology-based and community-engaged methods to explore the financial burden of cancer among LGBTQ+ individuals via online crowdfunding.

Methods: To center the LGBTQ+ community, we followed community engagement guidelines by forming a study advisory board (SAB) of LGBTQ+ cancer survivors, caregivers, and professionals who were involved in every step of the research. SAB member engagement was tracked through quarterly SAB meeting attendance and an engagement survey. We then used web-scraping methods to extract a data set of online crowdfunding campaigns. The study team followed an integrated technology-based and community-engaged process to develop and refine term dictionaries for analyses. Term dictionaries were developed and refined in order to identify crowdfunding campaigns that were cancer- and LGBTQ+-related.

Results: Advisory board engagement was high according to metrics of meeting attendance, meeting participation, and anonymous board feedback. In collaboration with the SAB, the term dictionaries were iteratively edited and refined. The LGBTQ+ term dictionary was developed by the study team, while the cancer term dictionary was refined from an existing dictionary. The advisory board and analytic team members manually coded against the term dictionary and performed quality checks until high confidence in correct classification was achieved using pairwise agreement. Through each phase of manual coding and quality checks, the advisory board identified more misclassified campaigns than the analytic team alone. When refining the LGBTQ+ term dictionary, the analytic team identified 11.8% misclassification while the SAB identified 20.7% misclassification. Once each term dictionary was finalized, the LGBTQ+ term dictionary resulted in a 95% pairwise agreement, while the cancer term dictionary resulted in an 89.2% pairwise agreement.

Conclusions: The classification tools developed by integrating community-engaged and technology-based methods were more accurate because of the equity-based approach of centering LGBTQ+ voices and their lived experiences. This exemplar suggests integrating community-engaged and technology-based methods to study inequities is highly feasible and has applications beyond LGBTQ+ financial burden research.

(JMIR Cancer 2023;9:e51605) doi:10.2196/51605

KEYWORDS

community-engaged; LGBT; SGM; financial burden; crowdfunding; sexual monitory; sexual minorities; crowdfund; fund; funding; fundraising; fundraise; engagement; finance; financial; campaign; campaigns; web scraping; cancer; oncology; participatory; dictionary; dictionary; term; terms; terminology; terminologies; classification; underrepresented; equity; inequity; inequities; cost; costs

Introduction

Lesbian, Gay, Bisexual, Transgender, Queer, Plus (LGBTQ+) populations, which represent at least 7% of all US citizens [1], experience greater economic instability than their non-LGBTQ+ counterparts, including being more likely to live below the poverty line (24.6% vs 12.1%) and more likely to experience substantial identity-related employment discrimination [2-5]. LGBTQ+ people also experience higher rates of several of the most common cancer types and disproportionate cancer-related burdens [6,7]. Emerging literature suggests LGBTQ+ cancer survivors may be at an elevated risk for cancer-related financial burden [8]. Financial burden among LGBTQ+ cancer survivors may be further exacerbated by anti-LGBTQ+ bias, discrimination, and stigma including inadequate familial social and financial support due to rejection of an LGBTQ+ identity [8]. However, national surveys and health systems have only recently begun to collect sexual orientation and gender identity data, limiting researchers' ability to study LGBTQ+ financial burden disparities [9,10].

At the same time, the volume of health-related information available online offers considerable opportunities to researchers adopting computational social science approaches [11]. In social media spaces and other online environments, LGBTQ+ identity is commonly disclosed through gendered language (eg, they/them) and self-disclosure when describing oneself [12]. Examples include posts on social media platforms and narratives included in crowdfunding campaigns. The latter is especially relevant for studies of medical financial burden since cancer survivors often use online crowdfunding for financial support and coping with cancer-related financial burden [13,14]. Thus, textual linguistic processing may offer an alternative mechanism to explore LGBTQ+ financial burden inequities.

Prior research into inequities in crowdfunding has often used web-scraping and machine learning methods to assemble and analyze data sets of health-related crowdfunding campaigns [15-18]. However, the use of machine learning to assist in identifying patients with stigmatized identities, such as LGBTQ+ identity, is potentially problematic as it may infuse the biases of the researchers into identification and analyses. These biases have a variety of potential consequences including findings that are not representative of the population of interest, or in the context of clinical decision-making tools, misdiagnoses of already vulnerable populations [19]. Such approaches may be problematic due to the LGBTQ+ population's long history of stigmatization, exclusion, and discrimination inside and outside of the health care setting—anti-LGBTQ+ legislation and attitudes are embedded in US society and thus within researchers conducting big data analyses [20]. At the same time, the existing research focused on LGBTQ+ inequities in crowdfunding outside of the cancer context often do not use machine learning methods and instead use the search function of the crowdfunding website to identify LGBTQ+ campaigns [21,22]. Use of the search function may result in findings that are of unknown representativeness of LGBTQ+ campaigns on crowdfunding sites.

More accurate and reliable methodological approaches are needed to study LGBTQ+ inequities in the context of historical and current anti-LGBTQ+ attitudes and beliefs. Current literature suggests that LGBTQ+ research should shift from studying LGBTQ+ disparities to creating co-owned engaged research [23]. Thus, an equity-based methodological approach, wherein community members are included in the design, planning, implementation, analysis, and interpretation of results, is needed to explore LGBTQ+ inequities in cancer-related crowdfunding. The primary aim of this paper is to describe the process by which we integrated community-engaged and technology-based methods to explore inequities in crowdfunding for cancer-related costs between LGBTQ+ and non-LGBTQ+ cancer survivors—the Crowdfunding Cancer-related Costs among LGBTQ+ cancer survivors (C3 LGBT) study. The methods section includes descriptions of community-engaged research and web-scraping methodological approaches used to collect data. The results section includes descriptions of the integration of community-engaged and technology-based methods and the resulting identification tools and data set. Our results describe and explain how to integrate community-engaged and technology-based methods in research.

While our study design was implemented for an LGBTQ+ and cancer-related topic, these examples on how to center equity in technology-based methods can be applied to a variety of existing outcomes and are intended to guide future researchers who wish to incorporate these unique methodological approaches.

Methods

Community-Engaged Research Methods

Community-engaged research is defined as a collaborative approach to research that includes the population being studied as informants in the development and execution of a research project [24]. Community involvement can include a variety of voices from the population of interest including leaders from relevant organizations as well as individual community members. Community-engaged research is positioned in epistemological paradigms outside of traditional positivism in which researchers assume that there is a universal truth to be discovered [25,26]. Rather, community-engaged methods promote colearning between the researchers and the community in a constructivist approach. Hallmarks of community-engaged research include but are not limited to building on strengths within the community, reciprocal mutually beneficial partnerships, cyclical processes, and engagement throughout the study and beyond [27]. Current community-engaged research methods exist on a continuum from community-informed research (ie, influenced by the community but no community involvement) to community-driven or led research (ie, support the community in conducting research) [28].

To center the LGBTQ+ community in the C3 LGBT study, we convened an LGBTQ+ study advisory board (SAB), with whom we developed and refined methods to scrape crowdfunding campaigns and accurately categorize them as LGBTQ+ and as cancer related. The goal of the SAB was to cocreate knowledge about LGBTQ+ cancer crowdfunding with the C3 LGBT analytic team by meeting to develop and refine study methods and participate in analyses. Individuals were eligible for the SAB if they (1) identified as LGBTQ+ and had a prior cancer diagnosis or cancer caregiving experience or (2) were clinical professionals working with the LGBTQ+ community. Recruitment, led by ARW and CT, included emailing a flyer with information about the SAB and study to professional contacts in LGBTQ+ research, existing cohorts of prior research participants who identified as LGBTQ+, and referrals from the Huntsman Cancer Institute at the University of Utah. Prior to recruitment, the C3 LGBT analytic team met to outline the role of SAB members in the study. Each SAB member would be expected to participate digitally via Zoom (Zoom Technologies, Inc) in at minimum 4 board meetings (60 minutes each) over the following year, receiving a US $200 per person honorarium for their time.

SAB members (n=8) worked with the C3 LGBT analytic team to further delineate their role and level of engagement with the outlined 4 meetings as the minimum level of engagement. That is, if board members were particularly interested in specific components or subprojects (eg, publishing or conference presenting), they were encouraged to discuss those ideas with the C3 LGBT analytic team and other SAB members. The SAB's engagement was measured by (1) tracking attendance in regularly scheduled meetings and additional voluntary meetings, (2) asking for feedback about engagement during meetings via an anonymous poll, and (3) sending an individual-level survey prior to the final SAB meeting that assessed each member's desired level of engagement with the proposed activities and provided an open space for feedback.

Web-Scraping Methods

We assembled a data set of all active US-based medical campaigns hosted on GoFundMe, a large crowdfunding platform, and then used term detection to classify cancer-related campaigns benefitting LGBTQ+ individuals (discussed later). First, we accessed a list of all URLs that the platform makes available to search engines (the sitemap.xml). We downloaded the static HTML from each URL and, using the Beautiful Soup 4 Python library, extracted the campaign title, creation date, campaign category (medical vs other), campaign status (active vs inactive), donation amount, number of donors, organizer's location, and the campaign description provided by the creator. Information that is not available in the static HTML, such as fundraising updates and donor comments, could not be captured using this method. We identified the campaign language using the langdetect library and excluded campaigns without a campaign description in English while retaining campaigns with descriptions in English and another language. Overall, 2,208,418 URLs were present in the sitemap.xml; of which 494,242 were active US medical campaigns written in English. Campaigns are determined to be medical campaigns by the user when they create the crowdfunding campaign. The sitemap.xml was accessed on November 14, 2022, and scraping was performed between November 14 and 22, 2022. All web scraping and data extraction were conducted in Python 3 (Python Software Foundation) [29].

Composition and Positionality of the Study Team

The C3 LGBT study team consisted of 3 subgroups including the SAB (MM, MP, HJ, LVG, and others listed in acknowledgments), a team of faculty collaborators with content and conceptual expertise (SAR, KGC, and ACK), and the analytic team (ARW, CT, CWE, IT, and ELW). As part of the analytic process (July 2022-June 2023), the study team took time to reflect on their positionality or how individuals are influenced by their world views and the social positions they adopt, in relation to the C3 LGBT study and LGBTQ+ population. To guide this process, everyone who worked on the study was prompted to think about their positionality through 3 mechanisms including locating themselves in relation to the subject, locating themselves in relation to the participants, and locating themselves in the context of the research process [30]. Each individual wrote their positionality statement; keywords and phrases are displayed as a word cloud in Multimedia Appendix 1.

The study team held a variety of intersectional identities that informed the way that they approached the C3 LGBT study. Researchers on the analytic team and faculty collaborators were located in Utah, Arizona, and North Carolina. The analytic team and faculty collaborators held identities that ranged from completely removed from the LGBTQ+ community to identifying as a part of the LGBTQ+ community. Lead author and analyst, ARW, identifies as part of the LGBTQ+ community and has experience as a caregiver for chosen and blood family with serious illnesses including cancer. Other analytic team members did not identify as part of the LGBTQ+ community but shared familial ties to the community and other perspectives. Faculty collaborator KGC identifies as a part of the LGBTQ+ community, has close family members who are LGBTQ+, and has chronic and serious illness caregiving experiences with both chosen and blood family.

SAB board members nearly all identified as part of the LGBTQ+ community and included cancer survivors who lived across the United States (ie, Utah, Michigan, and New York). SAB members shared how their cancer intersected with their LGBTQ+ identity with 1 SAB member even sharing that they chose not to disclose their identity in their crowdfunding campaign during their treatment due to fear of anti-LGBTQ+ attitudes impacting their ability to raise funds. Reflecting on how researchers' and community members' frames of reference, epistemological points of view, and lenses influence research is crucial. Reflections from the study team highlighted discrimination within the LGBTQ+ community, societally held anti-LGBTQ+ attitudes, deep ties to cancer and caregiving as well as the complexity of identity—all of which inform how the study team approached the C3 LGBT study. While not common in quantitative research, reflexivity and positionality are important in analyzing and interpreting big data [31].

Ethical Considerations

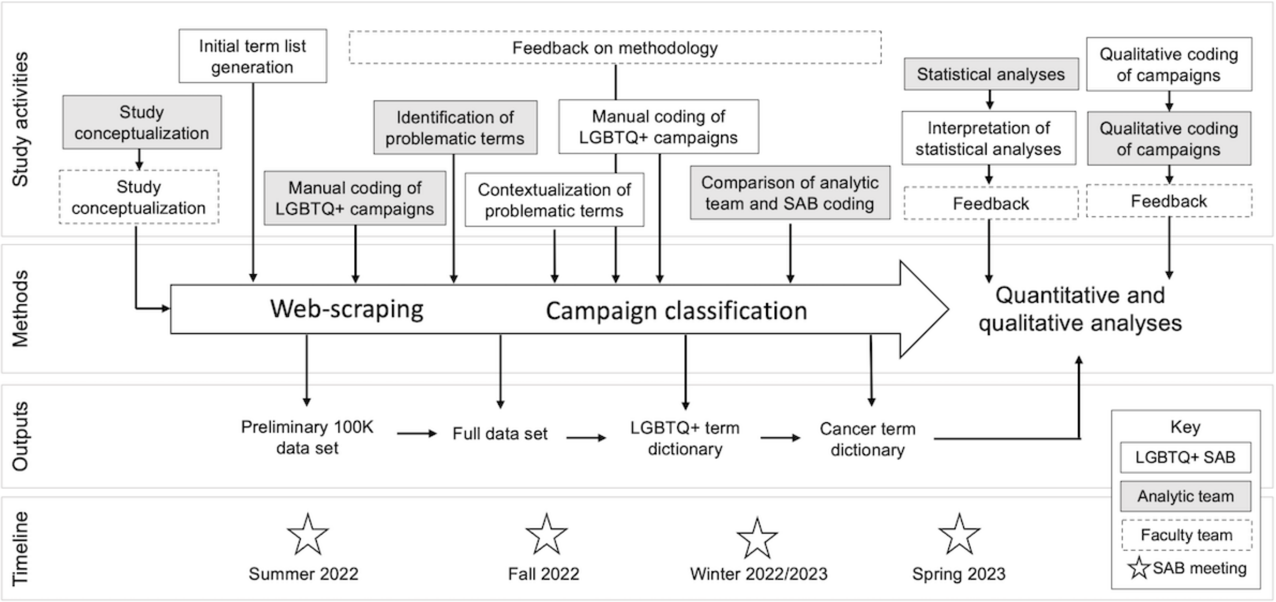
This study was considered exempt from ethics approval by the University of Utah's institutional review board as it only involves publicly available data (IRB#00154744). Data were not anonymous nor deidentified as all data are actively available on GoFundMe and web-scraped to create this data set. SAB members are considered to be study team members not as study participants.

Results

Integration of Community-Engaged and Technology-Based Methods

True to the principles of community-engaged research, the C3 LGBT SAB was engaged during every step of the study. Across the 4 SAB meetings, none of the 8 SAB members dropped out, 4 SAB members did not miss any meetings, and 4 missed 1 meeting. All SAB members took part in an online engagement survey to express interest in additional participation in study activities in addition to SAB meetings, which included opportunities to perform qualitative coding, review manuscripts, and participate in manuscript dissemination—4 SAB members opted into additional activities. The SAB was also heavily involved in the creation, refinement, and testing of the term lists used to categorize crowdfunding campaigns as LGBTQ+ and as cancer related (Figure 1). The first iteration of the cancer-related term list was previously published by Silver et al [17], while the first iteration of the LGBTQ+ term list was developed by the analytic team. The SAB then provided feedback by adding and removing terms from each term list, focusing primarily on the LGBTQ+ term list. The term lists were then applied to the first small-batch scrape of 100,000 campaigns. The campaigns were filtered down to LGBTQ+ cancer campaigns as identified by the term lists. The analytic team and the SAB, independently and without knowledge of the term list assignment, manually coded each campaign identified as LGBTQ+ and cancer to test the accuracy of the term lists and the reliability of the analytic team and SAB. Coding done by the SAB was considered the gold standard for this analysis. Pairwise percent agreement was calculated between the term list categorization and SAB categorization as well as between the term list categorization and analytic team categorization. The refined term list including words to be quality checked was applied to a subset of the final data set, and pairwise percent agreement was calculated. The final term lists were then applied to the full campaign data set.

Figure 1. Study design of the Crowdfunding Cancer Costs LGBT study: integration of community-engaged and technology-based methods. LGTBQ+: Lesbian, Gay, Bisexual, Transgender, Queer, Plus; SAB: study advisory board.



Term Dictionary and Classification of LGBTQ+ Campaigns

From the first small batch scrape, a total of 93 LGBTQ+ campaigns were randomly selected from 33,478 cancer-related campaigns identified using the initial LGBTQ+ term list. After manual coding of the 93 campaigns by the analytic team, the analytic team determined that the search results yielded by the term list had correctly identified LGBTQ+ campaigns 88.2% of the time and misclassified them 11.8%. To ensure the analytic team coding was representative of LGBTQ+ community members' interpretations, the SAB refined the term list in small breakout group discussions, and the term list was then reapplied to a small batch scrape with 87 LGBTQ+ campaigns. Manual coding by the SAB of 87 campaigns revealed a percent agreement of 79.3%, meaning that 20.7% of campaigns were identified by the SAB as being misclassified by the term list.

Reasons for misclassification were identified and included the use of the LGBTQ+ term list word "trans" used in medical terminology (eg, trans-metatarsal and trans-abdominal) as well as the LGBTQ+ term list word "gay" commonly occurring as a legal first or last name. Such terms were added to the term list that needed a manual quality check. Some LGBTQ+ term list words were also identified as commonly causing misclassification but did not discretely identify LGBTQ+ campaigns (ie, other words on the LGBTQ+ term list already identified the campaign as LGBTQ+ without the inclusion of such problematic terms) including "transitioning" and "fluid." Such words were removed from the LGBTQ+ term list. Once the term list was finalized, manual coding of 100 LGBTQ+ classified campaigns by the analytic team revealed a final percent agreement with the LGBTQ+ term list of 95%. The iterations of the LGBTQ+ term list can be found in Textbox 1.

Textbox 1. Iterations of the lesbian, gay, bisexual, transgender, queer term list.

Initial LGBTQ+ term list: 2-spirit, 2 spirit, 2S, Ace, AFAB, Agender, AMAB, Aromantic, Asexual, Assigned female at birth, Assigned male at birth, Bigender, Bisexual, Bottom surg, Demi, Drag k, Drag p, Drag q, Dyke, Dysphoria, Enby, Ey/, Fag, Femme, Fluid, Fruity, FTM, Gay, Gender-aff, Gender aff, Gender confirmation, Gender dysphoria, Gender euphoria, Gender f, Gender non, Gender queer, Gender transition, Genderf, Genderqueer, GNC, Her girlfriend, Her wife, His boyfriend, His husband, HRT, Intersex, Lesbian, LGBT, Masc, MTF, Mx., NB, Ne/, Non-binary, Nonbinary, Omnigender, Pansexual, Partner, Phalloplasty, Poly, QTPOC, Queer, Same-gender loving, Sex reassignment, Sexual and gender minority, SGM, They/, Top surgery, Trans, Transgender, Transitioning, Transsexual, Two-spirit, Two spirit, Vaginoplasty, Ve/, Xe/, Zie/

- Eliminated terms: Ace, Demi, Dyke, Femme, Fluid, Fruity, GNC, HRT, Masc, NB, Partner, Poly, Transitioning
- Terms to quality check: Gay, Trans
- Words with 0 hits: 2-spirit, 2 spirit, Agender, Aromantic, Bigender, Drag k, Enby, Ey/, Fag, Gender queer, Genderf, Intersex, MTF, Omnigender, Pansexual, Phalloplasty, Same-gender loving, Sexual and gender minority, SGM, Transsexual, Vaginoplasty, Xe/, Zie/
- Final term list: AFAB, AMAB, Asexual, Assigned female at birth, Assigned male at birth, Bisexual, Bottom surg, Drag p, Drag q, Dysphoria, FTM, Gay, Gender-aff, Gender aff, Gender confirmation, Gender dysphoria, Gender euphoria, Gender f, Gender non, Gender transition, Genderqueer, Her girlfriend, Her wife, His boyfriend, His husband, Lesbian, LGBT, Mx., Ne/, Non-binary, Nonbinary, QTPOC, Queer

Term Dictionary and Classification of Cancer Campaigns

Of the small batch scrape, the same 93 campaigns were manually coded by the analytic team to identify agreement with the cancer term list. This additional check was performed to assess the accuracy of the cancer term list and refine it if needed. The analytic team revealed an 89.2% agreement with the cancer term list—10.8% misclassification. The SAB board then manually coded an additional randomly selected 89 cancer campaigns from the small batch scrape with 68.5% agreement. The analytic team and SAB agreed that many misclassified campaigns were comparing other diseases to cancer or tangentially mentioning a family member's cancer. Specific treatment words such as "chemo" and "mastectomy" were identified by the SAB and analytic team to be driving misclassification as they were used in the context of other diseases. Such words were excluded from the term list after the SAB coding. Once the term list was finalized, manual coding of 93 campaigns by the analytic team revealed a percent agreement with the cancer term list of 89.2%. The iterations of the cancer term list can be found in Textbox 2.

Textbox 2. Iterations of the cancer term list.

Cancer term list: adenocarcinoma, astrocytoma, cáncer, carcinoid, carcinoma, chemo, chemotherap, clear cell, desmoplastic, ductal carcinoma, ductile carcinoma, ependymoma, glioblastoma, histiocytosis, immuno therap, immunotherap, langerhans, leukemia, luekemia, lukemia germ cell tumor, lumpectomy, lymphoma, malignan, mastectomy, medulloblastoma, melanoma, myeloma, myloma, neruoblastoma, neurblastoma, neuroblastoma, neuroendocrine tumor, non-hodgkins lymphoma, non hodgkins lymphoma nonhodgkins lymphoma, nueroblastoma, nuroblastoma, oligodendroglioma, radiation therap, radiotherap, renal cell, retinoblastoma, rhabdomyosarcoma rhabdomyosaroma, sarcoma, seminoma, squamous cell, thymoma, wilm's tumor, wilms tumor

- Eliminated terms: chemo, chemotherap, immuno therap, immunotherap, mastectomy, radiation therap, radiotherap
- Final term list: adenocarcinoma, astrocytoma, cáncer, carcinoid, carcinoma, clear cell, desmoplastic, ductal carcinoma, ductile carcinoma, ependymoma, glioblastoma, histiocytosis, langerhans, leukemia, luekemia, lukemia germ cell tumor, lumpectomy, lymphoma, malignan, medulloblastoma, melanoma, myeloma, myloma, neruoblastoma, neurblastoma, neuroblastoma, neuroendocrine tumor, non-hodgkins lymphoma, non hodgkins lymphoma, nonhodgkins lymphoma, nueroblastoma, nuroblastoma, oligodendroglioma, renal cell, retinoblastoma, rhabdomyosarcoma, rhabdomyosaroma, sarcoma, seminoma, squamous cell, thymoma, wilm's tumor, wilms tumor

Discussion

Principal Findings

We sought to design a study combining community-engaged and technology-based methods to center the LGBTQ+ community and explore inequities that are unable to be assessed due to limited sexual orientation and gender identity data collection. The identification of LGBTQ+ and cancer-related crowdfunding campaigns was more accurate than it would have been otherwise when pairing community-engaged research methods with technology-based methods. For example, a principal observation made during the refinement of the LGBTQ+ and cancer term dictionaries for use on the GoFundMe data set was that the SAB consistently identified more misclassified campaigns (ie, campaigns that were automatically coded as LGBTQ+ but should not have been or vice versa) than the analytic team. Similarly, the SAB also expanded on the original LGBTQ+ term list that the analytic team developed. Taken together, these 2 results demonstrate the increased rigor of combining community-engaged study methods with technology-based approaches. Increased rigor may contribute to successful community engagement throughout the development and refinement of the 2 term dictionaries. The SAB regularly contributed justifications for adding and excluding terms based on their lived experiences within the LGBTQ+ and cancer communities. Not only did each member of the SAB importantly contribute their individual experiences and knowledge but the structure of the SAB (ie, quarterly meetings) allowed for members to share and cocreate new knowledge with the analytic team in real time.

Importantly, it was only by working together that the analytic team and SAB were able to produce an LGBTQ+ term dictionary with a pairwise agreement of 95%. This finding highlights the importance of centering the LGBTQ+ community in research involving LGBTQ+ cancer survivor outcomes, even if the chosen methodology may seem to not align with community-engaged equity-based methods, such as web-scraping and multivariate modeling. The integration of the SAB minimized the potential for misclassification and therefore minimized the bias of our future quantitative findings. Further, adequately engaging LGBTQ+ community members in technology-based methods confront the normalization of anti-LGBTQ+ attitudes, which can be seen in an unprecedented number of anti-LGBTQ+ bills in the past few years [32]. Avoiding algorithmic biases that mirror institutional biases (eg, racism) via equity-based methods is a growing priority in modern society [33]. There are a variety of potential negative implications when equity-based methods are not integrated into research protocols and cause bias in studies like the C3 LGBT study. The existing literature on the financial burden experienced by LGBTQ+ cancer survivors is sparse, with only a few studies that have directly assessed financial burden and none, to our knowledge, have assessed LGBTQ+ inequities in crowdfunding [8,34]. If the original term dictionary generated by the analytic team alone were used to identify LGBTQ+ campaigns, findings would have been inaccurate and would have had the potential to move financial burden research among LGBTQ+ survivors in the wrong direction.

Furthermore, these results can be contextualized in community-engaged research theory, which emphasizes principles of "connected knowing," which is grounded in experiences, context, and relativism as opposed to "separate knowing," which emphasizes logic, deduction, and absolute truth [35]. Approaching LGBTQ+ cancer research from a connected knowing lens is one way to potentially ameliorate stigma and discrimination experienced within this community by shifting away from traditional objectivist methods of deductively creating knowledge [36]. For this study, using a connected knowing lens allowed for necessary interpretation by SAB members to elucidate the inherent nuance found in our data set, thus addressing limitations created by using web-scraping methods alone.

We designed this study in alignment with several published recommendations for conducting research with LGBTQ+ cancer populations, which include cultivating non-cishetereonormative spaces typically found in health care research settings, prioritizing mutually beneficial relationships, and implementing sustainable interventions [23,37,38]. We aligned with these guidelines by centering LGBTQ+ voices from the SAB at every step of the research, encouraging SAB members to choose the activities that would be most advantageous for them, and developing a data set and term dictionaries that can be used for future LGBTQ+ research. Importantly, the SAB was compensated for their time and free to choose their level of engagement. It is possible that the high level of SAB engagement can be explained by the integration of these recommendations, which were primarily generated by LGBTQ+ populations.

Limitations

This study had several limitations. The term dictionaries we developed are specific to the data set we were using, which may impact the ability for them to be adapted to other data sets without alterations. Additionally, LGBTQ+ GoFundMe cancer campaigns were identified solely through self-disclosure. While this was an appropriate method for our aims and can assist in research aiming to analyze the social position and the ways that homophobia and transphobia may be functioning within online crowdfunding for cancer, it is not a suitable method for assessing the prevalence of LGBTQ+ populations who use online crowdfunding sites as not all LGBTQ+ individuals may choose to disclose their identity online. Further, it is unclear how generalizable such data and subsequent analyses would be to the cancer survivor population as demographic factors are not systematically and consistently available. However, it is highly likely that such data and analyses are representative of the portion of cancer survivors who report behavioral financial hardship and cost-coping behaviors as this data set contains all active cancer-related crowdfunding campaigns available on GoFundMe. Finally, members of the SAB were highly educated. This may have influenced the level of engagement, particularly for SAB members who participated in additional data coding meetings and manuscript authorship and may impact the generalizability of these methods for groups with lower educational attainment.

Conclusions

Overall, our SAB was highly engaged throughout the entire study by metrics of attendance and participation at all 4 meetings. Integration of community-engaged and web-scraping methodologies resulted in a data set in which LGBTQ+ campaigns are able to be identified at 95% confidence. The methodological grounding and step-by-step methods outlined above provide a roadmap for future research in which technology-based methods are used for equity research. Our findings indicate high feasibility for integrating community-based methods with technology-based methods. In a time of research in which automation and big data are being used at an increasing rate, it is crucial to continue to center community-engaged equity-based methods in such research [39]. Doing so has the potential to produce more high-quality, unbiased research in hard-to-reach or historically underrepresented populations such as LGBTQ+ cancer survivors.

Acknowledgments

We would like to acknowledge and thank the Crowdfunding Cancer Costs LGBT Study (C3 LGBT) study advisory board members who did not opt into authorship: Audra Carlisle, Gabriel Glissmeyer, Aeden Abesse, and Susana Keeshin. We would also like to thank Leah Frerichs for her feedback on the conceptualization of this project. The research reported in this publication was supported by the National Cancer Institute of the National Institutes of Health (award P30CA042014-31S3). This content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. ARW is supported by the National Cancer Institute's National Research Service Award sponsored by the Lineberger Comprehensive Cancer Center at the University of North Carolina (T32 CA116339).

Data Availability

The data that support the findings of this study are available from the corresponding author, ARW, upon reasonable request.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Word cloud of words and phrases from reflections on positionality from members of the Crowdfunding Cancer Costs LGBT Study (C3 LGBT) study team.

[PNG File , 130 KB - cancer_v9i1e51605_app1.png]

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Abbreviations

C3 LGBT: Crowdfunding Cancer Costs LGBT Study
LGBTQ+: lesbian, gay, bisexual, transgender, queer
SAB: study advisory board

Edited by A Mavragani; submitted 04.08.23; peer-reviewed by M Bono, M Mullins; comments to author 04.09.23; revised version received 14.09.23; accepted 22.09.23; published 30.10.23.

Please cite as:
Waters AR, Turner C, Easterly CW, Tovar I, Mulvaney M, Poquadeck M, Johnston H, Ghazal LV, Rains SA, Cloyes KG, Kirchhoff AC, Warner EL
Exploring Online Crowdfunding for Cancer-Related Costs Among LGBTQ+ (Lesbian, Gay, Bisexual, Transgender, Queer, Plus) Cancer Survivors: Integration of Community-Engaged and Technology-Based Methodologies
JMIR Cancer 2023;9:e51605
URL: https://cancer.jmir.org/2023/1/e51605
doi:10.2196/51605
PMID:37902829

Original Paper

Exploring Cancer Incidence, Risk Factors, and Mortality in the Lleida Region: Interactive, Open-source R Shiny Application for Cancer Data Analysis

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Abstract

Background: The cancer incidence rate is essential to public health surveillance. The analysis of this information allows authorities to know the cancer situation in their regions, especially to determine cancer patterns, monitor cancer trends, and help prioritize the allocation of health resource.

Objective: This study aimed to present the design and implementation of an R Shiny application to assist cancer registries conduct rapid descriptive and predictive analytics in a user-friendly, intuitive, portable, and scalable way. Moreover, we wanted to describe the design and implementation road map to inspire other population registries to exploit their data sets and develop similar tools and models.

Methods: The first step was to consolidate the data into the population registry cancer database. These data were cross validated by ASEDAT software, checked later, and reviewed by experts. Next, we developed an online tool to visualize the data and generate reports to assist decision-making under the R Shiny framework. Currently, the application can generate descriptive analytics using population variables, such as age, sex, and cancer type; cancer incidence in region-level geographical heat maps; line plots to visualize temporal trends; and typical risk factor plots. The application also showed descriptive plots about cancer mortality in the Lleida region. This web platform was built as a microservices cloud platform. The web back end consists of an application programming interface and a database, which NodeJS and MongoDB have implemented. All these parts were encapsulated and deployed by Docker and Docker Compose.

Results: The results provide a successful case study in which the tool was applied to the cancer registry of the Lleida region. The study illustrates how researchers and cancer registries can use the application to analyze cancer databases. Furthermore, the results highlight the analytics related to risk factors, second tumors, and cancer mortality. The application shows the incidence and evolution of each cancer during a specific period for gender, age groups, and cancer location, among other functionalities. The risk factors view permitted us to detect that approximately 60% of cancer patients were diagnosed with excess weight at diagnosis. Regarding mortality, the application showed that lung cancer registered the highest number of deaths for both genders. Breast cancer was the lethal cancer in women. Finally, a customization guide was included as a result of this implementation to deploy the architecture presented.

Conclusions: This paper aimed to document a successful methodology for exploiting the data in population cancer registries and propose guidelines for other similar records to develop similar tools. We intend to inspire other entities to build an application that can help decision-making and make data more accessible and transparent for the community of users.

(JMIR Cancer 2023;9:e44695) doi:10.2196/44695

KEYWORDS

R Shiny; cloud computing; microservices; Docker; decision support system; cancer incidence; cancer risk factors, cancer mortality

Introduction

Cancer morbidity and mortality are increasing worldwide despite the development of new prevention strategies and screening programs. This increase can be attributed to several factors, including population growth, aging, and changes in lifestyle and environmental factors. The authors of [1] estimated that the global number of cancer patients (incidence rate) will increase over the coming years due to negative lifestyle and demographic changes related to population aging and growth.

The cancer incidence rate is essential for public health surveillance [2]. The incidence rate approximates the average risk of developing cancer, allowing geographic comparisons of the disease risk in different populations. This calculation requires a population-based cancer registry (PBCR) to record, store, and organize all the cancer cases in a reference region. This is achieved by a continuous process of systematic collection, storage, analysis, interpretation, and reporting of data on the occurrence and characteristics of cancer cases [3].

Over recent decades, there has been an exponential growth in PBCRs. The first volume of the Cancer Incidence in Five Continents (CI5), published in 1966, contained information from 32 registries in 29 countries, whereas the latest volume, published in 2021, included information from 343 PBCR in 65 countries.

Several data sources are integrated into PBCRs, including hospitals, death certificates, and laboratory services. Moreover, PBCRs follow international procedures, ensuring high-quality and reliable data. These goals are accomplished by performing exhaustive (automatic and manual) validity checks [4].

PBCRs are commonly used in epidemiological research. Thus, they have a crucial role in providing extensive information about tumor histology, stage at diagnosis, place and nature of the treatment, and survival [5]. Descriptive studies use registry databases to examine differences in incidence, survival, and prevalence of risk factors or comorbidities (obesity, tobacco consumption, or diabetes) across populations and their context (such as variables associated with time, place, sex, ethnicity, and social status) [6,7].

The data sets and databases stored in PBCRs grow year on year. Data visualization is essential for exploring and communicating findings in medical research, especially in epidemiological surveillance. Hence, there is an intrinsic need for rapid raw data visualization. The current situation and context (historical data) can be understood by navigating among descriptive analyses, and, before executing time-consuming predictive or prescriptive models, it is essential to generate alarms and accurate predictions or discover hidden trends or patterns.

Previous literature has described the research of the implementation of web platforms to analyze data information related to cancer. Petrov and Alexeyenko [8] implemented an application to explore molecular features and responses to anticancer drugs. Deng et al [9] presented another web application implemented on R Shiny that permitted the analysis of molecular cancer gene data sets. The user can analyze outcomes from individual genes and cancer entities. A similar application was designed by Yang et al [10]. It also analyzed and provided information on cancer gene isoform expression. Finally, another application about cancer genes was presented by Dwivedi et al [11]. In this case, it was used to perform a survival analysis on single-cell RNA sequencing data. A study by van de Water et al [12] presented a web-based tool to inform patients about esophagogastric cancer treatment options and their outcomes. These kinds of web applications can also be linked to a trained prediction tool, as demonstrated by Xu et al [13]. They developed a sexually transmitted infection prediction tool. Therefore, the literature has focused on cancer genes, cancer treatments, or other diseases, but few applications are based on epidemiological cancer data. In addition, our system is entirely adaptable to other PBCRs.

Currently, PBCRs expend resources and time to extract, analyze, and present the data to gain insight into the incidence, mortality, and survival rates for cancer. Moreover, these insights are generated manually.

One approach to solving this limitation is to develop a generic platform based on microservices for PBCRs capable of generating interactive plots, tables, and statistics to determine the epidemiological cancer situation. To address this challenge, in this paper, we propose a platform capable of (1) navigation across time and feature-based data, (2) plotting aggregated and disaggregated data on demand, and (3) automatic integration of new data.

The core activities of the PBCR have expanded beyond the provision of data to perform epidemiological research or the provision of cancer reports and statistics for a region. The data in PBCRs are the basis for estimating the cancer burden and its trends over time and are crucial in the scheduling and evaluation of cancer control programs in the registration area. One of the simplest ways of tackling this problem is to use segregated information to convince authorities about which population segments need more or different attention. For instance, geographical heat maps can be used to spot differences across urban or rural areas, while age pyramids can highlight age group differences. This can help authorities to invest and generate personalized prevention campaigns.

In summary, in this article, we propose a seed to develop this platform. The main contributions are the presentation of a successful case study for Lleida PBCR and guidelines to evolve these into a reference that can be adopted by the community. The platform was designed to be differentiated by end user. One end user is the PBCR professional who analyzes the incidence of cancer in a specific region and makes decisions to research or prevent cancer. Another end user is the nonprofessional user who wants to know the cancer situation in his or her area.

The paper is structured as follows. The next section presents the methodology involved in designing and implementing the web platform. The Results section describes the different views implemented in this application and how the customization works. The presented data visualizations are related to cancer incidence, risk factors, and mortality. Finally, the results are discussed in the Discussion section, which also includes our conclusions.

Methods

The application is based on the model-view-controller pattern. For the visual part, we used the open-source programming language R [14] in conjunction with RStudio [15], an open-source integrated desktop environment for R. The database was created by MongoDB [16], an open-source, nonrelational database, and based on document store database, where documents are grouped into collections according to their structure. To communicate these systems and obtain the information, we implemented an application programming interface (API). Finally, to encapsulate this system and facilitate the deployment, we ran it into Docker containers that Docker Compose orchestrated [17]. Docker permits encapsulating and deploying the execution of applications in packages. All these technologies are free of charge. The deployment and code are available to download in this GitHub repository [18].

Workflow

Until the implementation of this application, PBCR professionals were manually extracting the data on demand. Once the cases were received, they cleaned and prepared the tables and plots to analyze them. Finally, they added these results to a formal report sent to public health officials.

However, once the application has been deployed, the professionals can automatically present the data to public health officials. The data extraction and cleaning steps are done by an extract, transform, and load system deployed in a server; therefore, they do not need to spend time preparing the data. In addition, the application permits real-time comparison of cancer cases between the previous years. The following subsections show how the web application has been designed and implemented.

Front-end Service

The front end was implemented using the Shiny [19] package from the R programming language, making it easy to build interactive web applications. Shiny allows R users to create interactive web applications without extensive knowledge of web design. It also permits standalone applications to be hosted on a web page and extends the application with CSS themes, html widgets, and Javascript actions.

All the plots were made using the plotly library [20], which is defined as an interactive, open-source, browser-based graphing library. It contains over 30 types of plots, including scientific charts, statistical charts, 3D graphs, and more. The tables were made using DataTable [21], defined as a plug-in for the jQuery Javascript library, which enabled the building of interactive and flexible tables. The map was made with the GeoJSON package [22]. It is a format for encoding a variety of geographic data structures and uses a geographic coordinate reference system. It also permits a specific zone and highlighted part of this map to be represented by a palette of colors.

Back-end Service

The back end consisted of an API and a database for the web application. Both these services were encapsulated using the Docker system, which permits scalability to other infrastructures. The API established the communication between the database and the view. This system was implemented by NodeJS [23], which can be described as an open-source environment based on the JavaScript programming language. This technology has increased exponentially over the last few years because it is based on asynchronous tasks, which permit executing calls without the need to wait for a response from the previous one. In addition, this uses a single threaded model with an event loop and is based on JSON format. The database implementation was based on a nonrelational database using the MongoDB system [16,24]. It saves the information through documents that are grouped into collections. This database permits large volumes of constantly changing structured, semistructured, and unstructured data. Nonrelational databases are designed by dynamic schemes to insert data without a specific structure as the relational databases specify. Therefore, it makes it easy to make significant changes to applications in real time without service interruptions.

Docker and Docker Compose

The front-end and back-end technologies were encapsulated into Docker containers. Docker is a platform designed to build, share, and run modern applications into containers [17] where the applications are virtualized and executed. The main purpose of these containers is to implement some processes and applications separately to take advantage of the infrastructure simultaneously. The way Docker is designed is to give a quick and lightweight environment where code can run efficiently. Docker contains 4 main internal components: Docker client and server, Docker images, Docker registries, and Docker containers [25].

These containers were defined using Docker Compose, which orchestrated all of them. It composes a set of components, each of which is an image and a set of options that specify what the component should have. It uses a configuration file where the user selects the parameters, and when it is executed, it runs the needed processes to build the Docker container. The user can reuse the same image for different components, and these images will be managed in other containers once instantiated [26].

Data

The case data were extracted from the official Cancer Population Registry in Lleida and the Mortality Registry of Catalonia. Experts from the cancer registry previously validated these cases to ensure the validity of the tumor. In the case of mortality, the included individuals were those patients who died from cancer in the Lleida region. The cancer patients were complemented with their risk factors, extracted from the clinical history records at the time of diagnosis. This information permitted us to build the databases and show them in the visual part.

The database was structured into 3 collections: Patients, Tumors, and Mortality. The Patients collection included sociodemographic information and risk factors; the Tumors collection included such information as the diagnosis and the kind of tumor. Finally, the Mortality collection registered sociodemographic information and cause of death (tumor list). Table 1 specifies the variables in each collection.

Table 1. Database collections and their variables.

Variables	Specification
Patients	
sex	Gender (man/woman)
data_naix	Date of birth (date)
postal_code	Postal code of city residence (number)
postal_desc	Name of city residence (characters)
comarca	Specific region in Lleida (characters)
comarca_desc	Specific region description in Lleida (characters)
alcoholism	Alcohol consumption (yes/no)
diabetes	Diabetes diagnosed (yes/no)
smoking	Smoking consumption (yes/no)
bmi	Body mass index (number)
Tumors	
data_inc_pobl	Diagnoses date (date)
ltum	Tumor location (characters)
ltum_desc	Tumor location description (characters)
morf	Tumor morphology (characters)
morf_descr	Tumor morphology description (characters)
metode_dx	Diagnostic method (number)
metode_dx_descr	Diagnostic method description (characters)
Mortality	
data_naix	Date of birth (date)
data_def	Date of death (date)
cause10	Death cause (characters)
cause10_desc	Death cause description (characters)
sex	Gender (man/woman)
comarca	Specific region in Lleida (characters)
comarca_desc	Specific region description in Lleida (characters)
yeard	Year of death (number)

Ethical Considerations

All data were anonymized to protect patient privacy and confidentiality. The study was part of the public health response to the impact of cancer on the society. It was approved by the Committee of Ethics and Clinical Research of Lleida (CEIC 21/190-P). As it was a retrospective cohort study and the patients were blinded to the investigators, no written informed consent was necessary according to the CEIC. All methods were carried out in accordance with relevant guidelines and regulations.

Results

This web application consisted of an intuitive analytical web platform for rapid analysis of the population cancer registry data set, containing incidence, mortality, and risk factors related to tumor information. The application shows the incidence and evolution of each cancer during a specific period for gender and age groups. It also permits knowledge of the situation of all the cancers in a particular period and subregion in Lleida. The application also summarizes patients' risk factors detected in the cancer registry and shows results about cancer mortality.

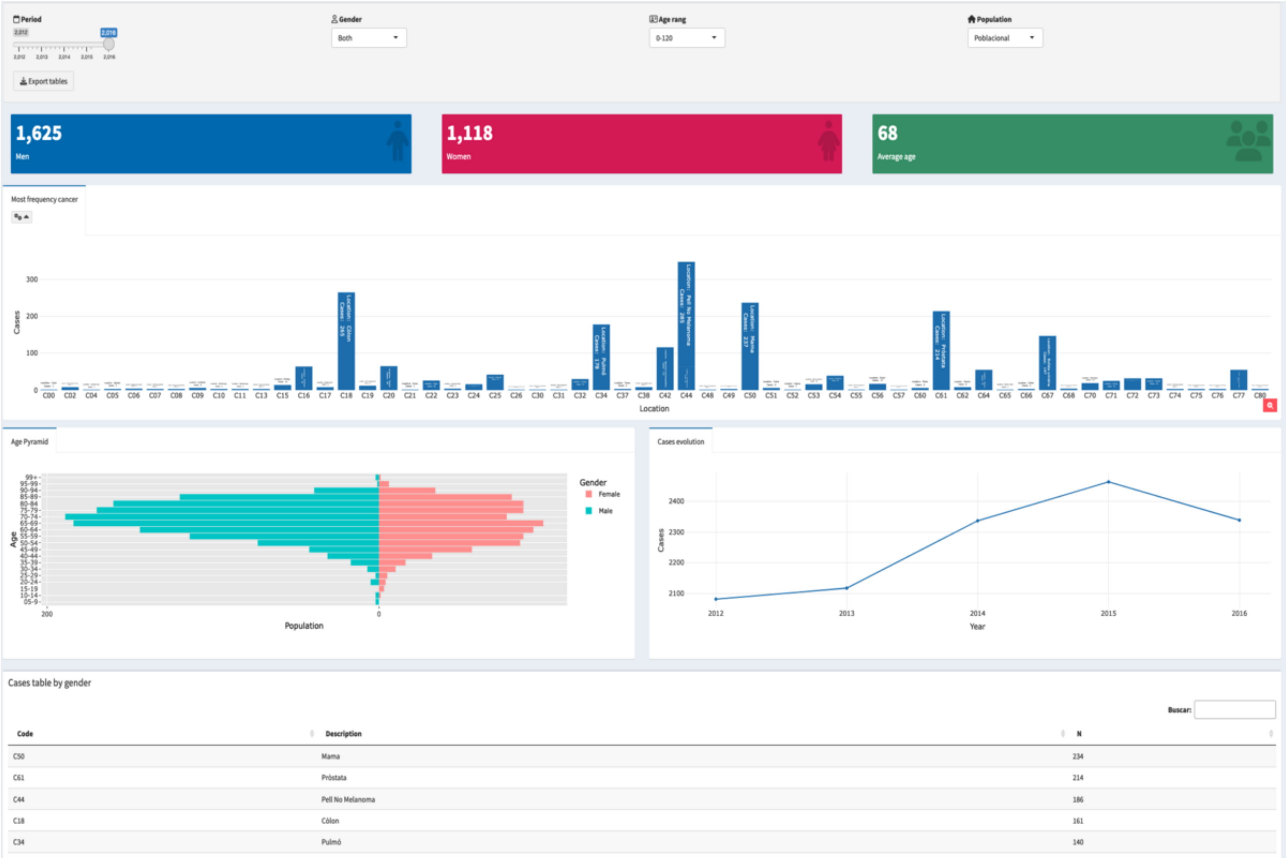
These plots enable the number of cases to be analyzed for each year, filtered by tumor location, gender, and age group.

Cancer Incidence

The web application was designed as a web browser–based dashboard (see Figure 1) to show the information according to what the user specifies in the filters. The users can filter by years between 2012 and 2016, gender, age group, and population. This last filter can show only residents of Lleida or all cases diagnosed in the reference hospitals. Below the input filters, 3 boxes show the numbers of men and women and the average age of the patients. If the user decides to filter by men, the women box will be hidden, and the average age box will be calculated only for men. Next, the bar plot represents the number of cases diagnosed by the tumor location. The pyramid age plot helps the user analyze which age group registered the most diagnosed cases among men and women. These plots can be recalculated for all the filter inputs. Next to the pyramid age plot, the display shows the evolution of the incidence for the available years, and it allows analysis of the change in men, women, or a specific age group, depending on the chosen filters. At the end, a table with the number of diagnosed cases by tumor location is displayed and can be updated using all the filters.

Figure 2 shows a view for analyzing the incidence in the Lleida region. Specifically, it permits observation of diagnosed cases by year and cancer for specific subregions in Lleida, as the filter header represents. The view is also designed as a dashboard to enable user interaction. First, a heat map of the Lleida region is implemented. It shows the cancer incidence (per 100,000 habitants) for each area, where the color represents the incidence value. The view also offers analysis of this incidence in a bar plot (see the blue button in the map box). On the right, it shows a table with the number of cases and incidence for each area represented in the map information. These 2 elements are updated by year and the kind of cancer the user chooses in the filter. Below them, there is an evolution plot of the number of cancer cases registered. This plot is only recalculated when the user chooses a different cancer, and the year filter does not affect it. Finally, the age pyramid plot is represented, and it can be calculated by cancer and year.

Figure 1. Main menu of the web application.



Period: 2,012 – 2,016

Gender: Both

Age rang: 0-120

Population: Poblacional

1,625 Men

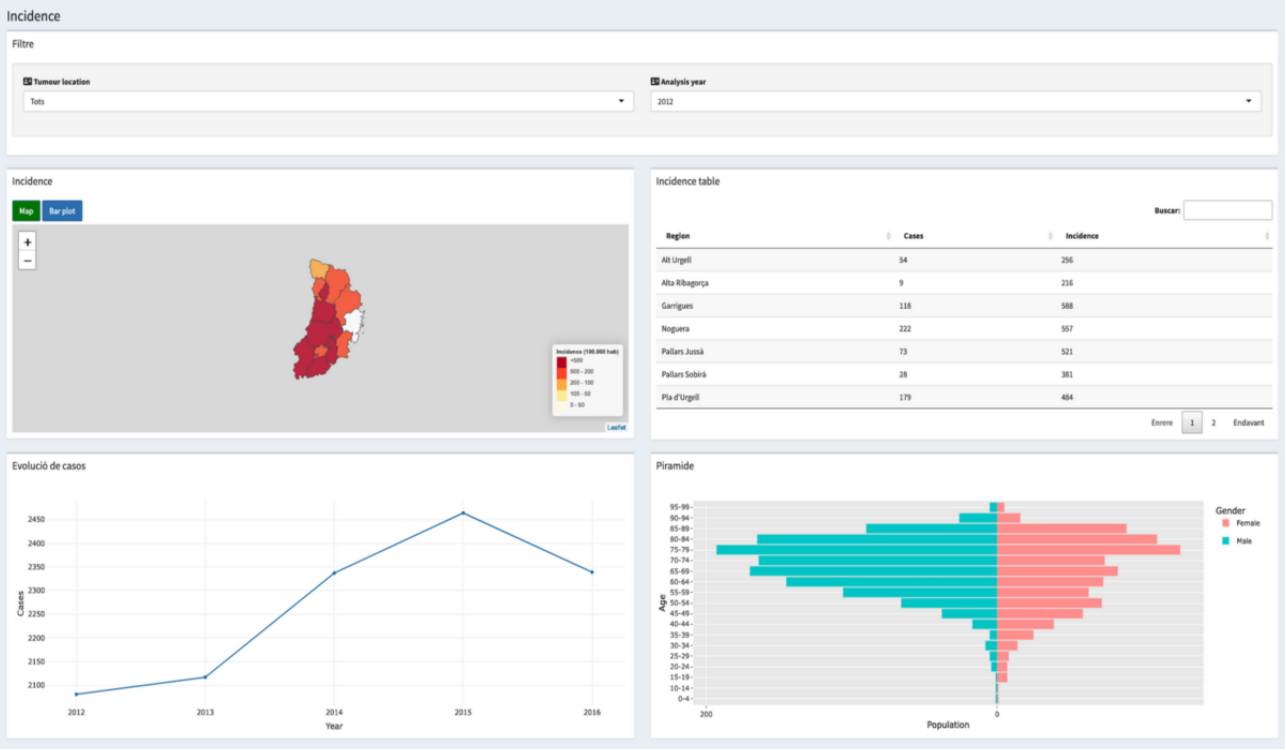
1,118 Women

68 Average age

Cases table by gender

Code	Description	N
C50	Mama	234
C61	Pròstata	214
C44	Pell No Melanoma	186
C18	Còlon	161
C34	Pulmó	140

Figure 2. Specific incidence view.



Incidence

Filtre

Tumour location: Tots

Analysis year: 2012

Incidence

Map | Bar plot

Incidence table

Buscar:

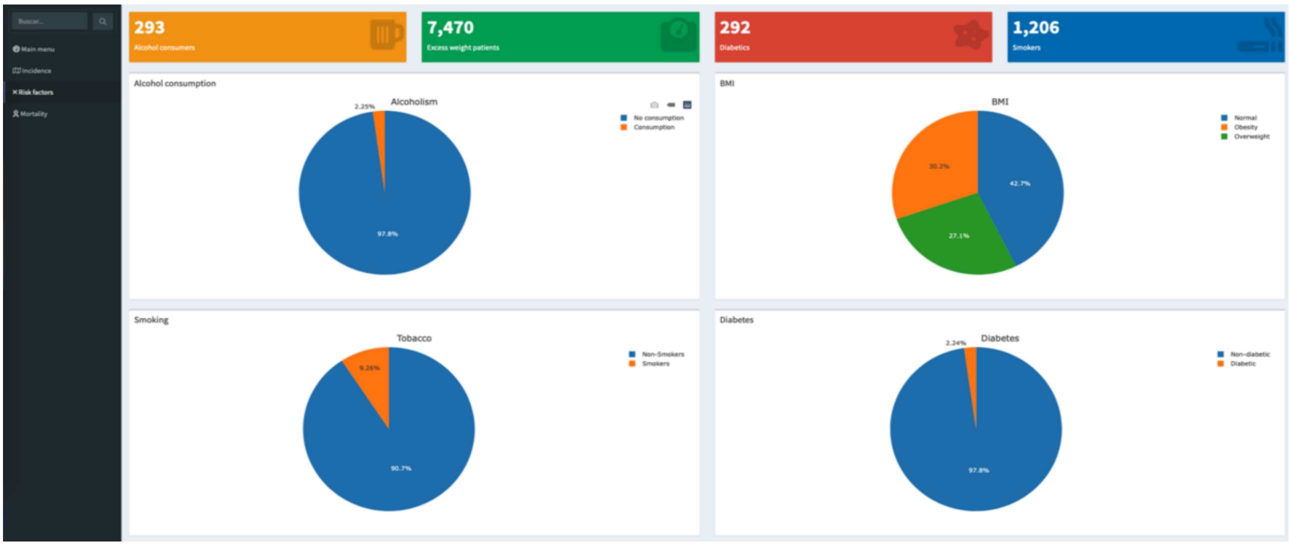
Region	Cases	Incidence
Alt Urgell	54	256
Alta Ribagorça	9	216
Garrigues	118	588
Noguera	222	557
Pallars Jussà	73	521
Pallars Sobirà	28	381
Pla d'Urgell	179	484

Enrere 1 2 Endavant

Cancer Risk Factors

This view permits the risk factors' impact on cancer patients to be analyzed. Figure 3 shows 4 value boxes with the number of cases for each risk factor. First, it shows the number of patients exposed to alcohol consumption before a cancer diagnosis. Next, the number of patients with excess weight (overweight or obese) and the number of patients diagnosed with diabetes before tumor registration are shown. Finally, the number of smokers among all those who were registered is shown. Below the value box, 4 pie charts were designed to compare the exposure to these risk factors. First, alcohol risk was represented, and only 2.2% (293/13,030) of the patients were exposed. On the right, body mass index was defined; overweight affected 27.1% (3532/13,030) of the patients, and obesity affected 30.2% (3938/13,030) of the patients. At the bottom, smoking was reported for 9.3% (1212/13,030) of patients, and diabetes was reported for 2.2% (292/13,030) of patients.

Figure 3. Risk factors view.



293 Alcohol consumers

7,470 Excess weight patients

292 Diabetics

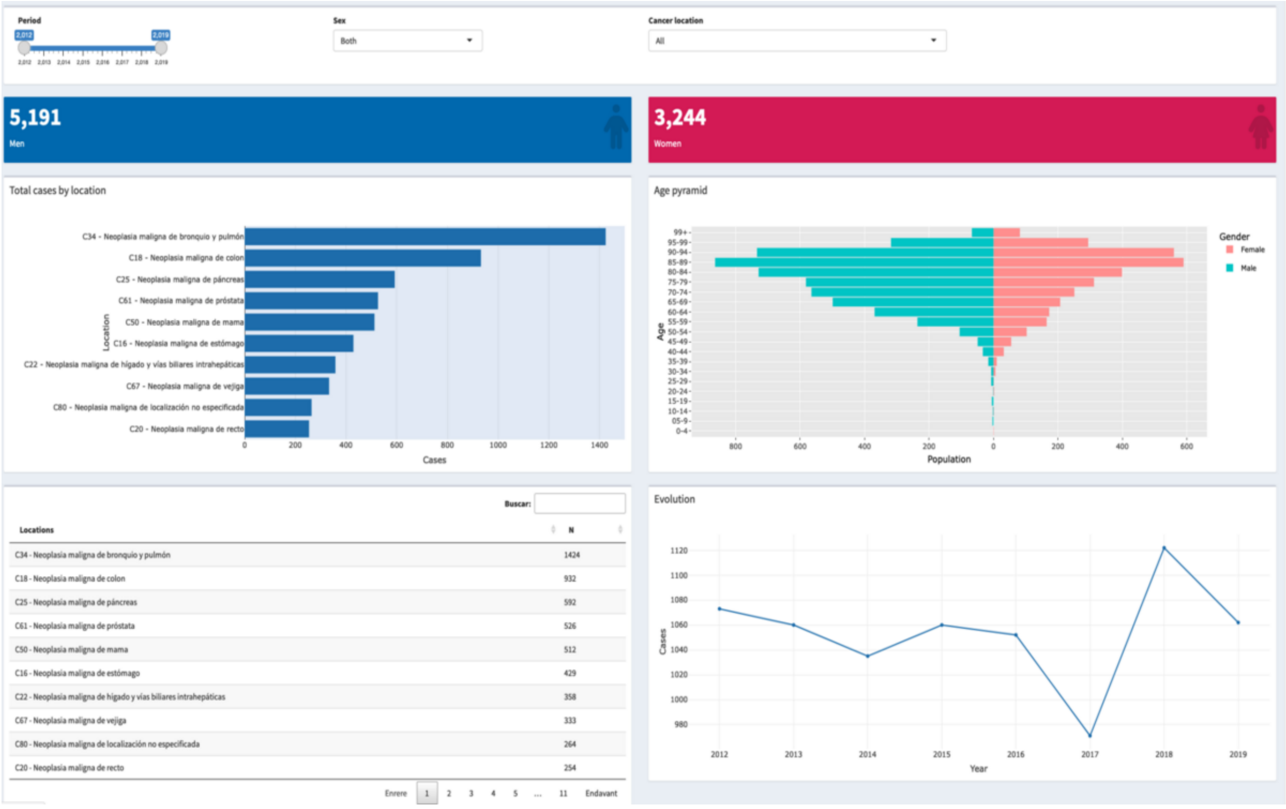
1,206 Smokers

Cancer Mortality

The last implemented view shows an analysis of Lleida residents affected by tumors. In this case, the observed years were between 2012 and 2019 because the Mortality Register of Catalonia was already available for this time. Therefore, as Figure 4 shows, the filter box enables filtering by a period of years or by only 1 year. It permits showing the information by only men or women and by specific tumor location. Below the filter box, the user sees 2 value boxes representing the number of men and women who passed away among the chosen years and by tumor location. When a specific gender is selected, the other is hidden, making visible the value box chosen in the filter.

This view also contains 4 figures, 3 plots, and 1 table. At the top left, there is a horizontal bar plot representing the 10 tumors with the most cases of mortality. It is recalculated by the period and gender chosen; the filtered cancer location does not affect it. On the right, an age pyramid plot analyzes the mortality in each age group by gender. This plot can also be recalculated by the period in years and by cancer location. At the bottom, a table has the tumor locations and the number of patients who passed away, sorted in descending order. The information is displayed by the chosen period of years and gender; the cancer location filter will not affect it. Finally, an evolution plot is calculated to analyze the increase or decrease in deaths for all locations or specific tumors. This plot is recalculated depending on the chosen year, gender, or tumor location.

Figure 4. Mortality view.



Period: 2,012 – 2,019

Sex: Both

Cancer location: All

5,191 Men

3,244 Women

Buscar:

Locations	N
C34 - Neoplasia maligna de bronquio y pulmón	1424
C18 - Neoplasia maligna de colon	932
C25 - Neoplasia maligna de páncreas	592
C61 - Neoplasia maligna de próstata	526
C50 - Neoplasia maligna de mama	512
C16 - Neoplasia maligna de estómago	429
C22 - Neoplasia maligna de hígado y vías biliares intrahepáticas	358
C67 - Neoplasia maligna de vejiga	333
C80 - Neoplasia maligna de localización no especificada	264
C20 - Neoplasia maligna de recto	254

Enrere 1 2 3 4 5 ... 11 Endavant

Customization

The research team designed the system for easy deployment. Therefore, the users only need to consider these items:

- Deploy the Mongo database by executing the docker-compose file. The system will download the Mongo image (if it is the first time it runs), build the Docker Container, and deploy the database. Finally, add the information to show in the dashboard web application.
- Download the web application project and specify the user and password in the config.js file. Next, execute the docker-compose file to build the containers for the API system and R Shiny application. The system will download the image to make these containers if it is the first time and then deploy the containers.

Discussion

Principal Findings

The research team designed and implemented a web application to rapidly analyze the cancer situation in the Lleida region. It contains information about the incidence of each cancer by subregion, related risk factors, and the cancer mortality registered in this region. The application can be used in computer and mobile browsers because it has been designed responsively. It has been implemented using open-source technologies such as Docker, MongoDB, NodeJS, and R Shiny, which permit easy deployment of cancer registries in other hospitals. The code is also free to download and can be deployed within 1 day.

Recently, new applications have been designed to facilitate the analysis of data sets. Some studies have suggested that the latest technologies can help to extract information and value of the data rapidly and obtain the results instantly in different contexts. Luz et al [27] designed an application called RadarR to analyze infection management. They described an accessible web application to analyze infection and antimicrobial stewardship information. Another study implemented a Shiny application for automatically coding text responses [28]. They offer an application in which users can add text to train a model to analyze this added information. For completely different information but with the same technologies, Möller et al [29] presented an R Shiny application for the visualization and extraction of phenological windows in Germany. As the literature shows, these kinds of applications are increasing for all themes as well as cancer. Miller and Shalhout [30] designed and implemented an application to generate anatomical visualizations of cancer lesions. They concluded that data visualizations of the characteristics of clinical tumors could help to understand the natural history of malignancies. Therefore, this interactive data visualization application could permit analysis of the tumor characteristics. Another R Shiny application related to cancer data was published by Zhang et al [31]. The researchers designed a platform to analyze cell line responses to an anticancer drug. They concluded that it helped researchers understand the response of tumor cell lines to 15 therapeutic agents. Finally, a similar platform was implemented by Xia et al [32]. This platform visualizes cancer risk factors and mortality [32]. They shared a data warehouse and R Shiny application to improve their understanding of spatial and temporal trends across the population served by the University of Kansas Cancer Center.

This system helped the research team rapidly analyze the cancer information and reach some conclusions about the data and the use of these technologies. Therefore, regarding cancer incidence, the analysis detected that the number of cases is higher in men than in women in all periods and years [33]. Regarding age, the average age was 67 years, considering both genders. Men aged 65 years to 79 years registered a significant number of cases. However, cases for women occurred more often between 65 years and 69 years of age and between 75 years and 84 years of age [34]. Additional observable information was that the most common were cancers of the colon, lung, breast, prostate, and bladder [33,34]. Finally, an evolution of the incidence in Lleida showed an increase in the cases until 2015. The specific cancer incidence view also gave important information about some regions in Lleida. We observed that some areas, considered more urban than rural, had a higher incidence of some kinds of cancer, such as colon or lung [35,36].

As the incidence showed, the risk factors view also provided the previous situation of patients with cancer. Regarding risky drinking, 2.2% of the patients diagnosed consumed high amounts of alcohol daily [37]. The same percentage, 2.2%, of patients had diabetes. However, smokers represented 9.3% of the patients, one of the highest risk factors related to cancer [38]. Finally, the percentage with excess weight was high (57.3%), and some studies have pointed out that excess weight is significantly associated with the risk of cancer [39]. These results, including the number of cases for each risk factor, were obtained by the implementation of this application, which also helps to understand the cancer situation better, as other research teams have done before [32,40].

The cancer mortality registry permitted us to analyze the severity and impact of this disease, considered the second cause of death globally [41]. As we showed previously, analysts need tools like our web application offers. The application indicated that more men than women died between 2012 and 2019 [42], which might be related to the number of observed cases of cancer diagnosed among men and women [33]. The application also permitted us to know that lung cancer was the most lethal cancer among men [43] and breast cancer was the most lethal cancer in women [44]. Regarding age, the age group of 85 years to 89 years registered the highest number of deaths in both genders. Finally, we observed a general decrease in cancer deaths until 2018, when the number of patients passing away increased significantly. In case a user wanted to analyze a specific cancer location, the web platform recalculates the plots and tables for this variable.

The application presents some strengths and limitations that should be noted. This kind of implementation increases the data's potential and adds value to the cancer registries. It permits an analysis and comparison of cancer information trends in specific areas in real time and helps make decisions about public health and the impact of cancer. The risk factor situation among cancer patients suggests some associations between risk factors and cancer. The scalability of the technologies used helps to deploy them to other cancer registries. Regarding limitations, the map plot has to be adapted to the region where it is deployed. The inconsistency between the cancer registry and cancer mortality did not permit them to be merged and analyzed in depth. The codification of some risk factors suggested underdiagnosis. A future systematic link between the cancer registry and the primary care medical records could improve the registry of risk factors. Related to the software, R Shiny presented some restrictions and incompatibility with some new libraries even though they were supplied with others that are accepted and adapted perfectly. MongoDB, in the beginning, requires extra effort to understand how it works, which delayed other parts of the application.

Conclusions

The web application discussed in this study offers an analytical model of population cancer information. In addition, the technologies used to build this system permit its deployment into other cancer registries. Although there are web applications based on similar technologies, none use population cancer registry data to show the cancer situation in a specific region.

The views presented in the platform show the incidence of cancer detected in a specific time and particular areas, allowing it to be filtered by such inputs as year, gender, and tumor location. It also shows the evolution of cancer in the years analyzed. In addition, it studies the impact of some risk factors among the patients in the registry. Finally, it permits users to explore cancer mortality and its evolution in the Lleida region, filtering by year, gender, and tumor location.

Regarding future work, the research team is designing new views to analyze cancer incidence and the impact of the second primary tumor in depth. They are also creating a new risk factor view to offer a filter to give the risk factors for specific gender and tumor locations and integrating treatment data, such as for radiotherapy and chemotherapy. Finally, new web views are being created to build machine learning algorithms, train models, and analyze the results.

Acknowledgments

This work was supported by contract 2019-DI-43 from the Industrial Doctorate Program of the Government of Catalonia and by the Spanish Ministry of Economy and Competitiveness under contract PID2020-113614RB-C22. Some of the authors are members of the research group 2014-SGR163, funded by the Generalitat de Catalunya.

The authors wish to thank to the Arnau de Vilanova University Hospital, Santa Maria University Hospital, and the Catalan Health Service in Lleida for the support and resources to conduct this study.

Data Availability

The data set is available from the corresponding author upon reasonable request.

Conflicts of Interest

None declared.

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Abbreviations

API: application programming interface

CEIC: Committee of Ethics and Clinical Research of Lleida
CI5: Cancer Incidence in Five Continents
PBCR: population-based cancer registry

Edited by A Mavragani; submitted 30.11.22; peer-reviewed by CM Moore, N Jiwani; comments to author 29.01.23; revised version received 13.02.23; accepted 07.03.23; published 20.04.23.

Please cite as:
Florensa D, Mateo-Fornes J, Lopez Sorribes S, Torres Tuca A, Solsona F, Godoy P
Exploring Cancer Incidence, Risk Factors, and Mortality in the Lleida Region: Interactive, Open-source R Shiny Application for Cancer Data Analysis
JMIR Cancer 2023;9:e44695
URL: https://cancer.jmir.org/2023/1/e44695
doi:10.2196/44695
PMID:37079353

Original Paper

Understanding the Needs and Lived Experiences of Patients With Graft-Versus-Host Disease: Real-World European Public Social Media Listening Study

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Abstract

Background: Graft-versus-host disease (GVHD) is the major cause of short- and long-term morbidity and mortality after allogeneic hematopoietic stem cell transplantation. Treatment options beyond corticosteroid therapy remain limited, and prolonged treatment often leads to impaired quality of life (QoL). A better understanding of the needs and experiences of patients with GVHD is required to improve patient care.

Objective: The aim of this study is to explore different social media (SM) channels for gathering and analyzing the needs and experiences of patients and other stakeholders across 14 European countries.

Methods: We conducted a retrospective analysis of SM data from the public domain. The Talkwalker social analytics tool collected data from open-access forums, blogs, and various social networking sites using predefined search strings. The raw data set derived from the aggregator tool was automatically screened for the relevancy of posts, generating the curated data set that was manually reviewed to identify posts that fell within the predefined inclusion and exclusion criteria. This final data set was then used for the deep-dive analysis.

Results: A total of 9016 posts relating to GVHD were identified between April 2019 and April 2021. Deduplication and relevancy checks resulted in 325 insightful posts, with Twitter contributing 250 (77%) posts; blogs, 49 (15%) posts; forums, 13 (4%) posts; Facebook, 7 (2%) posts; and Instagram and YouTube, 4 (1%) posts. Patients with GVHD were the primary stakeholders, contributing 63% of all SM posts. In 234 posts, treatment was the most discussed stage of the patient journey (68%), followed by symptoms (33%), and diagnosis and tests (21%). Among treatment-related posts (n=159), steroid therapy was most frequently reported (54/159, 34%). Posts relating to treatment features (n=110) identified efficacy (45/110, 41%), side effects (38/110, 35%), and frequency and dosage (32/110, 29%), as the most frequently discussed features. Symptoms associated with GVHD were described in 24% (77/325) of posts, including skin-related conditions (49/77, 64%), dry eyes or vision change (13/77, 17%), pain and cramps (16/77, 21%), and fatigue or muscle weakness (12/77, 16%). The impacts of GVHD on QoL were discussed in 51%

(165/325) of all posts, with the emotional, physical and functional, social, and financial impacts mentioned in 69% (114/165), 50% (82/165), 5% (8/165), and 2% (3/165) of these posts, respectively. Unmet needs were reported by patients or caregivers in 24% (77/325) of analyzed conversations, with treatment-related side effects being the most common (35/77, 45%) among these posts.

Conclusions: SM listening is a useful tool to identify medical needs. Treatment of GVHD, including treatment-related side effects, as well as its emotional and physical impact on QoL, are the major topics that GVHD stakeholders mention on SM. We encourage a structured discussion of these topics in interactions between health care providers and patients with GVHD.

Trial Registration: Not applicable

(JMIR Cancer 2023;9:e42905) doi:10.2196/42905

KEYWORDS

graft-versus-host disease; GVHD; infoveillance; patient journey; quality of life; real-world evidence; social media listening; social media

Introduction

Graft-versus-host disease (GVHD) is a systemic immune-related complication of allogeneic hematopoietic stem cell transplantation (HSCT) and is a major cause of short- and long-term morbidity and no relapse mortality [1,2]. GVHD occurs in two main forms: acute GVHD (aGVHD) and chronic GVHD (cGVHD), each of which is defined by distinct clinical presentations [3,4].

Treatment of GVHD remains challenging. Corticosteroids are the standard first-line therapy for both aGVHD and cGVHD, with response rates ranging from 40% to 60%, which highlights an urgent unmet need for the steroid-refractory patient population [5]. Several interventions, including extracorporeal photopheresis, Janus kinase (JAK) inhibitors, and other immunosuppressive therapies, are used for second-line therapy, although efficacy data for these interventions are limited [6-9]. Over the past 5 years, the US Food and Drug Administration has granted 4 approvals to therapies for the treatment of GVHD [10]. Ruxolitinib, a small-molecule JAK1/2 inhibitor, has received approval for the treatment of adult and pediatric patients with either steroid-refractory aGVHD or steroid-refractory and steroid-dependent cGVHD after failure of 1 or 2 lines of systemic therapy. Ibrutinib, a potent small-molecule Bruton’s tyrosine kinase inhibitor, was approved for adult patients with cGVHD after failure of 1 or 2 lines of systemic therapy. In addition, belumosudil, an oral selective Rho-associated kinase 2 inhibitor, has been approved for adult and pediatric patients with cGVHD after failure of at least 2 previous lines of systemic therapy [10].

Impaired quality of life (QoL) is often reported in patients with GVHD, particularly in those with cGVHD who experience physical challenges. In addition to reduced QoL, cGVHD has been associated with low functional status and high symptom burden [11-14]. A patient-reported outcomes study with patients who have ongoing cGVHD highlighted that 26.7%-39.4% of patients were unable to work due to health-related issues, compared with 12.1% whose cGVHD had resolved and 15.4% who did not have cGVHD [13]. Patients with moderate or severe cGVHD were more likely to take prescription drugs for pain, anxiety, and depression when compared with those who had resolution of GVHD [13]. The emotional impact of cGVHD was noted in a study of patients from the Chronic GVHD Consortium (N=482), with approximately one-fifth of patients having clinically significant depression or anxiety, of which depression was associated with lower overall survival [15]. A further prospective study (N=52) identified approximately one-third of patients with clinically significant depression or anxiety [16].

Social media (SM) has been widely used for health-related purposes, including health campaigns, medical education, and disease surveillance [17]. Patients can use SM for diverse reasons, including increasing disease knowledge, expression of emotions, experience-sharing of their disease and treatments, contact and community, and advice-gathering [18]. The data generated in SM are often anonymous, unfiltered, and uninfluenced [19] and may offer insights from other key stakeholders, such as caregivers. These types of data are not frequently available in the published literature. Social media listening (SML) has emerged as a valuable tool that uses technology to automatically monitor, track, review, and analyze conversations and interactions taking place on different SM platforms. Such a methodology has the capability to identify patients’ unmet needs and helps better understand their lived experiences with the disease. SML has been used in recent years across several conditions, including chronic obstructive pulmonary disease [20], presbyopia [21], Parkinson disease [22], bronchiectasis [23], inflammatory bowel disease [24], COVID-19 [25], and cancer [19,26-28]. These studies highlighted the value of SML in gathering and analyzing large volumes of real-world stakeholder-centered data that are available on SM channels. Such analyses have helped uncover the most troublesome disease symptoms, considerations behind patients’ choice of available treatment options, the impact of disease and treatment on QoL and emotional well-being, and financial repercussions associated with disease burden, among other factors. To our knowledge, there is no published literature on the use of SML to understand the lived experiences and needs of patients with GVHD. This study aimed to explore how GVHD stakeholders, including patients, caregivers, and health care professionals (HCPs), describe their experiences using SM. Furthermore, it explored the needs and perceptions using SML analysis to generate patient insights from across 14 European countries in terms of treatments received, predictors of outcome, treatment effectiveness and safety, and burden of illness.

Methods

Data Collection and Search Strategy

This study was a retrospective analysis of SM data freely available in the public domain. Data around GVHD-specific terms were collected retrospectively for 24 months from April 2019 to April 2021 across 14 European countries (the United Kingdom, Spain, France, Switzerland, Belgium, Germany, Austria, the Netherlands, Italy, Nordic countries [Denmark, Finland, Norway, and Sweden], and Portugal), in the following languages: English, Spanish, French, German, Dutch, Italian, Portuguese, Swedish, Norwegian, Danish, and Finnish. Predefined search strings were developed in each language to identify GVHD posts and conversations, including Boolean operators (AND, OR) to combine keywords within the search strings (Table S1 in Multimedia Appendix 1). The search string terms were originally identified through a literature review into the GVHD therapy area and a review of 2 web-based forums, Onmeda [29] and HealthUnlocked [30], which are the most frequently used health portals for sharing patients' and caregivers' experiences across European countries.

The SM aggregator tool, Talkwalker social analytics database [31], was used to collect data from SM posts for all included markets using the predefined search terms. A list of keywords was created to help identify and collect conversations on the topic of interest. These keywords were then used to create search strings that eventually formed a comprehensive search query, which was entered into the SM aggregator tool to streamline the search. Key information collected included demographics and any information on predefined research categories relating to the patient journey (Table S2 in Multimedia Appendix 1). Hashtags included within the search strings (Table S1 in Multimedia Appendix 1) were identified by the aggregator tool. All SM sources were included in the aggregator tool at setup. SM sources based on retrieval of information were open-access forums and blogs and social networking sites, including Twitter, Facebook (public), Instagram (public), and YouTube. SM data collected from all publicly available SM sources were evaluated for relevance to the topic of GVHD using the aggregator tool, and those open-access forums and blogs that provided the most relevant conversations were included in the study (Table S3 in Multimedia Appendix 1). Relevant posts were downloaded and tagged by channel and GVHD stakeholder, including patients, caregivers, and HCPs, and other stakeholders were also noted. Posts relating to specific stakeholders were identified based on the following predefined criteria: (1) SM users who mentioned that they are patients or have been diagnosed with GVHD and are looking for advice were defined as patients; (2) users who mentioned that their loved ones are affected with the disease and they are seeking disease-related information on behalf of their loved ones were defined as caregivers; and (3) HCPs were those users who identified themselves as doctors treating a patient or patients with GVHD; in Twitter posts, an HCP was identified using a publicly available bio associated with the Twitter profile (HCP/specialist). Posts that were originally written in languages other than English were analyzed and translated by local language specialists.

Data Analysis

A 3-tier technique was used to identify relevant data (Figure S1 in Multimedia Appendix 1) for the final deep-dive analysis. Using the predefined search terms (Table S1 in Multimedia Appendix 1), SM posts were identified from included countries and downloaded to form the raw data set (known as the data universe) of total posts for each geographical region from all stakeholders. Exclusion of irrelevant posts was carried out by an automated relevancy approach containing keyword-based relevancy algorithms, and manual review against predefined inclusion and exclusion criteria (Table S4 in Multimedia Appendix 1) forming the contextualized data set. Further information on Data Analysis is detailed in the Methods in Multimedia Appendix 1.

Definitions

In this study, the following definitions were used: a stakeholder is defined as a person who plays a role in the entire disease landscape and can include patients, caregivers, HCPs, researchers, patient support groups, and others. Positive or negative sentiments were defined as positive or negative mentions regarding treatment, for example, if a treatment is discussed in a positive or negative light. Treatment discontinuation was defined as a patient's or an HCP's action to stop treatment due to intolerable side effects or due to disease improvement. Unmet needs were defined as gaps perceived to exist in the care system by patients and caregivers, although specific unmet needs were not predefined before the study.

Ethical Considerations

All data utilized and presented in the present SML study were obtained from publicly accessible sources without accessing password-protected information. Nevertheless, ethical aspects of SML research should be considered, as patients affected by GVHD and other stakeholders did not formally consent to their discussions being used in data collection and analyses. In general, the privacy aspect is a major concern in SML studies. Despite the lack of clear guidance on how to deal with the lack of consent or anonymity of participants used in SML research, some recommendations have been published, stating that data should be collected only to answer specific research questions and presented in such a way that identification of a participant is minimized [32]. Publicly available posts used in this study were anonymized, and any information that could identify a GVHD stakeholder (such as usernames) was removed before analysis.

This study received internal pharmacovigilance approval [registry ID DE006979 (V1)] by Novartis AE and safety reporting team. All methods were performed in accordance with the relevant guidelines and regulations involving the secondary use of social media research.

Results

Overview of Analyzed Social Media Posts

The data universe extracted from the initial search using predefined keywords consisted of 9016 SM posts. Of these, 325 posts were identified as contextualized data relevant to study objectives and key research questions. Due to a low number of relevant posts containing records from key stakeholders (N=325), all posts were used for deep-dive analysis (Figure S1 in Multimedia Appendix 1). The countries contributed the following number of posts toward the contextualized data: United Kingdom, n=166; France, n=51; Germany, n=51; Spain, n=17; the Netherlands, n=11; the Nordic countries (Denmark, Finland, Norway and Sweden), n=8; Italy, n=7; Belgium, n=5; Switzerland, n=4; Portugal, n=3; and Austria, n=2. Due to the lower number of posts contributed by countries except the United Kingdom, France, and Germany, key findings from the study will be discussed generally.

Broad search term criteria allowed us to gather posts containing any conversations mentioning specific terms for GVHD across different SM channels (N=9016). Overall, Twitter was the most popular SM channel used, contributing to most of the overall volume around GVHD (5500/9016, 61%), followed by blogs (2524/9016, 28%), and forums (902/9016, 10%; Figure 1A). The majority of these conversations were generic discussions about GVHD. Curation of this raw data set using automation and manual relevancy checks reduced the number of posts to 325, resulting in a data set rich in patients' experiences and relevant to the research questions (Figure S1 in Multimedia Appendix 1). Of the 325 analyzed posts, Twitter contributed 250 (77%) posts; blogs, 49 (15%) posts; forums, 13 (4%) posts; Facebook, 7 (2%) posts; and Instagram and YouTube, 4 (1%) posts each. The number of posts retrieved from Facebook may have been impacted by restricted data access imposed by Facebook's application programming interface.

Twitter was the most prominent channel for the United Kingdom (2077/2885, 72%), France (950/1533, 62%), Spain (1102/1172, 94%), the Netherlands (81/180, 45%), the Nordic countries (377/992, 38%), Belgium (66/90, 73%), Switzerland (130/180, 72%), and Portugal (50/90, 55%). Blogs were the most prominent channel used for discussions in Italy (536/811, 66%) and Austria (47/90, 52%), whereas forums were the most prominent channel used in Germany (436/992, 44%; Figure 1B). The main contributor to the overall extracted data was the United Kingdom (2885/9016, 32%), followed by France (1533/9016, 17%), Spain (1172/9016, 13%), Germany and the Nordic countries (992/9016, 11% each), and Italy (811/9016, 9%). Fewer SM posts originated from the Netherlands and Switzerland (180/9016, 2% each), and Belgium, Portugal, and Austria (all 90/9016, 1%; Figure 1B).

From the analyzed data (N=325), patients with GVHD were the primary stakeholders across Europe, contributing 63% (205/325) of SM posts (Figure 1C). The second most prominent stakeholder group discussing GVHD was caregivers (49/325, 15%), followed by HCPs (23/325, 7%), and friends and family (13/325, 4%). Other stakeholders were categorized as miscellaneous and included organizations, communities, patient support groups, and experts, all of which were responsible for 11% (35/325) of posts. For overall extracted data, peaks in SM discussions were observed in March 2020 (584 posts) and March 2021 (758 posts; Figure 1D).

Gender was identifiable in 86% (279/325) of analyzed posts, with male contributors being slightly more prominent (145/279, 52%) than female contributors (134/279, 48%). Age was identifiable in 53% (171/325) of analyzed posts, with 31-40 years identified as the most common age range (Figure 2). Demographics of the SM population from analyzed posts (N=325) are shown in Figure S2 in Multimedia Appendix 1.

Figure 1. Data source and country of origin of relevant posts: (A) data source of relevant posts; (B) country of origin of relevant posts; (C) stakeholders for analyzed posts; and (D) data volume trend for relevant posts over 24 months. HCP: health care professional.

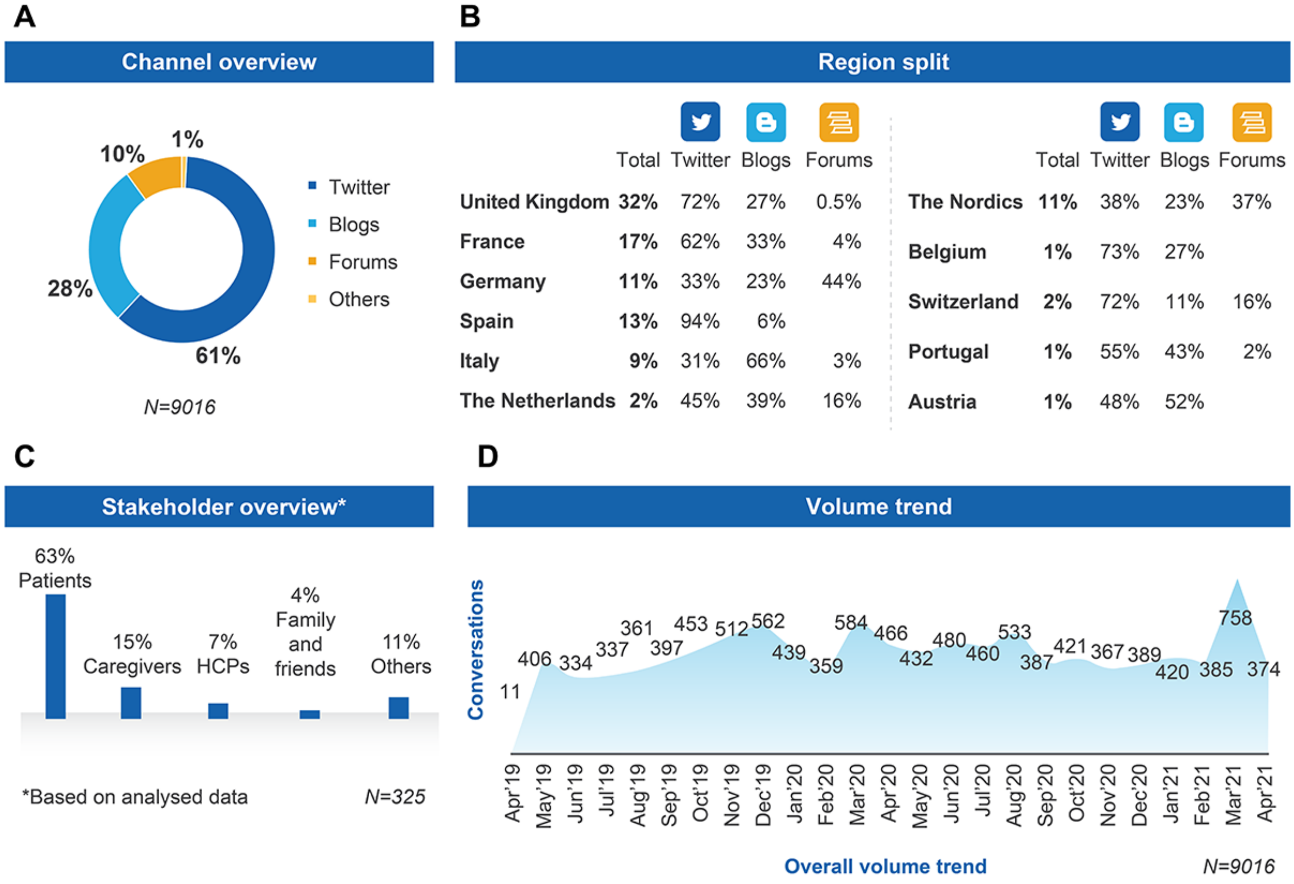
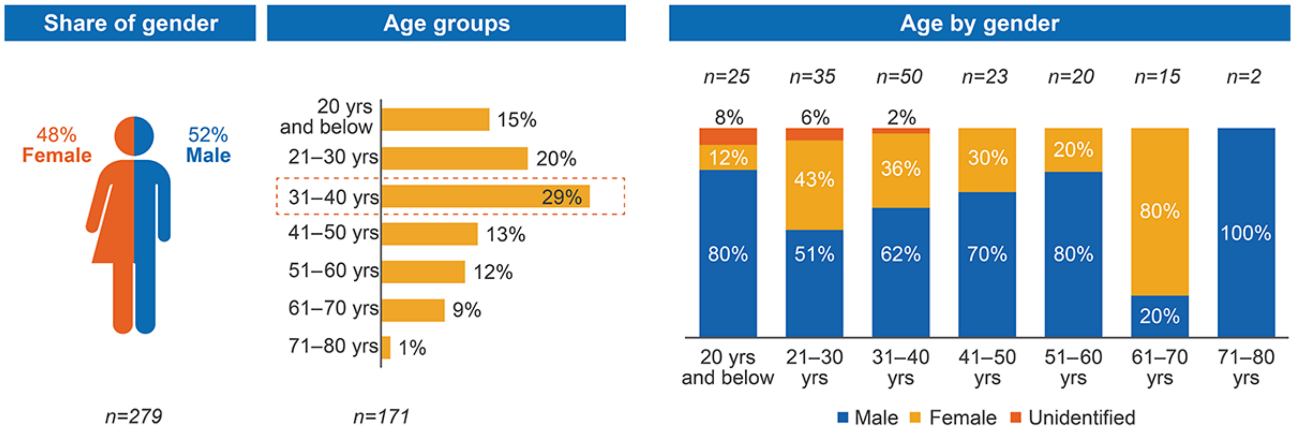


Figure 2. Age and gender of contributors in relevant posts. yrs: years.



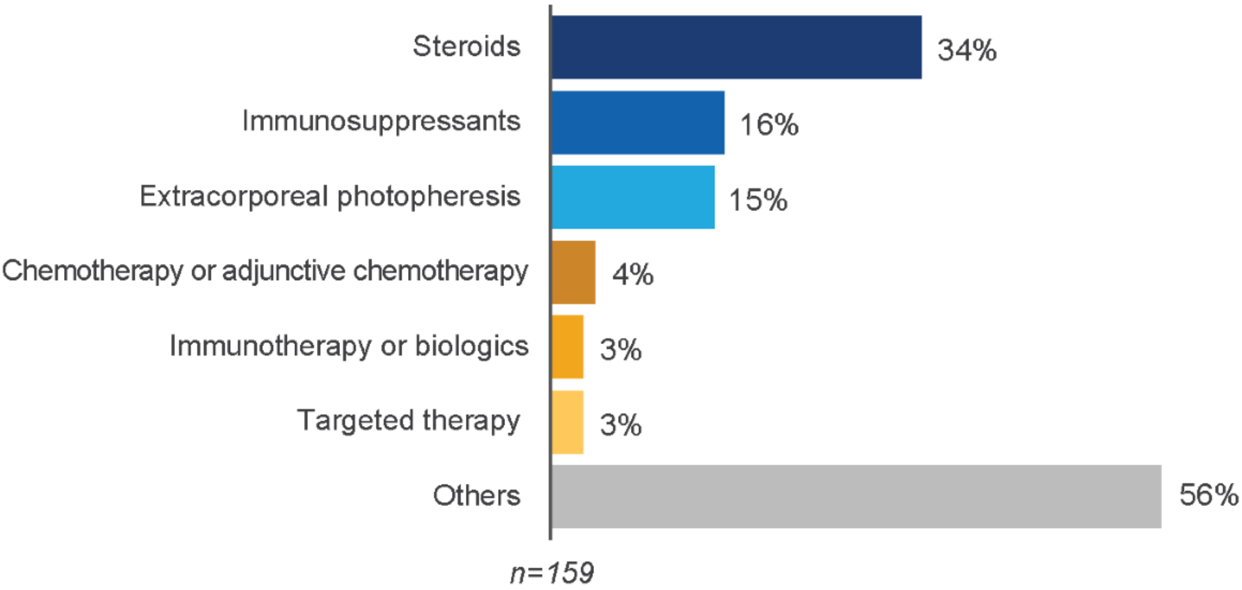
The Patient Journey in GVHD

This study provided key insights into the patient journey of those living with GVHD. Within the GVHD patient journey across Europe, analysis of 234 posts revealed that treatment was the most discussed stage (159/234, 68%), followed by symptoms (77/234, 33%), and diagnosis and tests (49/234, 21%; Figure S3 in Multimedia Appendix 1).

Treatment

For all 14 countries included in the analysis, discussion of treatment was evident in ≥50% (159/325) of the analyzed posts. Of treatment-related posts (n=159), steroids were the most common treatment for all countries (54/159, 34%), and conversations related to steroids were commonly associated with patients younger than 60 years of age. Immunosuppressants were the second most common treatment mentioned (25/159, 16%), followed closely by extracorporeal photopheresis (24/159, 15%; Figure 3). Other key treatment types (89/159, 56%) included generic mentions of treatment, medications, drugs in general, and alternative measures. Country-specific mentions of treatments are shown in Figure S4 in Multimedia Appendix 1. Alternative measures (5/159, 3%) of treatment included cannabis oil, curcuma supplements, and vitamins for the management of specific GVHD types, including cGVHD, eye-related GVHD, and steroid-resistant GVHD, respectively.

Figure 3. Treatments mentioned in relevant posts.



Treatment Sentiment

Stakeholders generally mentioned treatment options in a neutral tone, without positive or negative sentiment (Table 1). Of the 54 posts discussing steroids, side effects associated with these resulted in a relatively high negative sentiment (22/54, 41%; vs 7/54, 13% positive and 25/54, 46% neutral). Insights suggested that patients found it inconvenient to take additional medications to manage side effects. Efficacy led to positive sentiment in 13% (7/54) of posts, especially for skin GVHD. Similarly, for immunosuppressants, efficacy drove positive sentiments, while side effects drove negativity. Negativity around extracorporeal photopheresis was comparatively low (2/24, 8%), with patients experiencing relatively few or manageable side effects, such as looking tired for a few days and being more sensitive to the sun.

Table 1. Treatment features mentioned in relevant posts.

Treatment types	Positive sentiment, n (%)	Negative sentiment, n (%)	Neutral sentiment, n (%)	Total, n
Steroids	7 (13)[a]	22 (41)[b]	25 (46)[c]	54
Immunosuppressants	3 (12)[a]	5 (19)[b]	18 (69)[c]	26
Extracorporeal photopheresis	5 (21)[b]	2 (8)[a]	17 (71)[c]	24
Chemotherapy or adjunctive chemotherapy	1 (14)[b]	1 (14)[b]	5 (71)[c]	7
Immunotherapy or biologics	1 (20)[b]	2 (40)[c]	2 (40)[c]	5
Targeted therapy	1 (25)[b]	1 (25)[b]	2 (50)[c]	4

[a] Low prevalence.

[b] Medium prevalence.

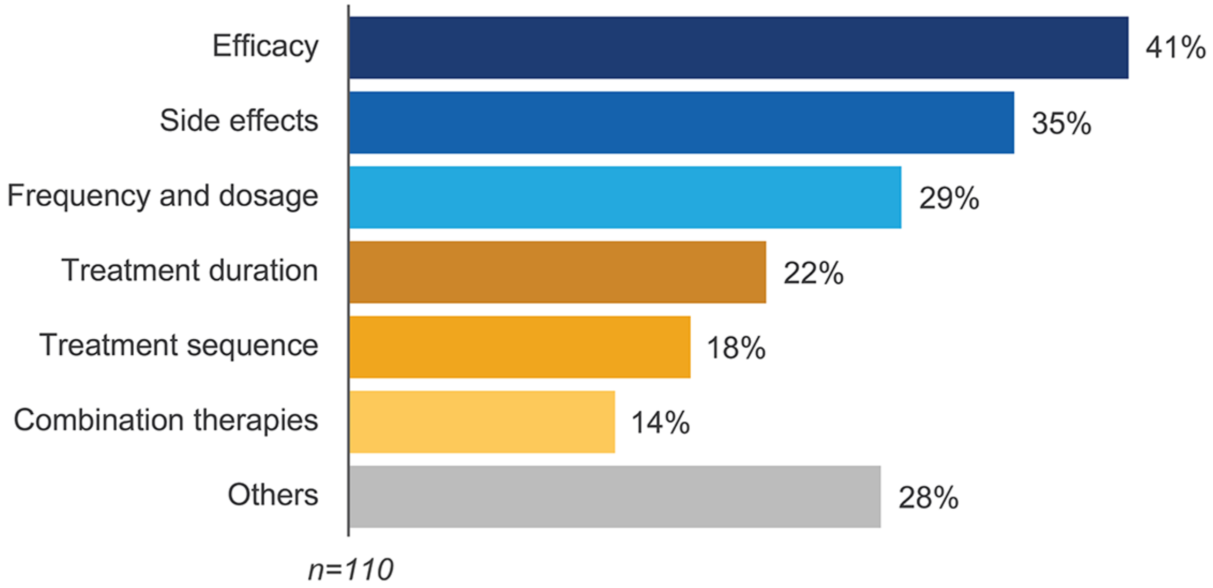
[c] High prevalence.

Treatment Features

Efficacy, side effects, and frequency and dosage were the most frequently addressed treatment topics across 110 posts (45/110, 41%; 39/110, 35%; and 32/110, 29%, respectively; Figure 4). Country-specific mentions are detailed in Figure S5 in Multimedia Appendix 1.

Duration of treatment was mentioned in 7% (24/325) of analyzed conversations and 15% (24/159) of treatment-related conversations. Around 29% (7/24) of patients were on treatment for less than 30 days, which was most commonly associated with steroids. About 21% (5/24) of patients had been on treatment for their GVHD for more than 1 year, with 8% (2/24) over 5 years. A total of 95% (19/20) of posts were classified as discussions on first-line therapy, 55% (11/20) on second-line therapy, and 10% (2/20) on third-line therapy; there were no posts on fourth-line treatment. Steroids and immunosuppressants were mostly used as first-line treatments across countries, although these were also used as second-line treatments with biologics in some cases. Discussion of treatment discontinuation was rare in GVHD, with mentions in only 1% (3/325) of analyzed conversations.

Figure 4. Treatment topics.



Clinical End Points

Clinical end points were mentioned in 31 (10%) of the 325 analyzed posts. Patients mostly mentioned feeling better or their condition improving in general terms as their end goals. Other end points identified in the analyzed posts included prolonged survival, reduced symptoms, improved QoL, remission, and mortality.

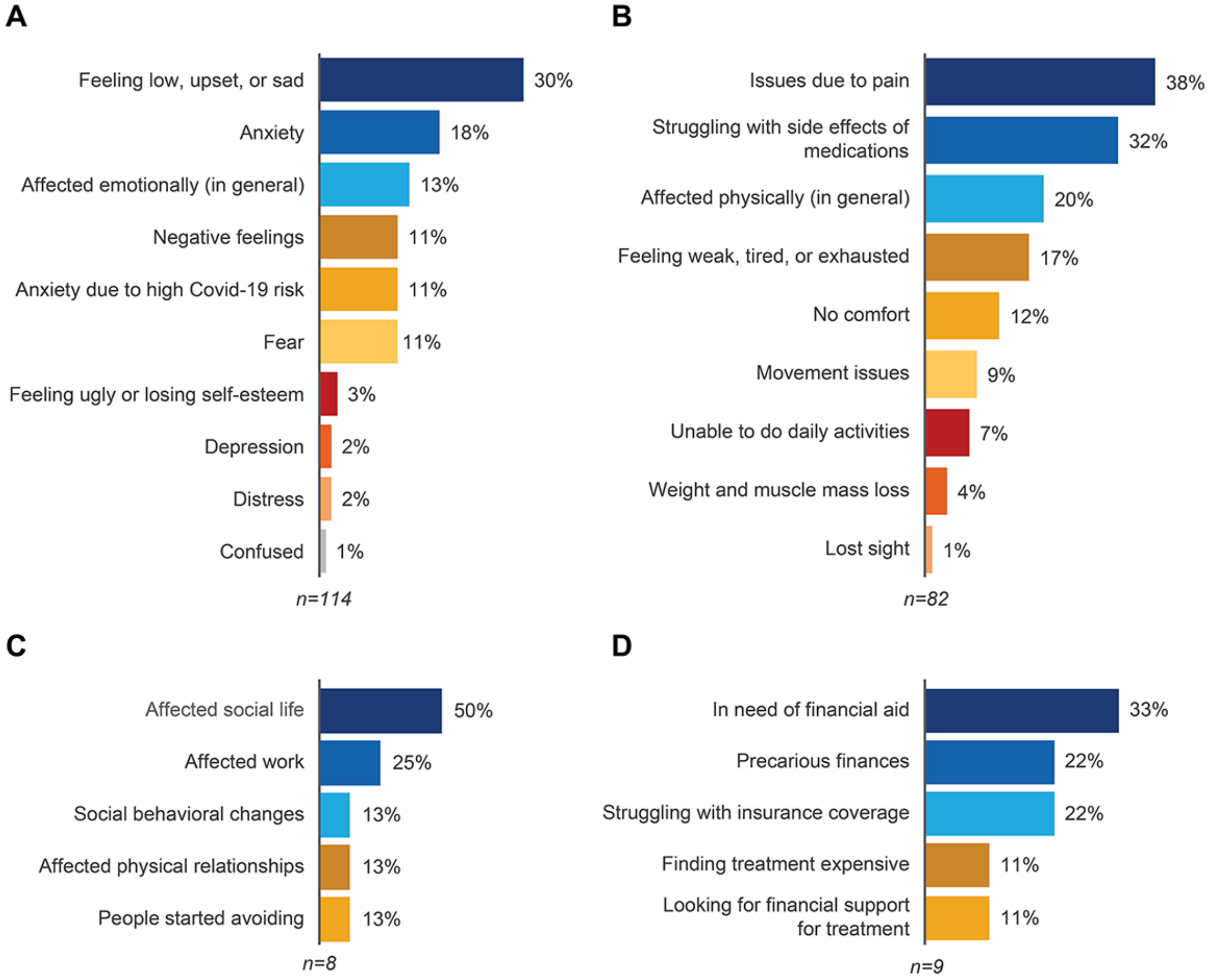
Symptoms

Patients described symptoms associated with their GVHD in 77 (24%) of the 325 analyzed posts. Symptoms reported from Europe included skin-related conditions such as rash, redness, itchiness, discoloration, and dryness (49/77, 64%), dry eyes or vision change (13/77, 17%), pain and cramps (16/77, 21%), and fatigue or muscle weakness (12/77, 16%).

Quality of Life

A total of 165 (51%) of the 325 analyzed posts referred to the impact of GVHD on QoL. Of these posts, the following impacts were discussed: emotional (114/165, 69%), physical and functional impact (82/165, 50%), social (8/165, 5%), and financial (3/165, 2%). Feeling low, sad, or upset (34/114, 30%), anxiety (21/114, 18%), feeling emotionally affected (15/114, 13%), and negative feelings, such as anxiety due to COVID-19 and fear (13/114, 11% all), were the most frequently reported emotional impacts (Figure 5A). Pain (31/82, 38%), struggles with side effects of medications (26/82, 32%), being physically affected (16/82, 20%), feeling weak, tired, or exhausted (14/82, 17%), and having no comfort (10/82, 12%) were the most frequently reported physical impacts (Figure 5B). Affected social life (4/8, 50%) and affected work life (25%, 2/8) were the most frequently reported social impacts (Figure 5C). Needing financial aid (3/9, 33%), precarious finances, and struggling with insurance coverage (2/9, 22% each) were the most frequently reported financial impacts (Figure 5D).

Figure 5. Impacts of graft-versus-host disease (GVHD) reported on social media: (A) emotional impact; (B) physical impact; (C) social impact; and (D) financial impact.

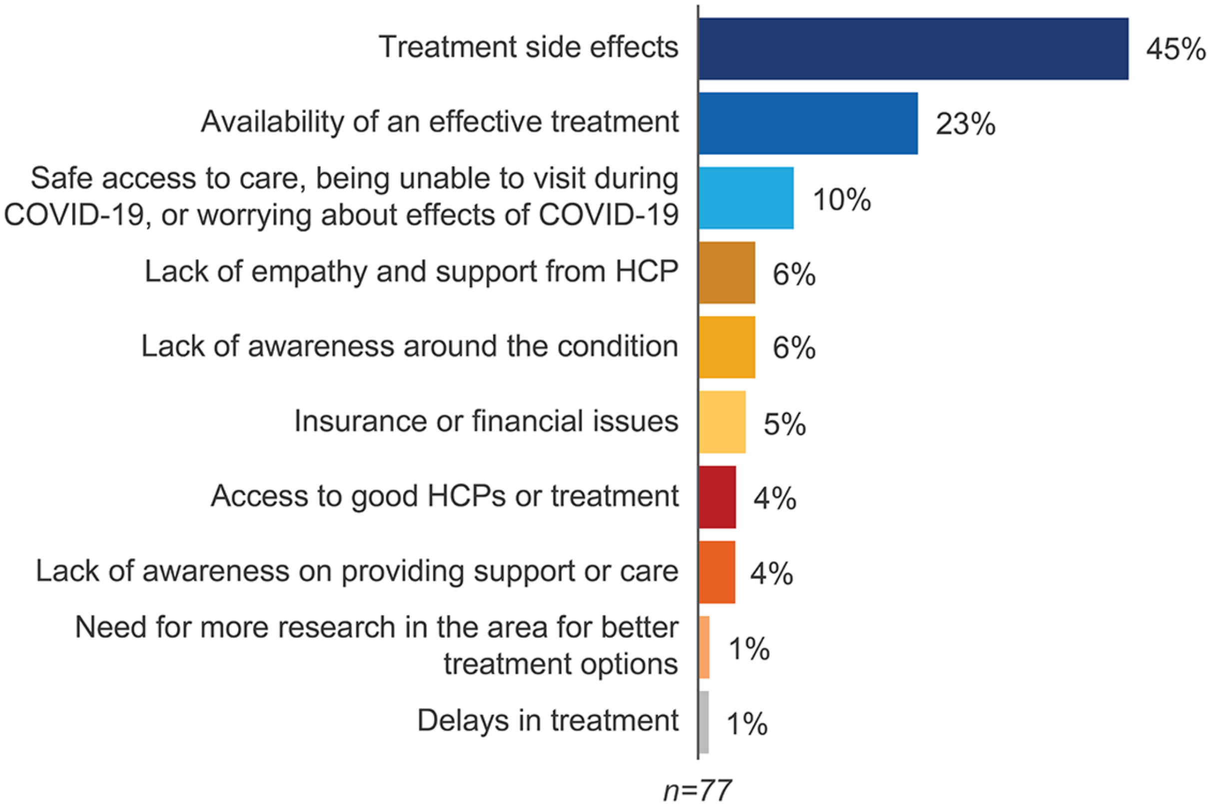


Unmet Needs

Unmet needs were mentioned by patients or caregivers in 24% (77/325) of the analyzed conversations. Treatment side effects (35/77, 45%), availability of an effective treatment (18/77, 23%), and safe access to care during the COVID-19 pandemic (8/77, 10%) emerged as key unmet needs of patients with GVHD and other stakeholders (Figure 6). Reported side effects ranged from mild (eg, sleeplessness and weight gain) to severe, including steroid-induced diabetes, loss of large bowel function, and weakness.

Other unmet needs included a lack of empathy and support from HCPs, a lack of awareness around GVHD, financial concerns, access to good HCPs or treatment, a lack of awareness about providing support and care, the need for research into better treatment options, and delays in treatment (Figure 6).

Figure 6. Key unmet needs of graft-versus-host disease (GVHD) stakeholders in Europe. HCP: health care professional.



Discussion

Overview

To our knowledge, this study provides the first qualitative insights into how the journey of a patient with GVHD is discussed on the web by multiple stakeholders and identifies key concepts relevant to individuals living with GVHD across Europe. European countries with larger populations (the United Kingdom, France, and Germany) were the highest contributors to the overall and relevant posts included in the study. This could suggest that the number of patients with GVHD in these countries is proportionally higher than in countries included in the study that have smaller populations, but it could also suggest varied usage of SM across countries. Furthermore, the number of stem cell transplantations across Europe continues to rise [33], suggesting that the prevalence of GVHD could continue to rise and SM usage may increase.

The total number of relevant posts (N=325) identified in SML was limited. However, there are several possible explanations for this, including high levels of distress and burnout, which can be experienced by patients and their parents, particularly in a pediatric setting [34,35]. Such feelings may prevent patients or caregivers from wanting to discuss their GVHD further. Furthermore, older adults and very young recipients may not use SM tools, suggesting these patient populations may be underrepresented in this study.

After a deep-dive analysis of 325 relevant posts, treatment was the most discussed stage, followed by symptoms and diagnosis within the patient journey. Steroids were the most reported therapy, as expected in line with published literature [5], and some negativity surrounding their use is unsurprising given the safety profile of these medications. Side effects from steroids are widely acknowledged [36], particularly at higher doses and with a longer duration of therapy [37], highlighting the need for improved supportive care [38] and multidisciplinary management [39,40], particularly for those with cGVHD. Future novel therapies and approaches for GVHD may see a shift away from steroid therapy, reducing the possibility of unwanted side effects [38,41].

This study identified emotional impact of the disease as a frequently discussed topic within the analyzed posts (165/325, 69%) across patients with GVHD, followed by a high physical impact across patients with GVHD within the analyzed posts. This finding may support the notion that patients often turn to SM for community support and advice in times of distress or lowered mood. It is documented that impaired QoL and functional status occur across GVHD [11-14], in particular the high emotional impact, in which feeling low, sad, or upset is highlighted in several QoL studies [15,16]. Together, these findings demonstrate the need to further understand the negative emotional impact of GVHD, how QoL can be improved, and what support can be provided for this patient population. The availability of web-based tools and programs for patients with GVHD may offer opportunities to improve outcomes, including mood, as demonstrated by the “INternet-based Survivorship Program with Information and REsources” (INSPIRE) for survivors of HSCT [42]. It is also important to recognize that among all symptoms (including skin-related conditions) most discussed by stakeholders within this study, pain and fatigue had the main physical impact on QoL.

The SM data analyzed in this study were collected from both the prepandemic and the COVID-19 pandemic periods. The multiple effects of the COVID-19 pandemic on patients' well-being and their lived experiences may have impacted the results of this study. The lack of safe access to HCPs and, in most cases, face-to-face consultations with HCPs, being quarantined, and being worried about the health implications of COVID-19 may have heightened stakeholders' sensitivity and impacted their emotional well-being. Indeed, this study identified safe access to care during the COVID-19 pandemic as one of the key unmet needs of patients with GVHD and other stakeholders. However, this study did not perform stratification and analysis of SM posts in the prepandemic and pandemic periods, and further research is needed to address whether there were significant differences in stakeholders' unmet needs and patients' symptom burden during the year leading to the outbreak of the COVID-19 pandemic and during the pandemic.

In this study, the key topics of SM discussions were received treatments, various treatment features (efficacy, side effects, frequency, and dosage), disease symptoms, QoL, and unmet needs. This type of data can provide a rich knowledge landscape and complement the data collected using more conventional survey approaches. Web-based data collection systems provide valid means to investigate different aspects of GVHD but often address issues surrounding only clinical aspects of the disease, for example, diagnostic precision and certainty, and are mostly aimed at HCPs [43,44]. Questionnaire-based surveys and interviews may not be the most effective methodology for gathering large amounts of data in a time-effective manner, and study outcomes are usually based on a small patient population [45,46]. Moreover, the restrictive nature of such surveys in terms of the breadth of topics is a drawback. In contrast, SML can be easily tailored to study objectives of interest, capturing either largely unfiltered stakeholder-related data or being tuned to answer specific research questions. This study demonstrated that SML can identify important topics relating to both clinical and QoL aspects of living with GVHD that may not be available in published studies using more conventional data collection and analysis methodologies. It is also noteworthy that patients with rare medical conditions, such as GVHD, may find SM particularly accommodating for sharing their disease-associated experiences, especially when patient populations are geographically distant [47].

Using SM may help improve patient-physician interactions, encourage informed and shared decision-making, improve treatment options by further understanding unmet needs, and increase patient satisfaction. Finally, SML may eventually assist clinical trial design by adjusting patient-reported outcome measures to better assess the impact of new therapeutic agents on improving the QoL of patients living with GVHD.

Limitations

This study has limitations that should be considered. SM research generally assumes that the information provided by patients is authentic. The quality of insights gathered from the analysis of digital conversations is dependent on the richness of patient conversations. The SM population is not representative of the whole community affected by GVHD, with a low number of relevant conversation volumes (N=325) and the median age of posts appearing to be slightly lower than the median age of typical patients in this setting [48]. The age of SM users may be skewed toward younger than average patients, and pediatric and elderly groups may be underrepresented.

Due to limited references to technical terms, results were provided overall and not separated by disease classification, severity, or affected tissue; this may influence the interpretation of treatment patterns, QoL, and unmet needs.

Public posting might introduce bias, as people are unlikely to share very personal information through such channels. In this study, only discussions publicly available through SM platforms were used; therefore, some discussions are likely to have been missed in closed channels, which are often active. Furthermore, verbal data that could be collected from platforms such as YouTube were not used in the analysis. All data were retrospectively collected from SM posts in the public domain. In some instances, information about the SM population could not always be identified, including demographic and clinical information.

Conclusions

This SML study further confirms that GVHD has a significant impact on patients' daily lives. Stakeholders experience a significant emotional and physical impact that affects their QoL. Although some limitations are apparent with SML, this study provides valuable insights into the GVHD experience, complementing published evidence from traditional studies. Future SML studies should be performed using the same approach described in this study to monitor whether GVHD stakeholders express novel concerns with respect to their disease and its treatment and how stakeholders' views and patients' lived experiences evolve over time, particularly with regulatory approvals of novel nonsteroid therapies for GVHD. Importantly, further SML studies should strive to validate the quality of SM data with regard to GVHD diagnosis, treatment, and side effects of current therapies by evaluating the SML data against evidence-based clinical and laboratory databases. Further real-world insights will strengthen our understanding of the lived experiences of those with GVHD and may reveal unmet medical needs for this patient population.

Acknowledgments

The authors would like to thank Emma Richards-Sirianni, PhD, and Egle McDonald, PhD, of Novartis UK Ltd for medical writing assistance. This study was funded by Novartis Pharmaceuticals GA in accordance with the Good Publication Practice (GPP3) guidelines. All data were retrieved from publicly available sources.

AS was affiliated with Novartis Pharmaceuticals AG, Basel, Switzerland at the time of the study, and is currently affiliated with Real World Evidence Post-Approval Studies in Oncology at Gilead Sciences Europe Ltd.

Data Availability

All data generated or analyzed during this study are included in this published article and its Multimedia Appendix 1.

Authors' Contributions

ZP and OP were responsible for the investigation, the writing of the original draft, and the reviewing and editing of the manuscript. GB, CK, IM, and SA were responsible for writing the original draft and reviewing and editing the manuscript. JC was responsible for conceptualization, data curation, formal analysis, methodology, validation, visualization, the original draft's writing, and reviewing and editing the manuscript. AS was responsible for conceptualization, the writing of the original draft, and the reviewing and editing of the manuscript. SG was responsible for project administration, supervision, the writing of the original draft, and the reviewing and editing of the manuscript.

Conflicts of Interest

IM has received consultancy fees, honoraria, and research grants from Novartis, research grants from Sotex, and honoraria from Jazz and Janssen. JC, SA, and SG are employees of Novartis. AS was an employee and shareholder of Novartis. OP has received honoraria or travel support from Gilead, Jazz, MSD, Novartis, Pfizer, and Therakos; received research support from Incyte and Priothera; and is a member of advisory boards for Gilead, MSD, Omeros, Priothera, Shionogi, and SOBI. ZP, GB, and CK have no conflicts of interest directly related to this manuscript.

Multimedia Appendix 1
Social Media Listening_Manuscript_Multimedia Appendix 1.
[DOCX File , 640 KB - cancer_v9i1e42905_app1.docx]

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Abbreviations

aGVHD: acute graft-versus-host disease
cGVHD: chronic graft-versus-host disease
GVHD: graft-versus-host disease
HCP: health care professional
HSCT: hematopoietic stem cell transplantation
INSPIRE: INternet-based Survivorship Program with Information and REsources
JAK: Janus kinase
QoL: quality of life
SM: social media
SML: social media listening

Edited by A Mavragani; submitted 18.10.22; peer-reviewed by R Matin, IC Hou; comments to author 10.01.23; revised version received 14.02.23; accepted 04.08.23; published 10.11.23.

Please cite as:
Perić Z, Basak G, Koenecke C, Moiseev I, Chauhan J, Asaithambi S, Sagkriotis A, Gunes S, Penack O
Understanding the Needs and Lived Experiences of Patients With Graft-Versus-Host Disease: Real-World European Public Social Media Listening Study
JMIR Cancer 2023;9:e42905
URL: https://cancer.jmir.org/2023/1/e42905
doi:10.2196/42905
PMID:37948101

Original Paper

Recruitment of Patients With Cancer for a Clinical Trial Evaluating a Web-Based Psycho-Oncological Intervention: Secondary Analysis of a Diversified Recruitment Strategy in a Randomized Controlled Trial

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Abstract

Background: Participant recruitment poses challenges in psycho-oncological intervention research, such as psycho-oncological web-based intervention studies. Strict consecutive recruitment in clinical settings provides important methodological benefits but is often associated with low response rates and reduced practicability and ecological validity. In addition to preexisting recruitment barriers, the protective measures owing to the COVID-19 pandemic restricted recruitment activities in the clinical setting since March 2020.

Objective: This study aims to outline the recruitment strategy for a randomized controlled trial evaluating the unguided emotion-based psycho-oncological online self-help (*epos*), which combined traditional and web-based recruitment.

Methods: We developed a combined recruitment strategy including traditional (eg, recruitment in clinics, medical practices, cancer counseling centers, and newspapers) and web-based recruitment (Instagram, Facebook, and web pages). Recruitment was conducted between May 2020 and September 2021. Eligible participants for this study were adult patients with any type of cancer who were currently receiving treatment or in posttreatment care. They were also required to have a good command of the German language and access to a device suitable for web-based interventions, such as a laptop or computer.

Results: We analyzed data from 304 participants who were enrolled in a 17-month recruitment period using various recruitment strategies. Web-based and traditional recruitment strategies led to comparable numbers of participants (151/304, 49.7% vs 153/304, 50.3%). However, web-based recruitment required much less effort. Regardless of the recruitment strategy, the total sample did not accurately represent patients with cancer currently undergoing treatment for major types of cancer in terms of various sociodemographic characteristics, including but not limited to sex and age. However, among the web-recruited study participants, the proportion of female participants was even higher ($P<.001$), the mean age was lower ($P=.005$), private internet use was higher (on weekdays: $P=.007$; on weekends: $P=.02$), and the number of those who were currently under treatment was higher ($P=.048$). Other demographic and medical characteristics revealed no significant differences between the groups. The majority of participants registered as self-referred (236/296, 79.7%) instead of having followed the recommendation of or study invitation from a health care professional.

Conclusions: The combined recruitment strategy helped overcome general and COVID-19–specific recruitment barriers and provided the targeted participant number. Social media recruitment was the most efficient individual recruitment strategy for participant enrollment. Differences in some demographic and medical characteristics emerged, which should be considered in future analyses. Implications and recommendations for social media recruitment based on personal experiences are presented.

Trial Registration: German Clinical Trials Register DRKS00021144; https://drks.de/search/en/trial/DRKS00021144

International Registered Report Identifier (IRRID): RR2-10.1016/j.invent.2021.100410

(JMIR Cancer 2023;9:e42123) doi:10.2196/42123

KEYWORDS

psycho-oncology; cancer; recruitment; social media; web-based interventions; web-based recruitment

Introduction

Background

Elevated levels of distress among patients with cancer [1-3] and lack of comprehensive psycho-oncological support, especially in the outpatient setting [4,5], have resulted in increased efforts to provide evidence-based psycho-oncological interventions (POIs). However, studies evaluating POIs face severe recruitment problems. In recent years, this situation has gained attention in the scientific literature, and a rising number of studies provide essential information on barriers to study participation. In a clinical correspondence, van Lankveld et al [6] called for a more extensive reporting about recruitment issues and negative experiences in psychosocial oncology research to share findings in the research community and to improve the feasibility of future studies by more realistic estimations of inclusion rates.

The reasons for low inclusion rates have been reported in previous studies and are manifold. In addition to recruitment barriers that occur in hospital-based recruitment among referring health care professionals (HCPs), such as limited time, increased workload, and prioritizing medical topics [7], studies identified barriers among patients with cancer that may prevent them from participating in POI studies. Limited interest in the intervention, no perceived symptom burden or need for a POI, scheduling difficulties, time commitment, and inappropriate timing of recruitment on the treatment trajectory (eg, too close to diagnosis) are among the reported barriers to study participation [8-11]. However, strict eligibility calculations and recruitment methods such as consecutive recruitment in hospitals may complicate patient enrollment, as they seem to lack practicability and feasibility in psycho-oncological research, often resulting in small sample sizes. For example, in a large multicenter randomized controlled trial (RCT) using consecutive screening for recruitment, only 25 (0.96%) of the 2608 approached patients with cancer were eligible and interested in participating in a psychological intervention, whereas the majority did not respond to the routine screening questionnaire, did not fulfill the inclusion criteria, already received treatment, or reported no need for treatment [11].

Web-based POIs may even face additional recruitment challenges compared with face-to-face POIs. Although the anonymity of web-based interventions may be regarded as an important benefit for people who feel more comfortable with anonymous help seeking (eg, because of the fear of stigmatization), other participants might wish for more personal contact to commit to the study. However, participants' characteristics also explain their attitudes toward web-based interventions. A study investigating preferences for internet-based mental health interventions revealed that younger, female, and more educated participants were more likely to prefer web-based programs compared with face-to-face support [12]. In the context of POI research, the association of age and uptake of web-based interventions may be particularly important, as the likelihood of developing cancer increases with age, and up to now, older persons report increasing but still less internet use than younger persons [13].

To overcome the abovementioned recruitment challenges in POI research, it is proposed to combine hospital-based recruitment with participant self-referral [14]. It has been argued that self-referral might provide important benefits, such as increased ecological validity and thus successful implementation into practice [14]. In web-based research and mobile health research, self-referral through web-based study promotion (eg, via Facebook advertisements) is widely used as a recruitment method, either as a single method of recruitment or combined with traditional methods (eg, HCP referral, flyers, and newspapers). A systematic review by Lane et al [15] concluded that web-based recruitment methods may be promising in mobile health research, but more empirical evidence is needed on the effectiveness of web-based recruitment methods and participant retention, compared with traditional recruitment methods. The review emphasizes the benefits of web-based recruitment methods (such as wide reach, flexibility, and the potential to reach underserved populations) but also points to serious issues (eg, less investment and commitment of participants), which might limit the validity of research findings [15]. A scoping review reported inconclusive results regarding whether social media recruitment is more effective than traditional methods but found evidence that social media is the best method for recruiting hard-to-reach populations [16]. In the field of psycho-oncology, there is a rising number of studies that—either additionally or exclusively—use web-based and social media recruitment [17-21], underlining the effectiveness of social media and web-based recruitment, especially with regard to participant enrollment.

Objectives

This secondary analysis is based on recruitment data gathered in the emotion-based psycho-oncological online self-help (*epos*) project. In this project, we developed and evaluated the web-based intervention *epos* that aimed at reducing psychological distress in people with cancer. Although it was not the explicit aim of the *epos* project to investigate and compare recruitment strategies, the study generated valuable data on the development and effectiveness of a recruitment strategy that combined traditional and web-based recruitment methods. The aim of this study is to provide results on the effectiveness of different recruitment strategies and to discuss the implications for improving response rates in psycho-oncological web-based intervention research. To achieve this, we will provide a comprehensive overview of our recruitment procedure, including the challenges we encountered, and explore how demographic and medical characteristics are linked to the recruitment method.

Methods

Study Design

The data reported in this study were collected from May 2020 to September 2021 within the scope of the *epos* project, in which we developed the web-based self-help program *epos* and evaluated its effectiveness in a monocentric RCT with a parallel group design. The RCT was registered at the German Clinical Trials Register (DRKS00021144).

Participants were randomly assigned to the intervention group (self-help program *epos*) or control group (treatment as usual+informational website) and completed 3 questionnaires (baseline, after intervention, and follow-up). In brief, participants in the intervention group had 10 weeks of access to *epos*, an intervention consisting of 1 introductory unit and 9 units related to specific psycho-oncological topics (eg, *talking about cancer* and *strengthening the soul*). *Epos* is designed as a self-guided program, giving users the opportunity to navigate through the content in a self-determined manner. It is advisable to focus on 1 unit per week, although the time it takes to complete a unit can vary depending on how thoroughly users engage with the content. On average, users are expected to spend approximately 30 to 60 minutes on each unit. Detailed information on the study design of the RCT has been provided elsewhere [22].

For this study, only data on recruitment as well as demographic and medical data assessed in the baseline questionnaire were used. All procedures, including patient information, diagnostic self-assessment regarding eligibility, informed consent, and registration for the web-based intervention, were conducted via the internet. Direct contact with the research staff was offered via email or telephone if (potential) participants needed it.

Ethical Considerations

All procedures were approved by the Ethics Committee of the Federal State of Rhineland-Palatinate (2019-14460) on July 26, 2019, and May 19, 2020. All study participants provided informed consent via an electronic form. To protect the privacy and confidentiality of the participants, study data underwent pseudonymization via assigned study ID numbers. No compensation was provided to the participants.

Participants

Patients met the eligibility criteria if they satisfied the following conditions: (1) age ≥18 years, (2) diagnosed with any form of cancer, (3) currently received cancer treatment or in posttreatment care, (4) possessed adequate German language proficiency, and (5) had internet access. The exclusion criteria were severe mental or physical disabilities (eg, severe depression). Screening for inclusion and exclusion criteria was conducted via self-assessment of the participants.

Procedures

Originally, the recruitment was planned to be conducted exclusively at the study center (University Medical Center of the Johannes Gutenberg University Mainz). The intended number of participants was determined based on our past experience, which considered the annual volume of oncological patients treated and the outcomes of routine distress screenings conducted in previous years. On the basis of 2018 and 2019 data, an average of 172 cancer patients received psycho-oncology care per month, of whom approximately 75% were undergoing curative treatment. Approximately 75% of these patients were assumed to meet inclusion criteria, resulting in an estimated number of 1354 eligible patients over the 14-month recruitment period. Thus, to achieve a sufficient number of participants of 325 patients, a 25% participation rate was required.

Owing to several reasons, the original recruitment strategy was revised and extended during the conceptual study phase. Recruitment experiences gained in the qualitative study, which was conducted between February and May 2019 during the intervention development phase [23], in which we aimed to assess the needs of patients with cancer by conducting interviews with 10 patients with cancer, showed that recruitment in the hospital was much lower than anticipated. The experience that many inpatient patients with cancer might be too burdened for study recruitment, implying that recruitment solely through direct contact by the HCP and in only 1 hospital would be less effective than expected, prompted us to revise the recruitment strategy. Targeted inquiries to several acute and rehabilitative hospitals resulted in 23 clinics that expressed an interest in supporting patient recruitment for the *epos* study free of charge. All hospitals received flyers of the *epos* study and were asked to display them in their clinics or even distribute them personally to potentially eligible and interested individuals to increase motivation.

The global COVID-19 pandemic severely affected medical and clinical routines beginning in February 2020 in Germany, including the recruitment for the RCT that began in May 2020 under lockdown conditions. Specifically, the research staff were not allowed to recruit participants in waiting areas or medical departments, as personal contacts should be as limited as possible to protect patients with cancer and medical staff. Hence, it was decided to extend the recruitment strategy and additionally integrate social media and web-based channels, as they experienced a strong demand owing to the pandemic in nearly every domain of life. Social media and web-based recruitment primarily involved recruitment activities through the Instagram and Facebook accounts of the *epos* study. The most prominent mechanism for recruiting via Instagram and Facebook are targeted advertisements (refer to the study by Arigo et al [24] for a valuable overview of the methodological and ethical considerations for using social media for health research). As web-based recruitment was not planned in the grant and study budget, costly advertisements (eg, on Facebook or Instagram) could not be afforded. Instead, we launched an *epos* Instagram account and a Facebook account, which we used for informing about the study and building a network within the community of survivors of cancer (Figure 1). Through own postings and reposts by influencer accounts with a wide reach, the Instagram account had 600 followers by the end of the recruitment phase. The Facebook account had substantially fewer followers, with 66 followers by the end of the recruitment phase. The posts on

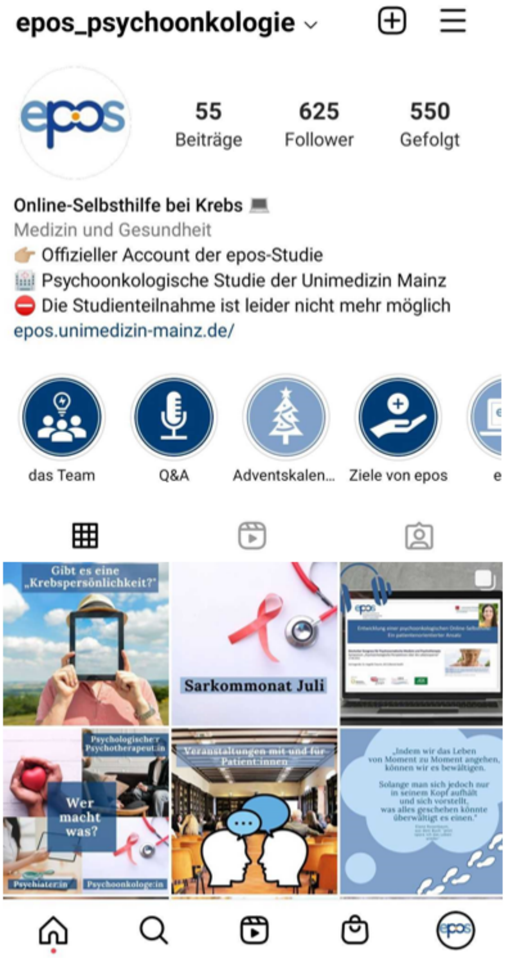
Instagram and Facebook were identical and were uploaded simultaneously. Social media posts mainly provided quotes or information, such as an introduction of the study team or psycho-educative topics such as the difference between a psychiatrist, a psychotherapist, and a psycho-oncologist, describing scientific methods for lay people (eg, describing an RCT) or informing about cancer awareness months. The main strategies for growing an Instagram community were reposts of our posts by cancer survival influencers or networks with a wide reach and generally increased social media activity (commenting and liking posts of relevant Instagram accounts and frequent posts, stories, and reels). Interactions with the community and networks of survivors of cancer have partly resulted in activities with wide reach, for example, an invitation to present *epos* at a conference for patients with breast cancer (*Mamma Mia!*) conducted on the internet via videoconferencing or an article in a breast cancer magazine.

Finally, a link to our study's home page was presented on several websites, including self-help networks or federal associations for specific cancer types. To reach people with less digital activity, we published information about the *epos* study in classic media (eg, daily newspapers and local radio).

To describe or—where possible—even quantify recruitment strategies, we monitored flyer distribution to hospitals and other institutions as well as important social media activities conducted by the research staff.

For all participants in the *epos* study, registration followed the same procedure. Participants received the URL to the study home page (eg, via the flyer of the HCP or the Instagram account). On the study home page, participants were provided with the study information and registration link and could sign up for the study. After completion of the baseline questionnaire that was presented directly after registration, study participants were informed about group allocation and received access to *epos* or the content for the control group. More details on the registration procedure are provided elsewhere [22].

Figure 1. Instagram feed of the emotion-based psycho-oncological online self-help account.



epos_psychoonkologie

55 Beiträge
625 Follower
550 Gefolgt

Online-Selbsthilfe bei Krebs
Medizin und Gesundheit
Offizieller Account der epos-Studie
Psychoonkologische Studie der Unimedizin Mainz
Die Studienteilnahme ist leider nicht mehr möglich
epos.unimedizin-mainz.de/

Variables

Sociodemographic and Medical Characteristics

Patient-reported data presented in this study were collected via the internet using the baseline questionnaire. Demographic and medical characteristics included sex, age, marital status, education, nationality, internet use, cancer type, time since diagnosis, administered cancer treatment, metastases and recurrence, and treatment setting. The number of comorbidities was assessed by providing a list of 18 somatic or mental conditions and a free-text field for additional answers. Psychological distress was assessed using the 16-item Patient Health Questionnaire Anxiety and Depression Scale, a combined measure of depression and anxiety [25]. Participants indicated symptoms of depression and anxiety on a 4-point scale ranging from 0 (not at all) to 3 (nearly every day).

Paths of Recruitment and Study Referral

Two self-developed items assessed information on recruitment into the study. Recruitment path was measured by the item "How did you become aware of the study," which provided 8 response options describing specific hospitals or (social) media methods as well as the response option "other" that could be specified in a free-text box. The data provided in the free-text box were recoded into the existing categories whenever possible. Repeated or similar answers in the free-text box were summarized as new response options for this item during data preparation. Furthermore, participants were asked whether they received an HCP recommendation for study participation (eg, from a psycho-oncologist, physician, or nurse) or if their study participation was based on self-referral. The response options were "yes, received an HCP recommendation" or "no, did not receive an HCP recommendation."

Adherence

Adherence, including the frequency of log-ins and duration of time logged in (in min), was assessed using objective data collected within the software. As the study questionnaires were also included in the software that provided the intervention, the reported frequency and log-in durations also included the questionnaire sessions, which represents a serious limitation for the validity of these data. To counteract this systematic bias, we also measured active engagement with the intervention content, which was operationalized by an activity score representing the proportion of completed interactive tasks within the content units. These interactions included, for example, filling out a free-text field or answering a multiradio question. In addition to treatment adherence measures, we tracked the number of completed study questionnaires intended to be completed at baseline, after the intervention, and at the 3-month follow-up, which allowed us to draw conclusions about trial adherence.

Statistical Analyses

Descriptive analyses were used to quantify recruitment strategies and determine the demographic and medical characteristics of the participants. Chi-square analyses and unpaired 2-tailed t tests were used to compare groups based on the recruitment method. Logistic regression analysis estimating odds ratios with 95% CIs was performed to determine the factors associated with self-referral. Self-referral was dummy coded as 0=not self-referred and 1=self-referred. Statistical analyses were conducted using SAS software (version 9.4; SAS Institute). We defined the level of significance at $P<.05$; we additionally report larger effects ($P<.01$ and $P<.001$). Because of the exploratory nature of this study, we did not perform alpha adjustment.

Results

Participant Characteristics

A total of 327 participants provided informed consent and were randomized into the RCT. After excluding 19 participants owing to withdrawals and incomplete data in the baseline questionnaire, the final population consisted of 308 participants. As 4 participants did not provide information on the recruiting strategy, data from 304 participants were used to analyze the population based on recruitment methods. The sociodemographic characteristics of the participants are shown in Table 1, and their medical characteristics are presented in Table 2. Briefly, the study population consisted of 84.7% (249/294) female participants with a mean age of 50.8 (SD 10.9) years. Significant group differences between traditionally and web-recruited participants were identified for sex, age, internet use, study referral, and treatment status.

Table 1. Sociodemographic characteristics of the study participants (N=304).

Characteristics	Total sample	Traditional recruitment[a] (n=153)	Web-based recruitment[b] (n=151)	*P* value
Sex, n (%)				*<.001* [c]
Female	249[d] (84.7)	114 (77.6)	135 (91.8)	
Male	45 (15.3)	33 (22.4)	12 (8.2)	
Age (years), mean (SD; range)	50.8 (10.9; 24-83)	52.5 (10.1; 30-83)	49.0 (11.4; 24-78)	*.005*
Marital status, n (%)				.72
Single	29 (9.6)	14 (9.3)	15 (10)	
In a relationship or married	233 (77.4)	115 (76.2)	118 (78.7)	
Divorced, separated, or widowed	39 (13)	22 (14.6)	17 (11.3)	
Education, n (%)				.89
No degree or lower secondary education diploma	16 (5.3)	9 (5.9)	7 (4.6)	
General secondary education diploma	56 (18.4)	27 (17.6)	29 (19.2)	
Diploma qualifying for university	228 (75)	115 (75.2)	113 (74.8)	
Other degree	4 (1.3)	2 (1.3)	2 (1.3)	
German nationality, n (%)	289 (96)	147 (97.4)	142 (94.7)	.23
Private internet use (min), mean (SD)				
On weekdays	106.7 (96.8)	91.8 (83.7)	121.7 (106.7)	*.007*
On weekends	109.8 (104.8)	95.2 (89.0)	124.3 (117.0)	*.02*
Study referral, n (%)				*<.001*
Self-referred	236 (79.7)	91 (61.5)	145 (98)	
Referred by a health care professional	60 (20.3)	57 (38.5)	3 (2)	

[a] Traditional recruitment includes all offline recruitment activities, that is, recruitment through health care professionals in hospitals and medical practices, cancer counseling centers, self-help networks, and print media.

[b] Web-based recruitment includes all web-based recruitment strategies, that is, social media (Instagram and Facebook) and study promotion on websites.

[c] Italicized values represent significant differences between web-based and traditional recruitment

[d] Numbers may not add up to 304 owing to missing data.

Table 2. Medical characteristics of the study participants (N=304).

Characteristics	Total sample	Traditional recruitment[a] (n=153)	Web-based recruitment[b] (n=151)	*P* value
Cancer type, n (%)				.41
Breast	178[c] (58.6)	82 (53.6)	96 (63.6)	
Hematologic	29 (9.5)	15 (9.8)	14 (9.3)	
Gynecologic	25 (8.2)	11 (7.2)	14 (9.3)	
Skin	13 (4.3)	10 (6.5)	3 (2)	
Colon	11 (3.6)	5 (3.3)	6 (4)	
Head and neck and thyroid	10 (3.3)	4 (2.6)	6 (4)	
Prostate	8 (2.6)	7 (4.6)	1 (0.7)	
Other[d]	30 (9.9)	19 (12.4)	11 (7.3)	
Time since diagnosis (in weeks), mean (SD)	74.0 (118.5)	82.9 (145.0)	64.9 (82.9)	.18
Metastases, n (%)	93 (31.4)	45 (30)	48 (32.9)	.59
Cancer recurrence, n (%)	31 (10.6)	18 (12.4)	13 (8.8)	.31
Ongoing acute treatment[e], n (%)	170 (55.9)	77 (50.3)	93 (61.6)	*.048* [f]
Treatment setting, n (%)				.39
Inpatient	8 (2.7)	4 (2.7)	4 (2.7)	
Outpatient	163 (54.9)	76 (51)	87 (58.8)	
After care	126 (42.4)	69 (46.3)	57 (38.5)	
Number of somatic or mental comorbidities, mean (SD; range)	1.7 (1.8; 0-13)	1.6 (1.6; 0-7)	1.8 (2.0; 0-13)	.51
Psychological distress[g], mean (SD; range)	17.8 (8.3; 0-44)	17.2 (8.0; 0-38)	18.5 (8.6; 3-44)	.20

[a] Traditional recruitment includes all offline recruitment activities, that is, recruitment through health care professionals in hospitals and medical practices, cancer counseling centers, self-help networks, and print media.

[b] Web-based recruitment includes all web-based recruitment strategies, that is, social media (Instagram and Facebook) and study promotion on websites.

[c] Numbers may not add up to 304 owing to missing data.

[d] Tumor sites are as follows: brain, liver, pancreatic, and testicular or penile: 0%; kidney, bladder, and stomach: 1%; and lung and soft tissue: 2%.

[e] Including chemotherapy, radiation, immune therapy, and hormone therapy.

[f] Italicized values represent significant differences between web-based and traditional recruitment methods.

[g] Assessed with the Patient Health Questionnaire Anxiety and Depression Scale (combined measure of anxiety and depressive symptoms); a higher total score indicates higher psychological distress.

Flyer Distribution

Figure 2 provides an overview of important traditional and web-based recruitment activities (eg, flyer distributions and social media activities) and registration numbers during the recruitment period. Traditional recruitment includes all offline recruitment activities, that is, recruitment through HCPs in hospitals and medical practices, cancer counseling centers, self-help networks, and print media. Web-based recruitment includes all web-based recruitment strategies, that is, social media (Instagram and Facebook) and study promotion on websites.

In Table 3, we report the number of cooperating institutions and flyers distributed during the 17-month recruitment period. A total of 4561 study flyers were provided to clinics, medical practices, and other institutions during the recruitment phase.

Figure 2. Important recruitment activities and registration numbers over time. HCP: health care professional.

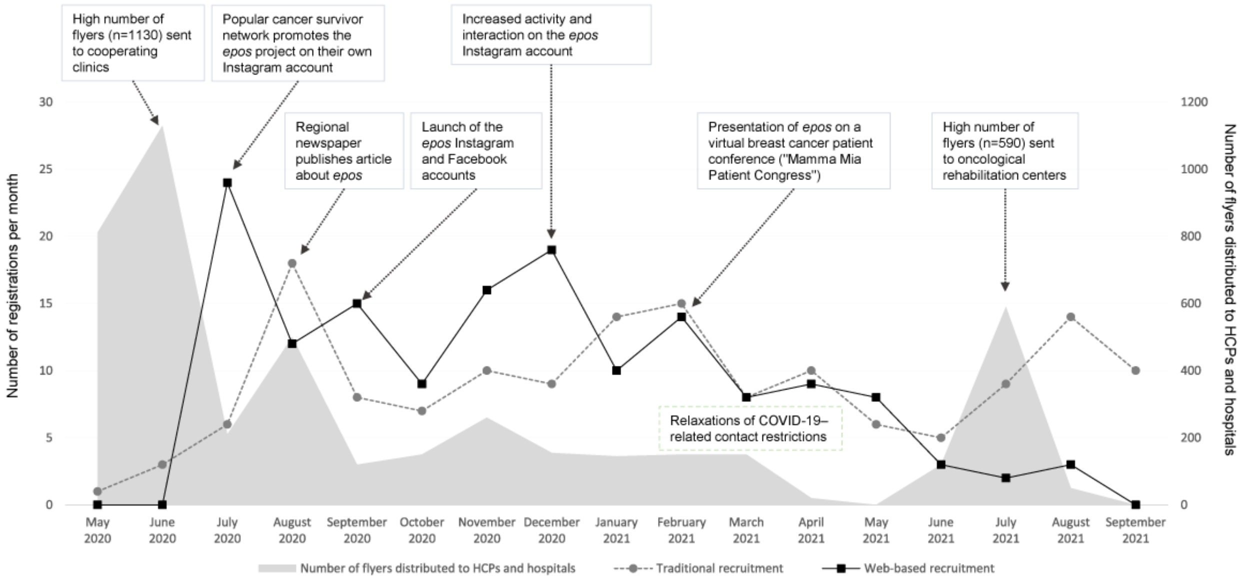


Table 3. Distribution of flyers (N=4561) in cooperating hospitals, medical practices, and institutions (N=78).

Institutions	Hospitals, medical practices, and institutions, n (%)	Flyers provided[a] n (%)
Internal recruitment—study center Mainz[b]	1 (1.3)	1371 (30.1)
External recruitment[c]	70 (89.7)	2910 (63.8)
Other (eg, cancer counseling centers and self-help networks)	7 (9)	280 (6.1)

[a] Number of flyers provided to the hospital, medical practice, or institution: this number does not include any information on the number of flyers that were eventually handed out to patients with cancer. Owing to reasons of clinical practicability, the total number of flyers that reached patients with cancer could not be assessed.

[b] Includes all departments at the University Medical Center of the Johannes Gutenberg–University Mainz relevant for cancer treatment as well as active health care professional recruitment and flyer distribution for self-referral at information desks, etc.

[c] External recruitment includes acute hospitals, specialized oncological practices, and oncological rehabilitation hospitals.

Paths of Recruitment and Study Referral

The absolute numbers and percentages for paths of recruitment are displayed in Table 4. Most participants (151/304, 49.7%) became aware of the study through web-based activities, whereas 34.9% (106/304) were recruited in hospitals, medical institutions, and practices: 17.4% (53/304) were treated in the Mainz study center and 17.4% (53/304) were treated in cooperating hospitals and medical practices.

A total of 296 participants provided data on whether they registered as self-referred or owing to an HCP recommendation. The majority of participants (236/296, 79.7%) registered as self-referred. The associated demographic and medical characteristics for self-referral are displayed in Table 5. Younger age, currently receiving cancer treatment, and nonuse of psycho-oncological offers were identified as significant variables associated with self-referral.

Table 4. Participants' reported paths of recruitment (n=304).

Paths of recruitment	Participants, n[a] (%)
Web-based	151 (49.7)
Internal recruitment—study center Mainz	53 (17.4)
External recruitment[b]	53 (17.4)
Print media	30 (9.9)
Through friends or family members	13 (4.3)
Self-help network and cancer counseling center	7 (2.3)
Other	5 (1.6)

[a] The total number of responses given regarding paths of recruitment exceeds 304, as multiple responses were allowed.

[b] External recruitment includes acute hospitals, specialized oncological practices, and oncological rehabilitation hospitals.

Table 5. Demographic and medical predictors for self-referred registration[a] (n=236).

Variable	Odds ratio (95% CI)	*P* value
Sex		
Female	Reference	N/A[b]
Male	0.48 (0.21-1.08)	.08
Age (years)		
Per 1 additional year	0.95 (0.92-0.99)	*.006* [c]
Time since diagnosis		
Per 1 additional week since diagnosis	1.00 (1.00-1.00)	.58
Ongoing cancer treatment[d]		
No	Reference	N/A
Yes	1.98 (1.02-3.84)	*.04*
Prior use of psycho-oncological offer		
No	Reference	N/A
Yes	0.23 (0.10-0.52)	*<.001*
Psychological distress[e]		
Minimal (0-9)	Reference	N/A
Mild (10-19)	1.16 (0.46-2.91)	.76
Moderate (20-29)	1.45 (0.55-3.80)	.45
Severe (30-48)	0.68 (0.20-2.38)	.55
Education level[f]		
Lower education	Reference	N/A
Higher education	1.11 (0.52-2.42)	.78

[a] Participants who indicated that they had registered for the study without a health care professional recommendation.

[b] N/A: not applicable.

[c] Italicized values represent significant *P* values.

[d] Including chemotherapy, radiation, immune therapy, and hormone therapy.

[e] Assessed with the Patient Health Questionnaire Anxiety and Depression Scale (combined measure of anxiety and depressive symptoms).

[f] Lower education: no degree, lower and general secondary education diploma; higher education: diploma qualifying for university.

Adherence

For the 155 participants who were randomized into the intervention group and therefore had access to the web-based self-help program, we calculated the number of log-ins, mean duration of log-in time, and activity within the web-based self-help program. Mean frequency of log-ins was 8.26 (SD 7.22) for traditional and 6.47 (SD 4.98) for web, mean duration of log-ins (in min) was 353.56 (SD 553.79) and 227.95 (SD 239.28), respectively, and mean proportion of completed interactive tasks within the program (in percentage) was 31.4% (SD 34.8) and 23.8% (SD 29.2), respectively. There were no significant differences in the frequency of log-ins, duration of log-ins, and activity within the program between the participants who were recruited traditionally and those who became aware of the study through a web-based recruitment channel.

In terms of trial adherence, 68% (52/77) of the traditionally recruited participants completed all 3 study questionnaires. In comparison, the completion rate of all 3 questionnaires was slightly lower among the participants recruited web-based (47/78, 60%). However, this difference was not statistically significant, indicating that the groups did not differ in trial adherence.

Discussion

Principal Findings

The aim of the study was to outline the development and effectiveness of the recruitment strategy of an RCT evaluating the newly developed psycho-oncological web-based intervention *epos*. The recruitment of participants for the RCT had to be adapted because of the challenges previously reported in POI research and the impact of the COVID-19 pandemic. At the start of the recruitment phase, which initially relied on the distribution of flyers in hospitals and health care provider referrals, it did not meet the anticipated and necessary participant numbers. However, a significant increase was only achieved through social media activities. The final sample was not representative, with female participants, younger age, and higher education being overrepresented. Over the course of the recruitment phase, web-based recruitment was the most successful recruitment strategy with regard to participant registration numbers, followed by recruitment in the study center Mainz. Participants who self-referred to the study were found to be more likely to be younger, undergoing current cancer treatment, and not have used psycho-oncological offers in the past compared with participants who were referred to the study by an HCP.

Comparison With Prior Work

In general, the recruited sample was not representative of several sociodemographic characteristics, especially with regard to the overrepresentation of female participants, younger age, and higher education. Female sex has been associated with the perceived need for or uptake of psycho-oncological face-to-face offers in previous German studies [4,5,26], suggesting that the self-selection bias revealed in this study is not just a matter of the web-based format and the recruitment procedure; rather, it is a well-known issue emphasizing that male patients with cancer are less likely to perceive the need for or make use of POIs. Similarly, the overrepresentation of higher education is in line with previous findings that suggest that the uptake of psycho-oncological support is associated with higher education [4,5]. Among the web-recruited study participants, the proportion of female participants was even higher compared with traditionally recruited participants, the mean age was lower, private internet use was higher, and the proportion of participants who were currently under treatment was higher. The remaining demographic and medical characteristics revealed no significant differences, suggesting that the web-based and traditionally recruited participants were comparable in terms of these characteristics. This finding is partly in line with a systematic review that found populations recruited via Facebook to be comparable with control populations, except for an overrepresentation of female participants and younger age groups [27]. Younger age among web-recruited participants might reflect the age demographics of Instagram users, with more than half of the global Instagram population being aged ≤34 years [28]. In terms of intervention and trial adherence, we observed no significant differences between participants using the web-based and traditional recruitment methods. Thus, our data do not support the assumption that web-recruited participants were less committed to the study than traditionally recruited participants, which has been reported as a possible limitation to validity elsewhere [15].

Although the overrepresentation of female participants is a frequently described finding in mental health research in general and also specifically in web-based POI research [19,20,29-32], it is unfortunate that more male participants could not be recruited for the study. Considering this potential self-selection bias, different measures were taken in the early phase of the study conception to gain the attention of male participants for *epos*. Special efforts were made in designing *epos* in a way that equally represented prototypes of male and female patients with cancer, not only in the written content but also visually with pictures showing prototypes of male patients with cancer. In the recruitment phase, we designed an additional version of the recruitment flyer with pictures of male patients and slightly different wording and icons (more technical and less emotion-based language). However, these specific measures did not come close to balancing out the other activities that targeted significantly more female participants (eg, the presentation of *epos* at a digital congress for survivors of breast cancer). As the followers of the *epos* Instagram account were predominantly female, our social media promotion activities mainly reached female participants. The aim of reaching out to male participants, who might be hesitant to make use of face-to-face offers because of the fear of stigma, was not achieved in this study. This suggests that a POI designed for all genders and cancer types (as *epos* was) might be too nonspecific to attract male and female participants equally and that recruitment might be more effective if the POI is designed specifically for the male population (as, for instance, in the study by Wootten et al [33]).

Most participants (236/296, 79.7%) registered as self-referred without an HCP recommendation, despite great efforts in face-to-face recruitment via the HCP. Self-referral was predicted by younger age, which might be associated with the web-based recruitment strategy, as web-recruited participants were younger and web-based recruitment is analogous to self-referred recruitment. To our knowledge, evidence on the demographic or medical predictors of self-referral into web-based intervention studies is scarce. A study investigating the success of different recruitment methods for a mobile internet intervention RCT with postpartum mothers found that HCP-referred mothers had higher levels of risk factors compared with self-referred mothers, concluding that the recruiting staff might have prioritized approaching female participants who were perceived as most vulnerable [34]. Our findings revealed no significant differences in psychological distress between self-referred and HCP-referred participants, suggesting that elevated distress levels did not play a central role in recruitment via HCP referral. Further research is needed to understand what characteristics play a role in how patients with cancer find their way into web-based intervention research.

Recruiting exclusively at the study center Mainz was less effective than originally estimated and did not result in the planned inclusion rates. Thus, the gradual expansion of the recruitment strategy to other hospitals and medical practices was necessary. As a result, the inclusion rates of participants recruited in the medical or clinical setting increased significantly but still did not exceed the inclusion rates that were achieved through web-based recruitment. Despite the comparably high effort, we conclude that traditional recruitment, especially hospital-based recruitment and HCP referral, is still crucial. Although both groups, traditionally and web-recruited participants, were not representative of several sociodemographic characteristics, we observed a higher proportion of male participants in the traditional recruitment setting (33/147, 22.4%) compared with the web-based recruitment setting (12/147, 8.2%), which is an important finding with regard to low participation in male participants. This finding indicates that diversified recruitment strategies may be suitable for successful recruitment into clinical trials in POI research, as suggested in previous studies [18,35].

Implications for Social Media Recruitment

The well-known challenges in hospital-based recruitment combined with the severe recruitment restrictions in hospitals owing to the COVID-19 pandemic have led us to engage in web-based recruitment activities. With web-based recruitment as a successful recruitment strategy, our results are in line with previous studies that emphasize the effectiveness of social media for recruiting patients with cancer into POI studies [18-20]. The 2 peaks in participant enrollment (June 2020 and February 2021) were temporally related to relevant social media activity. However, we noticed that recruitment via social media was not at a constant high level, as the number of followers did not increase steadily. We experienced a ceiling effect caused by a low turnover among followers, as already described elsewhere [19]. Although initial social media posts have led to a notable increase in participant numbers, subsequent actions had a smaller impact on registration numbers, indicating a serious limitation of social media recruitment. Another difficulty in social media recruitment, as conducted in this study, is creating an account that can compete with the fast-paced social media environment. As we did not use paid advertisements, we had to increase the account's visibility through regular content and interaction with other Instagram accounts (eg, liking and commenting on posts of other accounts and answering comments under our posts), always taking into account the methodological and ethical considerations for the use of social media in health research, which is associated with specific challenges [24]. From our personal experience in recruiting on social media, several factors appeared to be crucial in the development of posts and maintenance of the *epos* Instagram account, leading us to the following recommendations:

- Do not underestimate the workload behind a professional social media account. Creating new content (eg, posts and stories) is time intensive, including the design of the post, selection of a picture, and writing of appropriate captions. Unlike paid advertisements, building a social media community involves intensive community interaction, for example, with followers or other professional accounts. These interactions might happen to be outside regular working hours, in the evening, or on weekends.
- Before launching a study account, we recommend taking some time to observe and become familiar with the platform. As the social media environment is an emerging, but still not the usual, terrain for researchers, observing social media communities will help understand the code of conduct in the targeted population. Bringing someone with more social media experience to your team, for example, research assistants, can be a huge advantage.
- Be professional, authentic, and clear in the description of your study account to ensure that followers understand what they can or cannot expect and especially not expect from following your account. Especially in the often mentally burdened community of survivors of cancer, followers may ask for psychological help or counseling. Be prepared for such requests, and refer them to appropriate supportive services, for example, the cancer counseling centers. Furthermore, do not try to disguise the aim of the account, which is to promote the study (and maybe inform about the research activities), as it is inappropriate to mislead followers with false promises.
- As every Instagram user can check which other accounts are being followed by the research project's account, ensure to carefully decide whom to follow and avoid following untrustworthy accounts (eg, pseudomedical accounts). Rather, follow other HCPs who have trustworthy content.
- Encourage activities and comments under new posts but try to avoid comments that might lead to critical situations, for example, avoid asking questions that might invite participants of the study to report their experiences with the web-based intervention, as study-related comments could bias other participants.
- Try to avoid topics that could lead to negative (participant) responses in the comments of a post, as this might severely impact the project's reputation. Carefully check (ideally by multiple people) the wording of your posts, the pictures that are used for the post, and the timing of new content.
- Carefully review the content you post on the study account for its potential impact on the psychological variables considered in the study. As it is impossible to control who

views the account, do not post content that could potentially bias the study results.

Limitations and Strengths

The results of this study need to be interpreted in light of several limitations. First, it was not possible to calculate response rates or provide reasons for nonparticipation owing to the study design and recruitment strategy. To increase the commitment of HCPs and practicability in the complex and time-constrained hospital setting, we did not ask the HCPs to provide a documentation of distributed flyers or reasons for nonparticipation expressed by patients. The number of distributed flyers reported in this study refers to flyers that were handed out to the HCPs or were sent to hospitals or other cooperating institutions. It is not possible to draw any conclusions on how many of these flyers finally reached patients with cancer. Thus, it remains unclear whether the low response rate in hospital-based recruitment is owing to a lack of interest in study participation on behalf of patients or rather owing to lower recruitment activities than expected on the side of the HCPs (eg, owing to limited time). Second, it is not possible to report response rates for web-based recruitment strategies, as the link to our study home page was widely distributed and we did not use paid advertisements that provide statistics on the number of clicks. Third, following an adapted and combined strategy instead of a strict recruitment strategy could be seen as a methodological limitation. On the one hand, we acknowledge that our study lacks the benefits of consecutive recruitment; on the other hand, the described recruitment procedure might help overcome recruitment barriers in psycho-oncology and those related to the COVID-19 pandemic. Fourth, the reduced interpretability of adherence data is a further limitation. As mentioned in the section describing the adherence variables, the validity of objective adherence measures was limited, as these data do not only include adherence but also log-in data that were collected while participants completed the questionnaires. However, we sought to counteract this limitation by calculating an adherence measure that is based on the participants’ activity within the intervention. Finally, although we developed strategies to recruit a representative population (eg, male representation in the intervention and recruitment material and using traditional and social media recruitment), the final sample was not representative of sex, age, and education levels.

The flexibility of the recruitment procedure represents a strength. COVID-19–related recruitment problems that came on top of preexisting challenges in psycho-oncological research were countered by strengthening cooperation with other hospitals, networks, and institutions and by using social media methods. By combining HCP referral and self-referral, we fulfilled the number of intended participants, and the distribution enabled comparison of patient characteristics in subgroup analyses. The recruitment strategies described in this study represent an efficient method to create a wide reach.

Conclusions

This study outlined the development and effectiveness of a diversified recruitment strategy for a clinical trial evaluating an unguided psycho-oncological web-based intervention. In addition, implications and recommendations for social media recruitment based on personal experiences were presented. Although traditional recruitment did not result in the planned inclusion rates, social media recruitment provided a substantial increase in participant numbers. Although the population was not representative of several sociodemographic characteristics, we conclude that combining traditional recruitment in hospitals with web-based and social media recruitment is a feasible and effective method to overcome recruitment barriers. Given that almost half of the participants were recruited web-based, we recommend considering web-based recruitment as a viable option in POI research; this approach can enhance practicality and ecological validity. However, evidence on the benefits and pitfalls of social media recruitment in POI research is limited. Future studies may provide further evidence on how best to combine traditional and web-based recruitment in terms of increasing inclusion rates while maintaining validity to ensure quality research.

Acknowledgments

The authors thank Katrin Bhalla-Müller (Interdisciplinary Center for Clinical Trials, University Medical Center Mainz) for support in data preparation and analyses. The authors thank their research assistants Zoe Bünning, Katharina Hoffers, and Anna-Lena Spiess for contributing to participant recruitment. The authors also thank the Psycho-Oncology Section of the Department of Psychosomatic Medicine and Psychotherapy as well as the University Cancer Center Mainz at the University Medical Center Mainz for participant recruitment. The authors thank the AOK Federal Association and the company H6-Communications Berlin for the technical implementation of the emotion-based psycho-oncological online self-help (*epos*). Finally, we thank all cooperating hospitals and medical practices, cancer counseling centers, and self-help networks for their recruiting activities. This study was funded by the Innovation Fund of the Federal Joint Committee (grant 01VSF17018).

Authors' Contributions

AT, AM, JW, MEB, and RZ developed the web-based intervention. AT and AM planned and conducted the recruitment procedures and data collection. CR performed the data analyses. AT wrote the first draft of the manuscript, and AM critically revised the manuscript. JW, CR, MEB, and RZ then read and revised the manuscript and provided valuable feedback. All the authors approved the final manuscript. This publication is a part of the doctoral dissertation of AM.

Conflicts of Interest

None declared.

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Abbreviations

epos: emotion-based psycho-oncological online self-help
HCP: health care professional
POI: psycho-oncological intervention
RCT: randomized controlled trial

Edited by G Eysenbach; submitted 23.08.22; peer-reviewed by C Edwards, Y Hu; comments to author 22.10.22; revised version received 17.12.22; accepted 29.08.23; published 27.11.23.

Please cite as:
Tsiouris A, Mayer A, Wiltink J, Ruckes C, Beutel ME, Zwerenz R
Recruitment of Patients With Cancer for a Clinical Trial Evaluating a Web-Based Psycho-Oncological Intervention: Secondary Analysis of a Diversified Recruitment Strategy in a Randomized Controlled Trial
JMIR Cancer 2023;9:e42123
URL: https://cancer.jmir.org/2023/1/e42123
doi:10.2196/42123
PMID:38010774

Original Paper

Engaging Men of Diverse Racial and Ethnic Groups With Advanced Prostate Cancer in the Design of an mHealth Diet and Exercise Intervention: Focus Group Study

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Abstract

Background: Healthy diet and exercise can improve quality of life and prognosis among men with prostate cancer. Understanding the perceived barriers to lifestyle change and patient preferences in a diverse cohort of men with prostate cancer is necessary to inform mobile health (mHealth) lifestyle interventions and increase health equity.

Objective: We conducted a multisite study to understand the preferences, attitudes, and health behaviors related to diet and lifestyle in this patient population. This report focuses on the qualitative findings from 4 web-based focus groups comprising a racially and ethnically diverse group of patients with advanced prostate cancer who are on androgen deprivation therapy.

Methods: We used grounded theory analyses including open, axial, and selective coding to generate codes. Qualitative data were analyzed as a whole rather than by focus group to optimize data saturation and the transferability of results. We present codes and themes that emerged for lifestyle intervention design and provide recommendations and considerations for future mHealth intervention studies.

Results: Overall, 14 men participated in 4 racially and ethnically concordant focus groups (African American or Black: 3/14, 21%; Asian American: 3/14, 21%; Hispanic or Latino: 3/14, 21%; and White: 5/14, 36%). Analyses converged on 7 interwoven categories: context (home environment, access, competing priorities, and lifestyle programs), motivation (accountability, discordance, feeling supported, fear, and temptation), preparedness (health literacy, technological literacy, technological preferences, trust, readiness to change, identity, adaptability, and clinical characteristics), data-driven design (education, psychosocial factors, and quality of life), program mechanics (communication, materials, customization, and being holistic), habits (eg, dietary habits), and intervention impressions. These results suggest actionable pathways to increase program intuitiveness. Recommendations for future mHealth intervention design and implementation include but are not limited to assessment at the individual, household, and neighborhood levels to support a tailored intervention; prioritization of information to disseminate based on individuals' major concerns and the delivery of information based on health and technological literacy and communication preferences; prescribing a personalized intervention based on individuals' baseline responses, home and neighborhood environment, and support network; and incorporating strategies to foster engagement (eg, responsive and relevant feedback systems) to aid participant decision-making and behavior change.

Conclusions: Assessing a patient's social context, motivation, and preparedness is necessary when tailoring a program to each patient's needs in all racial and ethnic groups. Addressing the patients' contexts and motivation and preparedness related to diet and exercise including the household, access (to food and exercise), competing priorities, health and technological literacy, readiness to change, and clinical characteristics will help to customize the intervention to the participant. These data support a tailored approach leveraging the identified components and their interrelationships to ensure that mHealth lifestyle interventions will engage and be effective in racially and ethnically diverse patients with cancer.

Trial Registration: ClinicalTrials.gov NCT05324098; https://clinicaltrials.gov/ct2/show/NCT05324098

(JMIR Cancer 2023;9:e45432) doi:10.2196/45432

KEYWORDS

cancer survivorship; digital health; technology-based intervention; modifiable behaviors; metastatic; androgen deprivation therapy; race and ethnicity; social determinants of health; mobile phone

Introduction

Background

Healthy diet and exercise have been shown in numerous observational studies and randomized controlled trials to improve quality of life, treatment-related adverse effects, and prognosis among men with prostate cancer [1-7]. However, the ability to initiate and sustain healthy diet and exercise habits is contingent on contextual factors, skills, preferences, and perceptions, which are further constrained by patients' time and resources [8]. Consequently, there are numerous barriers to the effective design and implementation of interventions to improve the quality of life for men with advanced disease [9].

Mobile health (mHealth) interventions, defined by the World Health Organization as "Medical and public health practices supported by a mobile device, such as mobile phone, patient monitoring devices, personal digital assistants and other wireless devices" [10], are becoming increasingly common and are a promising approach for increasing physical activity and modifying dietary behaviors by supporting goal setting, self-monitoring, and instruction and providing feedback about lifestyle changes [11]. However, most of the participants in the studies conducted so far identified as White. More studies are needed to assess the feasibility of and preferences for mHealth interventions that include underrepresented populations. Qualitative studies are uniquely equipped to identify barriers to care and areas of concern for patients, particularly those from vulnerable populations. A recent qualitative study in Taiwan explored the experience of men undergoing androgen deprivation therapy (ADT), which ultimately concluded the need for great emphasis on the provision of topically relevant educational materials, avenues for emotional support, and opportunities to gain improved coping mechanisms [12]. Another recent study, including participants with prostate cancer, explored the role of partner support in cancer survivorship [13]. Studies such as these highlight the complexity of survivorship experience and the need for further qualitative studies.

Objective

Given the importance of healthy lifestyle habits, well-documented disparities in prostate cancer care, and need for remote mHealth interventions, we conducted a qualitative study exploring diet and lifestyle behaviors among a racially and ethnically diverse cohort of men with advanced prostate cancer, to guide the development of an educational intervention focused on men treated with ADT. Findings from this qualitative study may also inform the design and delivery of future mHealth interventions in diverse populations.

Methods

Design

There was a cross-sectional mixed methods study designed to examine preferences, attitudes, and health (PATH) behaviors in men with advanced prostate cancer via a web-based exercise and food habit survey and focus groups. Sampling was purposive to ensure that men from diverse racial and ethnic groups were included. English-speaking and Spanish-speaking participants (n=104) were recruited between July 6, 2019, and November 11, 2020, at the University of California, San Francisco (UCSF); Zuckerberg San Francisco General; and San Francisco Veterans Affairs hospitals. The study was introduced by the study clinician (principal investigator; HTB), clinician (TF), or clinical research coordinator (SZ or ET). The clinical research coordinator screened potential participants for eligibility by reviewing oncology clinic schedules and electronic health records and then approached these patients in the clinic, by phone, or by email to participate in the study. Clinicians also introduced patients to the clinical research coordinator in the clinic, who then introduced them to the study. Participants were aged ≥18 years, diagnosed with hormone-sensitive prostate cancer, on hormone therapy, able to read English or Spanish, and able to understand written informed consent. Participants had metastatic hormone-sensitive prostate cancer if recruited from UCSF; we allowed participants in the community to have metastatic or nonmetastatic hormone-sensitive prostate cancer and did not verify metastasis status for these participants. Any man with any self-reported cognitive or neurologic condition that, in the opinion of the study team, would prohibit the ability to read and navigate the internet or follow a diet or exercise prescription independently were excluded. Recruitment in the community setting occurred through Facebook and Google advertisements; through oncologists at Kaiser Oakland hospital; and at community-based events including church events, support groups, and so on, by a community health educator and outreach or engagement coordinator to increase sample size and include a wide range of perspectives.

Overall, 36 PATH study participants consented to be further contacted by the research team regarding optional study procedures (African American or Black: 14/28, 50%; Asian American or Native Hawaiian or other Pacific Islander or other: 7/9, 78%; Hispanic or Latino: 9/22, 41%; and White: 6/40, 15%). These participants were invited to a focus group via phone or email. All patients provided informed consent. Focus groups were stratified according to self-identified race and ethnicity. Overall, 14 participants—3 (21%) Asian American participants, 3 (21%) African American or Black participants, 3 (21%) Hispanic or Latino participants, and 5 (36%) White participants—attended focus groups between April and November 2020. Each participant received a gift card worth US $50 for participation in the PATH study, and focus group participants received an additional gift card worth US $50.

Focus Groups

Focus groups were conducted by researchers with expertise in urologic cancers, lifestyle, and associated disparities (SAK: non-Hispanic Native Hawaiian, Asian American, White female associate professor of Urology and Epidemiology & Biostatistics; HTB: non-Hispanic Middle-Eastern female assistant professor of Hematology/Oncology; SLW: non-Hispanic African American male assistant professor of Urology and Epidemiology & Biostatistics; and SZ: non-Hispanic Asian American female research coordinator). SZ was the primary contact for study participants. Focus groups were conducted in English and recorded via Zoom (Zoom Video Communications) video software. Participants were asked about their experience with and perceptions regarding various lifestyle tools (website, wearable technology, etc). For the interview guide, refer to Multimedia Appendix 1. Focus groups lasted 60 to 90 minutes and were transcribed using an external service. Data were deidentified. To optimize transferability, we also explored how diet and exercise were affected by the COVID-19 pandemic.

Grounded Theory Analyses

We used a grounded theory approach [14,15]. The grounded theory methodology is well suited for investigating topics without substantial previous qualitative literature owing to its characteristic emphasis on open or data-driven coding versus theory-driven analysis. EYW conducted the initial paragraph-by-paragraph open coding manually and the subsequent coding in ATLAS.ti (version 9). Open codes were refined into axial codes and selective codes (categories) using embodied categorization [16] and constant comparison methods [17]. Codes and categories were finalized with other investigators (HTB, SZ, SLW, and SAK). We report findings in adherence with COREQ (Consolidated Criteria for Reporting Qualitative Research) [18].

Data Saturation

The number of focus group participants required to reach data saturation is debated and largely dependent on the scope of the topic of interest [19]. We designed this study to balance privacy and data saturation. ADT can have a wide range of side effects, including hot flashes, loss of muscle mass, increased fat mass, weight gain, lowered libido, erectile dysfunction, and reduced quality of life. To respect the potentially sensitive and culturally specific aspects discussed in the focus groups related to the cancer diagnosis, cancer treatment, and diet and lifestyle habits, we used small groups and assigned men to racially and ethnically concordant focus groups. Given the narrow and focused nature of the research question (Multimedia Appendix 1), few participants were required to reach saturation. In consideration of the small number of participants within each focus group, the transcripts were analyzed as a whole and presented together. Codes that were only represented in a subset of focus groups are specified.

Ethics Approval

The study was conducted in accordance with the Declaration of Helsinki and approved by the institutional review board (or ethics committee) of UCSF (protocol number 19-27137; March 18, 2019).

Results

Overview

Self-reported characteristics of focus group participants are presented in Table 1. The mean age was 67 (SD 8.9) years, with racial and ethnic composition of 21% (3/14) African American or Black, 21% (3/14) Asian American, 21% (3/14) Hispanic or Latino, and 36% (5/14) White. Most participants were retired (10/14, 71%), had Medicare insurance (11/14, 79%), and had a 4-year college degree or higher (11/14, 79%). Approximately half (8/14, 57%) of the participants were married. All participants (14/14, 100%) were found to have adequate health literacy based on a validated survey [20]. These men were diagnosed with prostate cancer an average of 4 years before enrollment in the study, and many (8/14, 57%) had Gleason grades of 8 to 10.

Analyses yielded 67 open codes, 25 axial codes, and 7 selective codes (categories), which are presented in Figure 1. These seven categories include (1) context (home environment, access, competing priorities, and lifestyle programs), (2) motivation (accountability, discordance, feeling supported, fear, and temptation), (3) preparedness (health literacy, technological literacy, technological preferences, trust, readiness to change, identity, adaptability, and clinical characteristics), (4) data-driven design (education, psychosocial factors, and quality of life), (5) program mechanics (communication, materials, customization, and being holistic), (6) habits (eg, dietary habits), and (7) impressions (regarding the intervention; Figure 1). Each code represents an actionable component, as demonstrated by the participant quotes in the following sections. Illustrative quotes are organized according to 7 categories (column 1 in Figure 1) and open or axial codes (green or blue boxes, respectively, in Figure 1) for the design and delivery of mHealth interventions. Codes represented in all focus groups are bolded, and codes not represented in all focus groups are italicized (Figure 1). Quotes have been edited for clarity and to illustrate the breadth of responses representing selected codes (Table 2).

Table 1. Participant characteristics (n=14)[a].

Characteristics	Values
Age (years), mean (SD)	66.6 (8.9)
Race and ethnicity, n (%)	
Asian American	3 (21)
Hispanic or Latino	3 (21)
Non-Hispanic African American or Black	3 (21)
Non-Hispanic White	5 (36)
Household income (US $), n (%)	
<50,000	5 (36)
50,000-99,999	3 (21)
100,000-199,999	4 (29)
≥200,000	2 (14)
Education, n (%)	
High school	1 (7)
2-year college or university	2 (14)
4-year college or university	2 (14)
Graduate degree	9 (64)
Current level of employment, n (%)	
Full time	2 (14)
Part time	1 (7)
Retired	10 (71)
Disabled	1 (7)
Insurance type, n (%)	
Private	2 (14)
Medicare	11 (79)
Medicaid or other state program	1 (7)
Marital status, n (%)	
Married	8 (57)
Never married	2 (14)
Divorced	4 (29)
Health literacy[b], mean (SD)	13.9 (1.3)
Adequate	14 (100)
Inadequate or marginal	0 (0)
Years since prostate cancer diagnosis, mean (SD)	4.2 (3.7)
PSA[c] at diagnosis, n (%)	
<10	5 (36)
10 to <20	3 (21)
>20	4 (29)
Not sure or do not know	2 (14)
Stage at diagnosis, n (%)	
T1	1 (7)
T2	3 (21)

Characteristics	Values
T3	3 (21)
T4	4 (29)
Not sure or do not know	3 (21)
Gleason grade, n (%)	
6	1 (7)
7	4 (29)
8-10	8 (57)
Not sure or do not know	1 (7)
Treatment history[d], n (%)	
Radiation	9 (64)
Chemotherapy	3 (21)
Surgery	5 (36)
Hormone therapy	14 (100)
Androgen signaling inhibitors[e]	7 (50)
Androgen deprivation therapy[f]	10 (71)
Unknown type	2 (14)

[a] Participants were from University of California, San Francisco (8/14, 57%); community (5/14, 36%); and Zuckerberg San Francisco General (1/14, 7%). Demographic information was self-reported.

[b] Scored from 3-15; high numbers indicate high health literacy; >10 indicates adequate health literacy.

[c] PSA: prostate-specific antigen.

[d] Participants were asked to check all that apply.

[e] Abiraterone, enzalutamide, darolutamide, or bicalutamide.

[f] Leuprolide.

Figure 1. Focus group findings organized according to codes, axial codes, and categories. Codes represented in all focus groups are presented in bold, codes not represented in all focus groups are presented in italics. *Additional open codes under safety include COVID-19 (in person and mask), fires, and police. Additional open codes under treatment experience include radiation, chemotherapy, surgery, and androgen deprivation therapy.

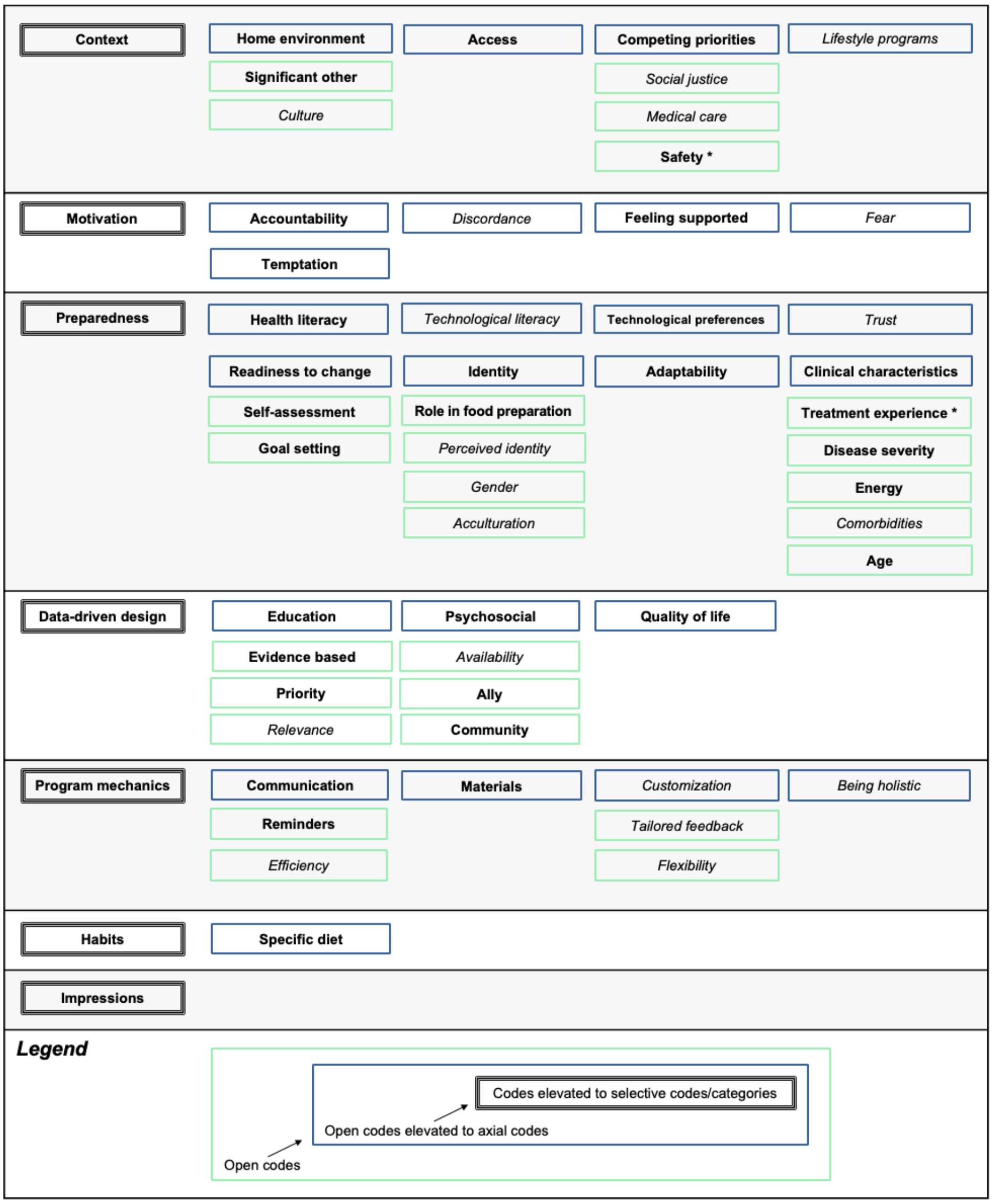


Table 2. Categories and illustrative quotations.

Category and subcategory	Overview and illustrative quotation
Context	
Overview	• Contextual factors, such as home environment (ie, significant other and culture), access to fresh food, competing priorities, safety, and lifestyle programs, were identified as important factors that directly or indirectly influence dietary and exercise behaviors.
Home environment—significant other	• "My wife and I are trying to eat as healthy as possible...We do incorporate tomatoes in the diet." [African American or Black focus group] • "My wife and I seem to have more disagreement...Sometimes, I just do things just to keep the peace, but I know it's not good for me." [African American or Black focus group]
Home environment—culture	• "I'm from a Black family, and the Southern-type cooking...oh, it tastes so good. I do hogshead cheese every day. It's just bad." [African American or Black focus group]
Access (to locally available fresh food and places to exercise)	• "Well I'm lucky that I live close to a park, so I just go there...you can get some boxing gear, on the floor for pushups...stations for work out." [Hispanic or Latino focus group] • "I feel better going out and getting my food from the farmers' market and from the butcher's shop." [African American or Black focus group] • "We would love to not have canned goods. But unfortunately, in Vallejo, there's not a lot of opportunity, unlike San Francisco, to get to farmer's markets." [Asian American focus group]
Competing priorities	• "One of the harder things is avoiding the processed meats and keeping the good vegetables going...I'm going to pull the work card...I do a poor job of preplanning so you need something fast and furious and on the run sort of thing." [White focus group]
Competing priorities—safety (open codes included COVID-19 [in person and mask], fires, and police)	• "This is a fear of me being a Black man growing up in Oakland and stuff...since I've been 18 years old, as I was out jogging around, I always feared that I might get shot by the police." [African American or Black focus group] • "The mask increases these [therapy-related] hot flashes [during exercise]." [Hispanic or Latino focus group]
Competing priorities—social justice	• "Prior to the COVID-19 epidemic, I was going to 24 Hour Fitness for weight training three days a week, I was playing ping-pong at the senior center two days a week, and I was volunteering at a free kitchen one day a week." [African American or Black focus group]
Competing priorities—medical care	• "I made an appointment with my doctor, with my primary...I think once I see him, I think the mood swings will probably change. Again, it may not...I have to play it day-by-day." [African American or Black focus group]
Lifestyle programs (experiences with other diet-related or exercise-related resources or programs)	• "I'm with Kaiser's cardio program for cardiovascular, I'm with UC Davis with their dementia program, and they were going to start an exercise program for me that was going to be held at a gym." [African American or Black focus group]
Motivation	
Overview	• Similarly, motivation to change behavior was identified as a meaningful influence on behavior change; notably, we identified accountability, discordance, support, fear, and temptation as codes within this category.
Accountability	• "You need to make exercise more like your job...you don't just say, I'm not going to go to work today...You do it because it's your job." [White focus group] • "Being in the military, it's a group thing of...When you do things as a group and we're encouraging each other and things like that, that's what I need to stay on track." [African American or Black focus group] • "I'm pretty okay with the results that I get from my healthcare system. If I wouldn't have got proactive and I didn't threaten a few people, I wouldn't be in the position I'm in now. I'd probably be worse." [African American or Black focus group]
Discordance	• "One of the things that's caused me a lot of concern...is the lack of any input from my oncologist or urologist of what I should be eating or...exercise." [White focus group] • "Sometimes I hear two different stories or two different opinions from different physicians. Then that makes it even harder for me to decide which the right thing to do." [Asian American focus group]

Category and subcategory	Overview and illustrative quotation
Feeling supported	• “When I was first diagnosed there were two people who had similar Gleason scores...the three of us formed kind of a triumvirate to do research on, and to support each other in the decision-making process...that was immensely helpful.” [Hispanic or Latino focus group] • “I used to go to one mixed [race/ethnicity prostate cancer support] group here in the city of San Francisco and also one Latino group.” [Hispanic or Latino focus group]
Fear	• “I was told I would benefit in a plant-based diet, and that’s what I did. I won’t eat fish. And my main motivator was fear.” [Hispanic or Latino focus group]
Temptation (impeding dietary change)	• “Maybe once a week...we’ll have a family get together and we’ll make desserts...Resisting those things is really hard for me.” [Hispanic or Latino focus group]
Preparedness	
Overview	• Participants discussed varying levels of preparedness to change behavior owing to unique skill sets and experiences. Health literacy, technological preferences, trust in the health care system, readiness to change, identity, adaptability, and clinical characteristics all contributed to an individual’s preparedness to engage in behavior change.
Health literacy	• “I’ve got a doctorate in Food Microbiology and Food Safety; spent the last 40-some years working on food safety, and spent the last 12 years-or-so working in the area of fresh produce.” [White focus group] • “I’m comfortable with electronics, but I think we all have to recognize, not everybody has the skills to click, to do web searches and some people may don’t even have computers.” [Asian American focus group]
Technological preferences	• “[Support groups online and social media] tend to be a double-edged sword...it can become a bit overwhelming...so you have to moderate yourself.” [White focus group]
Trust (specifically in the health care system or health care providers)	• “I had to tell my urologist that I had prostate cancer. He didn’t believe me until I went to volunteer...I’m also a community activist. I volunteered, and the way I found out that I was in Stage IV, I was at a church, I had my blood drawn, and they come to find out that my PSA was extremely high.” [African American or Black focus group]
Readiness to change—self-assessment and goal setting	• “I can’t even do the exercises I did before ADT today. So, managing those expectations of what actually should I be doing to be considered vigorous exercise.” [White focus group]
Identity—food preparation role, perceived identity, gender, and acculturation	• “I’m an ENTJ...she’s an ISFJ...So my wife really is all about making the home and the meals and the garden and everything as perfect as possible...And my passion is the realm of ideas and concepts and my consulting work and reading and politics...She stimulates my tummy while I’m trying to stimulate her mind.” [Hispanic or Latino focus group] • “I’m single. I cook for myself...I usually find it if I want on the internet or I’m subscribed to food magazine, so I keep up with what’s going on as far as foods, food ideas and new techniques.” [Asian American focus group] • “I’m an extrovert. And I relate to being in [exercise] classes with other people and the whole social aspect is very motivating.” [Hispanic or Latino focus group] • “The biggest challenge for me is getting my 11-year old to eat the same thing as me. He would rather have his burger than my veggies...my mom’s around also.” [Asian American focus group]
Adaptability	• “I previously had a gym membership...Since COVID, I’m in lockdown...Most of my exercise are either going out for a jog, a mile jog or walking the dog or cycling, getting on a bike and going out for a 10-miler or something like that. Occasional jump roping and shooting hoops and yard work.” [White focus group]
Clinical characteristics—treatment experience (radiation, chemotherapy, surgery, and ADT), disease severity, energy, comorbidities, and age	• “Then when the radiation started...every day was a struggle. Then after the radiation stopped, I did not suddenly get stronger again...I had no strength or no desire to do anything physical.” [Asian American focus group] • “After I had the prostatectomy...I dropped significantly down on what I was capable of doing, and I...probably never will get back to the pre-operation kind of level.” [White focus group] • “The ADT, frankly, was a very major physical shock to my body...I lost about six pounds of muscle mass just overnight.” [Asian American focus group] • “For those [who are] metastatic, there’s a lot of stuff going on inside and I always want to encourage men to seek support.” [Hispanic or Latino focus group] • “As we all get older...what is vigorous exercise for me versus...somebody else who’s a different age or different condition?” [White focus group]
Data-driven design	

Category and subcategory	Overview and illustrative quotation
Overview	• From a design perspective, participants identified education, psychosocial factors, and quality of life as important factors influencing or driving intervention engagement.
Education—evidence based, priority, and relevance	• "My thing is data...I want to know that the things that are actually going to have an impact on my likelihood of remission versus a recurrence." [White focus group]
Psychosocial—availability, ally, and community	• "It's all mostly psychosocial, too...What type of activities, when you have a real stressful event, that can keep you away from getting off-track and things like that, like a death in the family, or being a caregiver of somebody with extreme health problems and stuff like that?" [African American or Black focus group] • "I'll be doing fine, and then a stressful event will pop up...It's hard for me to recoil and get back on track. I think if I'm doing individual stuff and then having people follow up with me, that keeps me from getting way off track, I think." [African American or Black focus group]
Quality of life	• "What may not extend my life any further will definitely increase the quality of life...that needs to be emphasized a lot." [White focus group]
Program mechanics	
Overview	• Various aspects of program mechanics were identified, including communication, materials, customization, and being holistic.
Communication—reminders and efficiency	• "Tracking the diet is...a lot of manual intervention daily...and that's where I probably would fall down on even achieving the goals...as opposed to automatically done for me." [White focus group]
Materials	• "I'd like to see...the latest research...published by NIH or others that show the efficacy or not of certain herbs or pharma." [White focus group]
Customization—tailored feedback and flexibility	• "After you're diagnosed, besides doctors, everybody sends you so much information and you get overwhelmed...I know you can't customize it for every person, but like asking, 'Are you vegetarian?'" [Asian American focus group]
Being holistic (interest in programs that comprehensively and synergistically address survivorship concerns)	• "We do talk about diet and exercise some in those workshops, a lot of emotional support as well, but I'm wondering what we could do to integrate that support with the holistic health kind of approach." [Hispanic or Latino focus group]
Habits	
Overview	• Participants discussed various lifestyle habits and habit formation, including the adoption of specific diets (ie, vegan, plant based, and keto).
Specific diet	• "There's the home favorites...Tuesday night comfort food." [White focus group] • "I'm really lucky to have a wife who is a very interested in diet and health and we garden a lot. So we eat a lot of salads. And planted 47 tomato plants and cucumbers and so on." [Hispanic or Latino focus group]
Impressions	
Overview	• Lifestyle interventions leave a lasting impression on participants, which may affect both sustainability of program participation and motivation and preparedness to engage in future interventions.
Sustainability of program participation and motivation and preparedness to engage in future interventions	• "The tracking feature on [this website] is going to be useful...once it was set up, if somebody typed in an avocado or typed in a slice of baloney, it would be able to analyze what the nutritional contents...and how did that relate to the entire diet." [White focus group] • "It took me like six hours to go through all your material...No one is really going to ever do that...get the clinical data that the patient's doing and just give him things that he might need or understand more of." [Asian American focus group]

Special Cases

Codes only represented in a subset of focus groups are presented in Table 3. Safety was mentioned in all groups, but notably, police were noted only in the African American or Black group. Identity contributed to preparedness in the Hispanic or Latino, African American or Black, and Asian American groups, with some clinical characteristics affecting preparedness across all groups. White and Asian American groups generated similar codes for data-driven design and program mechanics, including relevance, efficiency, and tailoring.

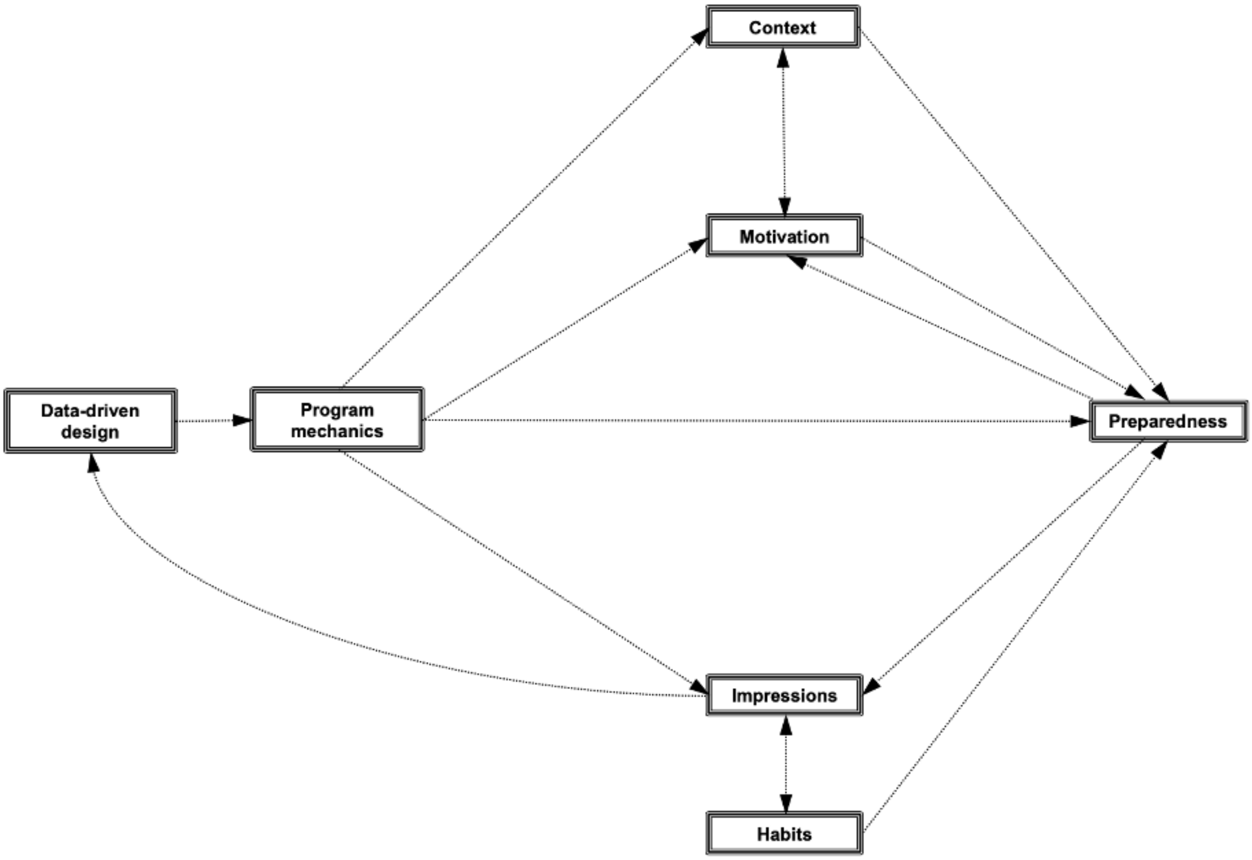
The relationships among these codes (Figure 2) represent actionable pathways to increase program intuitiveness for survivors of prostate cancer engaged in mHealth interventions that could occur via multiple strategies. For example, we might increase motivation by performing a detailed intake assessment using an intake form to characterize participants' preparedness that can be used to provide a tailored step-wise program, understanding the participants' home environment, assessing the influence of other family members on diet and exercise and involving them in lifestyle goals and plans, understanding the participants' preferences for communication for better participant engagement, and tailoring educational material and behavior change plans to the participant using a customized approach. These and other grounded theory–based solutions (Multimedia Appendix 2) may result in a more engaging and integrated intervention for survivors of prostate cancer, which could improve benefits. Broad themes noted in Multimedia Appendix 2 focus on assessment at the individual, household, and neighborhood levels to support a tailored intervention; tailoring of the intervention to the patient where possible (eg, considering the individual's health and technological literacy, communication preferences, baseline responses and major concerns, home or neighborhood environment, and support network); and implementing strategies to foster engagement during the intervention (eg, feedback systems, routine check-ins, earning, and sustaining trust).

Table 3. Codes represented in a subset of focus groups. Codes not listed here were represented in all focus groups.

Categories and codes	African American or Black focus group	Asian American focus group	Hispanic or Latino focus group	White focus group
Context				
Home environment—culture	✓[a]	✓	✓	
Competing priorities—social justice	✓	✓		
Competing priorities—medical care	✓		✓	
Competing priorities—safety—police	✓			
Lifestyle programs	✓		✓	✓
Motivation				
Discordance	✓	✓		✓
Fear	✓			✓
Preparedness				
Technological literacy		✓	✓	✓
Trust	✓			✓
Identity—perceived identity	✓			
Identity—gender	✓		✓	
Identity—acculturation		✓	✓	
Clinical characteristics—treatment experience—radiation		✓	✓	✓
Clinical characteristics—treatment experience—chemotherapy	✓	✓	✓	
Clinical characteristics—treatment experience—surgery		✓	✓	✓
Clinical characteristics—comorbidities	✓		✓	✓
Data-driven design				
Education—relevance		✓		✓
Psychosocial—availability		✓		
Program mechanics				
Communication—efficiency		✓		✓
Customization	✓	✓		✓
Customization—tailored feedback		✓		✓
Customization—flexibility	✓	✓		✓
Being holistic			✓	✓

[a] Indicates representation in the focus group.

Figure 2. Relationships among categories—arrows illustrate the probable pathways among categories.



Discussion

Principal Findings

The purpose of this paper was to elucidate the perspectives and attitudes surrounding lifestyle change in racially or ethnically diverse men with advanced prostate cancer, as this has not previously been studied. Our results suggest that lifestyle-related preferences, needs, and limitations of men with prostate cancer from diverse racial and ethnic backgrounds are affected by multiple inherent, learned, and contextual dimensions, precluding a one-size-fits-all approach to intervention design for men of any given race and ethnicity. Lifestyle interventions may be improved and tailored to the individual by leveraging these components and their interrelationships. The findings from this study are informing a digital platform that provides lifestyle resources and support for men receiving ADT (supportive therapy in androgen deprivation–technology; ClinicalTrials.gov NCT05324098).

So far, few studies have qualitatively explored the experiences of diverse groups of survivors of prostate cancer. The recent COVID-19 pandemic has presented novel challenges, especially among minoritized racial or ethnic populations [21,22] and an increased urgency to optimize remote interventions, particularly for patients from minoritized racial or ethnic groups who have been underrepresented in clinical trials [11,23]. Given the highly social nature of both diet and exercise, race, ethnicity, and other factors related to social determinants of health also likely influence the implementation of lifestyle interventions. Although lifestyle interventions will not mitigate the negative effects of systemic and policy-driven contributors to racial disparities, a design that incorporates the multilevel nature of these issues should address an individual's experience of detrimental systemic and societal influences.

Many codes under "context" (home environment and access) and "preparedness" (literacy, identity, and adaptability) represent the downstream effects of social determinants of health [24,25] or "factors that involve a person's relationships to other people" including race, ethnicity, socioeconomic status, and gender identity [24]. To add to the Fundamental Causes Theory, Riley [26] has challenged researchers to take a more nuanced "systems of exposure" approach and to blend theories such as spatial polygamy, intersectionality, systems theory, and the life course perspective. The theory of intersectionality proposes that social identities interact at multiple levels of oppression to collectively influence health outcomes [27,28]. Applied to lifestyle interventions, the interactions among each participant's various social identities need to be understood at baseline and again at incremental time points, and the intervention needs to be comprehensively tailored to participants' evolving identities and social environment. The importance of a comprehensive and tailored approach is further illustrated by the breadth and interconnectedness of the codes we observed, demonstrating the intersectionality of the multiple facets of participants' lives and perspectives influencing behavior change over time.

As a first step, the codes generated in this study may serve as a preliminary guide for designing a comprehensive intake form.

The breadth and interrelatedness of codes generated by participants signaled the need for a holistic and integrated mHealth intervention design; for example, our recommendations include providing education about normal adverse effects of prostate cancer treatments and the evidence surrounding diet and exercise recommendations as they relate to energy, strength, and motivation and gaining an understanding of participants' current habits to identify realistic and priority areas for change (Multimedia Appendix 2). Future interventions should focus on increased tailoring that could include prioritizing information to disseminate based on participants' major concerns, health literacy, and technological preferences; prescribing personalized educational materials and interventions based on individuals' baseline responses; and incorporating responsive and relevant feedback systems to aid participant decision-making and behavior change in real time. In addition, high-technology interventions may pair well with high-touch aspects such as a patient navigator model for patients with limited technological literacy. The navigator role could be reimagined to provide digital intervention–related support to patients, such as assistance with using internet-based resources (eg, a study web portal), setting up and using app-based devices (eg, Polar heart rate monitors and Fitbit devices that connect to smartphone apps), and setting up video visits (eg, Zoom-based coaching visits).

Every category was constructed with input from all focus groups, but certain codes were not represented in every focus group (Table 3). These variations should not be overinterpreted to signify differences between racial and ethnic groups; however, certain themes appeared in groups for which those themes are most prevalent and relevant. Additional studies are needed to identify unique combinations of themes across groups and to assess which themes are most relevant for different groups. Race and other social constructs are dynamic, and certain intersections will be most salient based on the research focus and the population studied [29]. The patients' context, motivation, and preparedness that may be associated with race; ethnicity; and other factors associated with social determinants of health such as income, access to nutritious foods, and neighborhood characteristics should be considered when formulating an individualized plan for each patient and when discussing the barriers and solutions that will help them to make and maintain healthy behavior changes.

Limitations and Strengths

Limitations of the study include the small subgroup sample size. Overall, 13.5% (14/104) of the eligible participants were both interested and available to participate in the focus groups at scheduled times. Although our sample size is acceptable because our objectives were to explore themes using a grounded theory approach, the absence of theoretical sampling precluded certainty of data saturation. However, open coding minimized researcher assumptions. Our focus groups of 3 to 5 participants provided a more intimate environment for people to share their experience with cancer, their treatments, side effects, and so on and thus was effective for eliciting responses to potentially sensitive research questions such as ours [30]. The corroboration of our findings with other previous studies of prostate cancer, which similarly highlighted important themes related to context (eg, identity), motivation, preparedness (eg, competencies), and mechanics (eg, tailored feedback and goal setting) to consider for a successful intervention [31,32]; consistency with prominent public health theories; and inclusive recruiting bolster study validity as defined by Whittemore et al [33] (credibility, authenticity, criticality, and integrity). Interview guides did not explicitly probe how race or culture played a role in lifestyle change, but the diverse focus groups enabled us to identify more specific themes surrounding social environment and individual-level factors influencing receptiveness to lifestyle change compared with a similar study in a less diverse group [8]. Our participants were well educated and demonstrated adequate health literacy, limiting the generalizability of our findings to broad groups. However, the study's strengths include the inclusion of racially or ethnically diverse participants and researchers, insights during an acute stressor (COVID-19 pandemic), and consistency with previous theories around this topic. This study highlights the need for future ethnographies and in-depth interviews to explore these concepts in participants from diverse racial or ethnic, socioeconomic, and educational backgrounds.

Conclusions

The discussions with focus groups of racially and ethnically diverse patients with prostate cancer about mHealth lifestyle interventions support a tailored approach that leverages the identified components and their interrelationships to ensure that the final intervention will engage and be effective in diverse patients with a cancer diagnosis. Addressing the home environment and patients' roles related to diet and exercise in the household, access (to food and exercise), competing priorities, health and technological literacy, readiness to change, and clinical characteristics will help to customize the intervention to the participant. This study provides preliminary evidence that multiple dimensions should be considered in behavior change interventions and that each contributes to the totality of an individual's social identities and contexts that influence dietary and exercise behaviors. Thus, an intersectional approach to tailoring interventions for all men that accounts for their needs based on an assessment of their context, motivation, preparedness, habits, and impressions, while incorporating design and program mechanics preferences of the participant, would most likely enhance prostate cancer survivorship.

Acknowledgments

The authors sincerely thank the participants in the preferences, attitudes, and health study, who have made this research possible. The authors sincerely thank Ghilamichael Andemeskel for his assistance with community-based recruitment. This study was supported by a University of California, San Francisco Integrative Cancer Pilot Award. The funders had no role in the design of the study; in the collection, analyses, or interpretation of data; in the writing of the manuscript; or in the decision to publish the results.

Data Availability

Focus group transcripts from the preferences, attitudes, and health study are available via application.

Authors' Contributions

HTB and SAK conceptualized the study. HTB, SLW, and SAK led the methodology. EYW, HTB, SZ, SLW, and SAK led the statistical analysis. HTB, SZ, ET, SLW, TF, and SAK led the investigation. HTB and SAK provided resources. HTB, SZ, ET, and SAK curated the data. EYW wrote the original draft. All authors were involved in reviewing and editing the manuscript. HTB and SAK supervised the study. HTB and SAK administered the project and acquired funding.

Conflicts of Interest

HTB is the founder of Trial Library, Inc. SSM's spouse is employed by Welltrust Medical. All other authors declare no other conflicts of interest.

Multimedia Appendix 1
Focus group guide.
[DOCX File , 27 KB - cancer_v9i1e45432_app1.docx]

Multimedia Appendix 2
Recommendations for mobile health intervention design and implementation, according to category and code.
[DOCX File , 20 KB - cancer_v9i1e45432_app2.docx]

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Abbreviations

ADT: androgen deprivation therapy
COREQ: Consolidated Criteria for Reporting Qualitative Research
mHealth: mobile health
PATH: preferences, attitudes, and health

UCSF: University of California, San Francisco

Edited by A Mavragani; submitted 30.12.22; peer-reviewed by G Aguayo, N Jiwani; comments to author 25.01.23; revised version received 31.03.23; accepted 03.04.23; published 01.06.23.

Please cite as:
Wang EY, Borno HT, Washington III SL, Friedlander T, Zhang S, Trejo E, Van Blarigan EL, Chan JM, Shariff-Marco S, Beatty AL, Kenfield SA
Engaging Men of Diverse Racial and Ethnic Groups With Advanced Prostate Cancer in the Design of an mHealth Diet and Exercise Intervention: Focus Group Study
JMIR Cancer 2023;9:e45432
URL: https://cancer.jmir.org/2023/1/e45432
doi:10.2196/45432
PMID:37261885

Original Paper

Effectiveness of a Self-Monitoring App in Supporting Physical Activity Maintenance Among Rural Canadians With Cancer After an Exercise Oncology Program: Cluster Randomized Controlled Trial

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Related Article:

Comment in: http://mhealth.jmir.org/2023/1/e53602/

Abstract

Background: Despite the benefits of physical activity (PA) for individuals with cancer, most remain insufficiently active. Exercise oncology interventions can improve PA levels. Individuals struggle to maintain PA levels after interventions because of persistent psychological and environmental PA barriers. Health technology (eHealth) may address some PA barriers and deliver effective, scalable PA interventions in oncology, yet its effectiveness for changing PA levels remains mixed. Using eHealth to support PA maintenance among rural populations with cancer, who may need greater PA support given lower PA levels and worse health outcomes, remains under-studied.

Objective: This study examined the effectiveness of an app-based self-monitoring intervention in supporting PA maintenance among rural populations with cancer after a supervised web-based exercise oncology program.

Methods: This 2-arm, cluster randomized controlled trial was embedded within the Exercise for Cancer to Enhance Living Well (EXCEL) effectiveness-implementation study. Upon consent, participants were randomized 1:1 by EXCEL class clusters to the intervention (24 weeks of app-based PA self-monitoring) or waitlist control (app access after 24 weeks). Both groups completed a 12-week supervised web-based exercise oncology program followed by a 12-week self-directed PA maintenance period. Baseline demographics, eHealth literacy, and patient-reported outcomes were compared using chi-square and 2-tailed *t* tests. App use was measured throughout the intervention. The primary outcome—self-reported moderate-to-vigorous PA (MVPA) minutes—and secondary outcomes—objective MVPA minutes and steps and app usability ratings—were collected at baseline, 12 weeks, and 24 weeks. Intervention effects on self-report MVPA maintenance were assessed via linear mixed modeling, with secondary outcomes explored descriptively.

Results: Of the 359 eligible EXCEL participants, 205 (57.1%) consented, 199 (55.4%; intervention: 106/199, 53.3%; control: 93/199, 46.7%) started the study, and 183 (51%; intervention: 100/183, 54.6%; control: 83/183, 45.4%) and 141 (39.3%; intervention: 69/141, 48.9%; control: 72/141, 51.1%) completed 12- and 24-week measures, respectively. Mean age was 57.3 (SD 11.5) years. Most participants were female (174/199, 87.4%), White (163/199, 81.9%), and diagnosed with breast cancer (108/199, 54.3%). Median baseline self-report weekly MVPA minutes were 60.0 (IQR 0-180) and 40.0 (IQR 0-135) for the intervention and waitlist control groups, respectively (P=.74). Median app use duration was 10.3 (IQR 1.3-23.9) weeks, with 9.6 (IQR 4.4-17.8) self-monitoring entries/week. Both groups increased their weekly MVPA minutes significantly at 12 weeks (P<.001) and maintained the increases at 24 weeks (P<.001), relative to baseline, with no between-group differences (P=.87). The intervention group had significantly higher step counts for 7 of the 12 weeks during the PA maintenance period (P=.048 to <.001).

Conclusions: The app-based self-monitoring intervention did not improve MVPA maintenance but may have contributed to increased step counts during the PA maintenance period. More work is needed to realize the full potential of eHealth in exercise oncology.

Trial Registration: ClinicalTrials.gov NCT04790578; https://clinicaltrials.gov/study/NCT04790578

International Registered Report Identifier (IRRID): RR2-10.1016/j.cct.2021.106474

(JMIR Cancer 2023;9:e47187) doi:10.2196/47187

KEYWORDS

eHealth; mHealth; mobile health; mobile apps; self-monitoring; cancer; oncology; physical activity; exercise; randomized controlled trial; intervention; mobile phone

Introduction

Background

Physical activity (PA) can improve physical function, fatigue, mental health (anxiety and depression), and the overall quality of life (QoL) among populations with cancer [1,2]. However, despite these benefits and emerging efforts to increase PA levels in oncology, recent cross-sectional data show that only 12% of individuals living with and beyond cancer meet guideline recommendations for weekly PA, with below-average PA levels for rural individuals compared with their urban counterparts [1,3-6]. Although supervised in-person interventions show promise for increasing PA levels and improving QoL in oncology, systems-level (eg, cost, the lack of resources, and environmental impacts such as COVID-19) and individual-level (eg, lack of time and access to facilities) barriers, which are often exacerbated in rural and remote areas, have limited their implementation and impact to date [7]. Furthermore, most prior studies on exercise oncology interventions examined short-term interventions lasting up to 3 months and focused primarily on the initial adoption phase of PA behavior change [8].

Although it is crucial to sustain the positive impacts of exercise oncology interventions, PA maintenance—supporting individuals to stay active in the long term—remains a key challenge. According to the transtheoretical model of behavior change, maintenance is defined as sustained behavior change for 6 months after adoption, with a recent review in exercise oncology suggesting that PA levels 3 months after the intervention provide a good indicator of PA maintenance [9,10]. Even after starting exercise behavior change in a supervised exercise oncology program, participants may still face significant PA maintenance barriers (eg, the lack of motivation, confidence, access to exercise facilities, and time), and PA levels thus tend to decline rapidly after a formal program ends [10-12]. Given these challenges and the importance of PA maintenance, further research on how to support PA maintenance in exercise oncology is warranted.

To address the existing challenges to understanding PA maintenance in exercise oncology, research has begun to examine health technology–based (eHealth) exercise oncology interventions [13,14]. Interventions delivered via eHealth, including mobile technologies (mobile health, eg, apps and wearables) and others (eg, videoconferencing and websites), may be able to address some of the systems-level and individual-level barriers to PA maintenance [15]. For example, self-directed eHealth PA interventions can be less resource intensive than supervised in-person PA interventions [16]. Furthermore, they have been shown to increase motivation and confidence while reducing time and access barriers to individual PA participation in both healthy adults and populations with cancer [17,18]. Surveys of populations with cancer indicate high levels of interest in eHealth PA interventions; high use of technology such as smartphones and computers; and positive perceptions of the usefulness of mobile health, specifically to support PA habits [19-22]. However, research to date has shown only mixed effectiveness of eHealth exercise oncology interventions in increasing PA [23], and less than 20% of interventions to date have measured PA maintenance. Of those that did, only 41% reported positive outcomes on PA maintenance, and none targeted rural and remote populations with cancer [23].

Study Objective

This study sought to address this knowledge gap by examining the effectiveness of an eHealth intervention in promoting PA maintenance in individuals living with and beyond cancer after their participation in an exercise oncology program. Specifically, this study was embedded within the Exercise for Cancer to Enhance Living Well (EXCEL) 5-year effectiveness-implementation research project. EXCEL provides rural and remote Canadians living with and beyond cancer with a 12-week exercise oncology program featuring twice-weekly group-based exercise classes and integrated PA behavior change education through an *exercise and educate* approach [24,25].

This study's eHealth intervention was based on a digital journaling mobile app designed to empower users via self-monitoring, a behavior change technique that has been linked to increased effectiveness of PA behavior change interventions in populations with cancer and healthy adults [26,27]. In response to the mixed effectiveness of prior eHealth exercise oncology interventions, multiple rounds of codevelopment with industry partners and individuals living with and beyond cancer were carried out before the study to create a study-specific version of the app to specifically support PA maintenance [19,23,28]. The aim of these primary analyses was to evaluate the effectiveness of the app-based self-monitoring intervention in supporting PA maintenance among rural Canadians living with and beyond cancer after the completion of a supervised web-based exercise oncology program.

Methods

Study Design

This paper presents the primary quantitative results of a 2-arm, cluster randomized controlled trial (RCT), which was embedded within the EXCEL effectiveness-implementation study [24,25,29]. This RCT was prospectively registered (ClinicalTrials.gov; NCT04790578). A brief overview of the study is presented below. Additional protocol details for the present RCT and the larger EXCEL project are available elsewhere [24,29].

Ethical Considerations

Ethics approval was obtained from the Health Research Ethics Board of Alberta's Cancer Committee (HREBA.CC-20-0283).

All study participants provided informed consent via an electronic form. Study data were deidentified using study ID numbers to ensure participant privacy and confidentiality. No compensation was provided to participants.

Setting

All components of this study were delivered remotely to participants in rural and remote regions across Canada. Contact with participants occurred via email, Zoom (Zoom Video Communications, Inc) videoconferencing, or a chat function directly in the mobile app.

Participants and Recruitment

Study participants were required to meet the following eligibility criteria: they should (1) be currently participating in EXCEL exercise oncology classes; (2) have any cancer diagnosis; (3) be aged >18 years; (4) be physically able to participate in mild PA (assessed by a clinical exercise physiologist during prestudy screening); (5) be in pretreatment or on treatment or have completed treatment within the past 3 years; (6) provide written consent in English; (7) have access to internet speeds that support Zoom use; and (8) be located in remote, rural, or underserved (ie, with no exercise oncology resources) areas in Canada.

The study coordinator visited all web-based EXCEL classes during the second week of the 12-week program to provide a study overview, answer questions, and invite participants to join the study. An email invitation with a link to the electronic informed consent form was then sent to participants, with 2 reminders sent at 3-day intervals to those who had not replied. To reach the target sample size, 4 rounds of recruitment were conducted from April 2021 to April 2022, in line with the start times of the 12-week EXCEL exercise oncology program (April 2021, September 2021, January 2022, and April 2022).

Randomization and Allocation

Upon informed consent, participants were randomized using Sealed Envelope (Sealed Envelope Ltd), a web-based randomization program, to either the app-based self-monitoring intervention or waitlist control group using 1:1 stratified block randomization [30,31]. Randomization by exercise class clusters was performed to improve the integration of the app-based self-monitoring intervention within the group-based EXCEL exercise oncology program by having a class assigned to either include intervention or not, thereby avoiding potential control group contamination within a class. Stratification was done according to class location, with block sizes set according to the number of classes scheduled at each location for each 12-week EXCEL exercise oncology program. The study coordinator (ME) performed the randomization, enrollment, and allocation of participants to groups. The study coordinator was not aware of participants' baseline measures and had no contact with participants before the recruitment and randomization processes.

App-Based Self-Monitoring Intervention

Overview

The total study duration was 24 weeks, with an initial 12-week EXCEL exercise program period (twice-weekly EXCEL supervised web-based exercise oncology classes), followed by a 12-week PA maintenance period (self-directed PA, ie, participants were encouraged to maintain PA levels) [24]. All participants were enrolled in the 12-week EXCEL exercise program. In addition to the supervised web-based exercise oncology classes, intervention group participants received access to a self-monitoring app for 23 weeks, from week 2 until the end of the 24-week study period. Those in the waitlist control group were able to access the app only after study completion at 24 weeks.

More details about this RCT, including a timeline of the intervention period, screenshots of the app interface, and a complete list of the behavior change techniques (eg, self-monitoring of behavior, prompts and cues, feedback on behavior, and credible source) applied within the study-specific version of the Zamplo app and accompanying support resources, have been previously published [29].

App-Based Self-Monitoring

During the second week, intervention group participants received access to a codeveloped study-specific version of

Zamplo, a self-monitoring app that could be used via a smartphone or on any device via a web browser [28,29]. Participants were asked to use Zamplo regularly for the remaining 23 weeks of the 24-week study period, including 11 weeks during the EXCEL exercise program period and throughout the subsequent 12-week PA maintenance period, to self-monitor their PA levels and track personally relevant (mental and physical) health outcomes.

Study-specific tracking templates, created by the study team in collaboration with the app developer and individuals living with and beyond cancer, were available on participant home screens upon logging in, each of which could be completed in under 5 minutes [28,29]. The templates included (1) a daily check-in to track total PA, energy, and fatigue; (2) pre– or post–EXCEL exercise class check-ins to track energy, fatigue, and class completion; (3) a weekly check-in for setting a weekly PA goal, recording completion of their previous weekly PA goal, and noting any barriers to and facilitators of achieving the goal; and (4) a monthly check-in featuring the 10-item Edmonton Symptom Assessment System (ESAS) questionnaire [32]. Participants received daily (template 1), biweekly (template 2), weekly (template 3), or monthly (template 4) emails and push notifications to complete these tracking templates.

In addition to using these tracking templates, participants were encouraged to personalize their self-monitoring in Zamplo by adding relevant activities, symptoms (eg, pain and soreness), medications, or other health data (eg, weight and sleep quality) to existing templates or by creating their own templates. For all tracked data, graphs were automatically generated and displayed on the home screen to help participants visualize and reflect on changes in their PA levels and health over time. Graphs could be customized by adding or removing items and changing the colors or format (bar, line, or dotted line) for each item.

Additional App Support

Reminders to use Zamplo, instructions on how to customize self-monitoring, and technical support were provided through different tools, as outlined in Table 1.

Table 1. Overview of the additional support provided to intervention group participants.

Tool	Details
Notifications	Smartphone, email, and in-app notifications were set up for all study-specific Zamplo journal templates. For user-created templates, participants could choose whether to receive notifications. Participants were shown how to customize notification frequency, timing, and format (smartphone, email, or both) to suit their preferences.
Weekly emails	Weekly emails were sent by the study coordinator (ME) at the start of each week for the first 12 weeks. The emails contained prompts to stick to daily and weekly self-monitoring habits, encouragement to try customizing Zamplo as desired, and a reminder to contact study staff for technical support as needed.
Introductory workshops	Two 1-hour Zoom sessions were hosted during the first 2 weeks of the study to enhance self-efficacy and motivation for using Zamplo. The first workshop focused on the value of self-monitoring for supporting PA habits and interactive demonstrations of basic Zamplo features to help participants with initial learning. The second workshop focused on graphing and customizing Zamplo to individual needs and preferences. Prerecorded versions of both workshops were sent to participants unable to attend, and all participants could revisit content as desired.
Infographic PDF user guides and tutorial videos	Written, verbal, and visual instructions were provided on how to set up, use, and customize Zamplo for self-monitoring during the study.
Ongoing technical support	The study coordinator could be contacted via email or direct messaging in Zamplo in case of any issues, who could help resolve them directly or organize a Zoom support session, if needed. A tracking sheet was used to record details on the type of issue and how it was resolved.

Protocol Deviations

No changes were made to the intervention after publishing the study protocol [29]. However, a minor change was made to the data collection methods. Given the limited availability of Garmin (Garmin International Inc) devices in EXCEL, not all participants wore the Garmin Vivosmart 4 for collecting objective PA as initially planned. More information on the allocation of Garmin devices is provided in the *Outcomes and Data Collection* section.

Outcomes and Data Collection

Data were collected at baseline, after the EXCEL exercise program period at week 12, and after the PA maintenance period at week 24. All questionnaires were via the web-based REDCap (Research Electronic Data Capture; Vanderbilt University) system, with data stored securely on the University of Calgary REDCap server [33].

Baseline Measures and Exercise Class Attendance

Baseline study measures included self-report demographics, patient-reported psychosocial variables (cognitive function: Functional Assessment of Cancer Therapy-Cognitive Function; FACT-Cog [34]; health-related QoL: Functional Assessment of Cancer Therapy-General; FACT-G [35]; fatigue: Functional Assessment of Chronic Illness Therapy-Fatigue; FACIT-F [36]; and symptom burden: ESAS [32]), prior technology use, perceived usefulness for PA (in-house questionnaire [19]), and eHealth literacy (eHealth Literacy Questionnaire; eHLQ [37]). Responses for the FACT-Cog, FACT-G, and FACIT-F range from 0 (not at all) to 4 (very much) [34-36]. The ESAS items are scored from 0 (best) to 10 (worst) [32]. Finally, the eHLQ scores for individual items range from 1 (strongly disagree) to 4 (strongly agree) [37]. EXCEL exercise class attendance was tracked for the 12-week exercise oncology program period.

Measures of Adherence to the Intervention Components

Patterns of app use were collected continuously via the self-monitoring app during the entire 24-week study period. Attendances at the first and second introductory workshops were recorded. In addition, technical issues reported by participants and details of how each issue was resolved were logged by the study coordinator (ME). No a priori cutoffs were defined for the intervention adherence measures.

Primary Outcome

The primary outcome of the study was the maintenance of self-report moderate-to-vigorous PA (MVPA) minutes at 24 weeks and 12 weeks after completing the EXCEL exercise oncology program. Weekly MVPA minutes were self-reported via the modified Godin Leisure Time Exercise Questionnaire (m-GLTEQ) at all time points [38]. The m-GLTEQ asked participants to report the frequency and average duration of mild, moderate, strenuous or vigorous, and resistance PAs performed in the past week. Weekly MVPA minutes was selected as the primary PA outcome, as (1) MVPA is a key component of the exercise oncology guidelines [1], and (2) within research using the m-GLTEQ in exercise oncology, MVPA minutes is the most commonly used PA measure and has established validity for use in populations with cancer [38].

Secondary and Exploratory Outcomes

Secondary outcomes, which were collected at all time points, included mild aerobic PA and resistance PA minutes measured via the m-GLTEQ [38] and Zamplo app usability and satisfaction measured via the Mobile App Usability Questionnaire (MAUQ) [39]. Responses on the MAUQ range from 1 (strongly disagree) to 7 (strongly agree).

All participants were asked to participate in the objective PA tracking component of EXCEL by wearing a Garmin Vivosmart 4 PA tracker for objective PA measurement. This device was used only for data collection and not as an active component of the intervention. Owing to resource constraints, Garmin devices were not available for all participants; thus, only a subset who consented to wear a Garmin device as part of EXCEL were provided with one. Specifically, the EXCEL study coordinator (JD) provided Garmin devices to participants on a “first-come, first-served” basis according to the number of devices available for the given study period. Objective MVPA minutes and steps measured via Garmin Vivosmart 4 devices were thus included only as exploratory outcomes in this study.

Data Processing

After extraction from REDCap, all measures were processed and scored according to standard practices for the respective questionnaires. Specifically, the FACT-Cog scores were calculated by summing the responses in each of the 4 subscales (Perceived Cognitive Impairments: 0-72; Impact on QoL: 0-16; Comments from Others: 0-16; and Perceived Cognitive Abilities: 0-28) [34]. The FACT-G was scored using the 4 standard subscales (Physical: 0-28; Social: 0-28; Emotional: 0-24; and Functional: 0-28) and a total score (0-108) [35]. For the FACT-Cog and FACT-G, higher scores indicate higher QoL. The FACIT-F responses were summed to a total score of 0 to 52, with lower scores indicating higher fatigue [36]. Individual symptom scores (0-10) as well as total ESAS symptom burden (0-100) were calculated using the ESAS, with lower scores reflecting lower symptom burden [32]. For each eHLQ domain, the score was calculated by averaging responses across all items belonging to the domain, with the score ranging from 1 (lowest eHealth literacy) to 4 (highest eHealth literacy) [37]. App use summaries were determined via participant Zamplo use logs, which included details on the weeks, days, and minutes used, as well as what was tracked during the study period. The m-GLTEQ self-report PA data were converted to weekly aerobic MVPA (2 × vigorous PA frequency × vigorous PA duration + moderate PA frequency × moderate PA duration), weekly resistance PA minutes (resistance PA frequency × resistance PA duration), and weekly mild aerobic PA minutes (mild PA frequency × mild PA duration) [38]. Mobile app usability was assessed via an overall MAUQ score and scores for each of the 3 MAUQ subscales (MAUQ Ease of Use and Satisfaction; MAUQ System Information Arrangement; and MAUQ Usefulness), calculated by averaging the ratings across all corresponding items, ranging from 0 (low) to 7 (high) [39]. Finally, daily Garmin data summaries were processed to determine the number of valid wear days per week (at least ten hours per day), valid weeks (at least four valid wear days), steps per day and week, and MVPA minutes per day and week [40].

Sample Size

On the basis of the primary outcome of self-report weekly MVPA minutes during the PA maintenance period and an anticipated mean between-group difference of 60 minutes of MVPA per week, a sample size requirement of 140 participants was determined (70 participants per group, 80% power, 120 min/wk SD, 5% two-tailed α, and 10% attrition) using a web-based tool developed by the Department of Statistics at the University of British Columbia [41,42]. A 60-minute difference was selected based on typical between-group differences seen in previous literature on PA maintenance after exercise oncology interventions and associations between PA levels and clinically meaningful outcomes such as treatment-related side effects, QoL, mortality, and recurrence [10,43].

Data Analyses

All data were collected and stored in REDCap and exported to RStudio (version 1.3; RStudio, Inc), where the analyses were performed [33]. The data were first explored to examine the nature of missing data and visualize distributions. Descriptive statistics (frequencies and percentages for categorical variables, means and SDs for normally distributed continuous variables, and medians and IQRs for nonnormally distributed continuous variables) were then calculated for baseline characteristics, including demographics, cancer type and treatment, eHealth literacy, technology use, patient-reported outcomes, and self-reported preintervention weekly MVPA minutes. Unpaired 2-tailed *t* tests (continuous and normally distributed), Mann-Whitney *U* tests (continuous and nonnormally distributed), and chi-square tests (categorical) were used to check for between-group differences in the demographics and baseline levels of outcome variables. Descriptive statistics were also calculated for the primary (m-GLTEQ weekly MVPA minutes) and secondary (Garmin MVPA minutes and steps) PA outcomes. Data were then inspected using scatterplots and Pearson correlation coefficients for continuous variables or box plots for categorical variables to examine the relationships between m-GLTEQ weekly MVPA minutes and baseline characteristics. Histograms and residual plots were used to visualize data distributions in preparation for linear mixed modeling. Owing to the skewed nature of the primary outcome (m-GLTEQ weekly MVPA minutes), log-transformed data were used for the analyses to align with the normality assumption in linear mixed modeling [44]. Intracluster correlations were calculated at each time point to examine the potential effect of class clusters on the primary outcome, self-report weekly MVPA minutes. Given the small intracluster correlation values, the clustering (ie, classes) was not included in the linear mixed modeling.

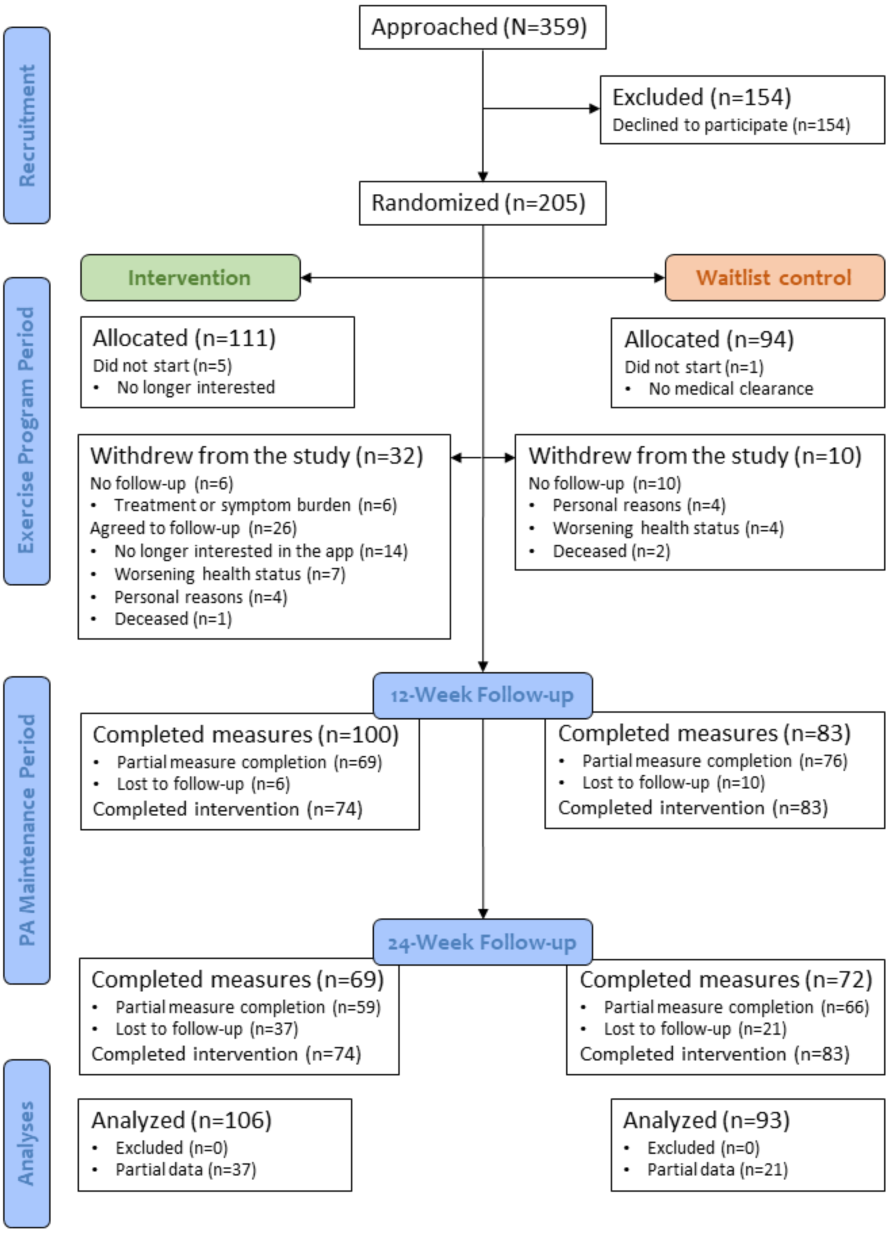
To assess the impact of time, group, and group by time on the m-GLTEQ weekly MVPA minutes, linear mixed modeling was used via the *lme4* package in R (R Foundation for Statistical Computing) [45]. This approach was chosen because of its ability to handle unequal group sizes and retain participants with partial data (lost to follow-up). The models included fixed effects for group, time, group by time, and demographic variables with significant between-group differences at baseline that were not balanced via randomization. As random effects, random intercepts were included for participants to account for individual variation. The initial models included data from the baseline, 12-week, and 24-week time points. In line with the primary aim of the study, modeling was repeated using only the 12- and 24-week self-reported weekly MVPA data to further examine PA patterns during the PA maintenance period. Primary analyses followed intention-to-treat principles, with all the available data included in the models. To explore whether the extent of self-monitoring via Zamplo impacted intervention effectiveness (PA maintenance) relative to the waitlist control group, linear mixed modeling was repeated after splitting the intervention group using a tertile split according to participant app use in weeks (highest, middle, and lowest thirds). Sensitivity analyses were performed to determine the robustness of the modeling results to the impact of outliers and intervention noncompliance [46]. *P* values were obtained from the linear mixed models using Wald *F* tests with Satterthwaite approximation for denominator *df*. For the exploratory analyses of objective MVPA minutes and steps, the *P* values obtained from unpaired 2-tailed *t* tests were used to check for between-group differences at each week. Statistical significance was defined as *P*<.05 a priori.

Results

Recruitment and Study Completion

Details on participant flow throughout the study, including reasons for withdrawal, can be found in Figure 1. After 4 recruitment rounds over a 1-year period, 359 eligible EXCEL participants were approached, and 205 (57.1%) provided informed consent to participate in this study. Cluster randomization by EXCEL class resulted in 54.1% (111/205) of participants allocated to the intervention group and 45.9% (94/205) of participants allocated to the waitlist control group across 36 class clusters (intervention: n=18, 50%; waitlist control: n=18, 50%). A total of 6 participants (intervention: n=5, 83%; waitlist control: n=1, 17%) did not start this study, either owing to loss of interest or inability to obtain timely medical clearance. Over the first 12 weeks, 20.5% (42/205) of participants withdrew from the study. No withdrawals occurred between weeks 12 and 24. Of the 106 participants in the intervention group, 100 (94.3%) and 69 (65.1%) completed questionnaires at the 12- and 24-week time points, respectively. Of the 93 waitlist control participants, 83 (89%) and 72 (77%) completed follow-up questionnaires at the 12- and 24-week time points, respectively.

Figure 1. CONSORT (Consolidated Standards of Reporting Trials) diagram for the flow of participants through the study. PA: physical activity.



Participants

Participant demographics are summarized in Table 2. The mean age of the study participants was 57.3 (SD 11.5) years (intervention: mean 56.7, SD 11.4 years; waitlist control: mean 58.0, SD 11.6 years; Table 2). All Canadian provinces and territories, except Nunavut, were represented by the participant population, with one-third (68/199, 34.2%) from Ontario. Most participants were female (174/199, 87.4%), White (163/199, 81.9%), and diagnosed with breast cancer (108/199, 54.3%). Other common cancer types included lung (24/199, 12.1%) and digestive (15/199, 7.5%) cancers. No significant between-group differences were found in age, sex, ethnicity, marital status, or employment status (all *P*>.05). However, the intervention group featured participants who were more educated (*P*=.01) and had higher incomes (*P*=.02) than those in the waitlist control group. Median m-GLTEQ weekly MVPA minutes at baseline were 60.0 (IQR 0-180) and 40.0 (IQR 0-135) for the intervention and waitlist control groups, respectively (*P*=.74).

Participants reported moderate QoL (FACT-G total score: mean 74.78, SD 15.61) and fatigue (FACIT-F: mean 35.15, SD11.03) at baseline, with no differences between groups (Table S1 in Multimedia Appendix 1). Both participant groups had similarly low eHealth literacy and high technology use (intervention: mean 7.1, SD 2.0 out of 10; waitlist control: mean 6.7, SD 2.7 out of 10), including smartphone use (intervention: 98/106, 92.5%; waitlist control: 82/93, 88%). Median EXCEL exercise class attendance was 83.3% (IQR 69.9%-95.7%) for the intervention group and 87.0% (IQR 71.3%-92.0%) for the waitlist control group (*P*=.80).

Compared with those who completed the study, participants who withdrew from the study were more likely to be male, widowed, or divorced; lack a university education; have a lower income; be off treatment; and report lower MVPA minutes at baseline (all *P*<.001).

Table 2. Participant baseline demographics.

	Total (n=199)	INT[a] (n=106)	CTR[b] (n=93)	*P* value[c]
Demographics				
Age (years), median (IQR)	59.0 (48.0-67.0)	58.0 (47.0-65.0)	61.0 (49.3-67.0)	.44
Sex, n (%)				.12
Female	174 (87.4)	91 (85.8)	83 (89.2)	
Male	25 (12.6)	15 (14.2)	10 (10.8)	
Ethnicity, n (%)				.08
East or Southeast Asian	8 (4)	6 (5.7)	2 (2.2)	
Southern Asian	9 (4.5)	7 (6.6)	2 (2.2)	
White	163 (81.9)	81 (76.4)	82 (88.2)	
Other	24 (12.1)	17 (16)	7 (7.5)	
Location, n (%)				N/A[d]
Ontario	68 (34.2)	48 (45.3)	20 (21.5)	
Saskatchewan	38 (19.1)	13 (12.3)	25 (26.9)	
Nova Scotia	28 (14.1)	13 (12.3)	15 (16.1)	
British Columbia	24 (12.1)	10 (9.4)	14 (15.1)	
Alberta	16 (8)	7 (6.6)	9 (9.7)	
New Brunswick	9 (4.5)	6 (5.7)	3 (3.2)	
Manitoba	8 (4)	3 (2.8)	5 (5.4)	
Other	8 (4)	6 (5.7)	2 (2.2)	
Income (CAD $[e]), n (%)				.02
<20,000	7 (3.5)	3 (2.8)	4 (4.3)	
20,000-39,999	18 (9)	8 (7.5)	10 (10.8)	
40,000-59,999	21 (10.6)	14 (13.2)	7 (7.5)	
60,000-79,999	32 (16.1)	13 (12.3)	19 (20.4)	
80,000-100,000	28 (14.1)	15 (14.2)	13 (14)	
>100,000	72 (36.2)	44 (41.5)	28 (30.1)	
Not disclosed	21 (10.6)	9 (8.5)	12 (12.9)	
Education, n (%)				.01
Some high school	0 (0)	0 (0)	0 (0)	
Completed high school	13 (6.5)	5 (4.7)	8 (8.6)	
Some university or college	37 (18.6)	15 (14.2)	22 (23.7)	
Completed university or college	96 (48.2)	52 (49.1)	44 (47.3)	
Some graduate school	3 (1.5)	2 (1.9)	1 (1.1)	
Completed graduate school	50 (25.1)	32 (30.2)	18 (19.4)	
Marital status, n (%)				.57
Never married	11 (5.5)	6 (5.7)	5 (5.4)	
Married	133 (66.8)	69 (65.1)	64 (68.8)	
Common law	23 (11.6)	11 (10.4)	12 (12.9)	
Separated	5 (2.5)	3 (2.8)	2 (2.2)	
Widowed	11 (5.5)	7 (6.6)	4 (4.3)	
Divorced	16 (8)	10 (9.4)	6 (6.5)	

	Total (n=199)	INT[a] (n=106)	CTR[b] (n=93)	*P* value[c]
Employment status, n (%)				.06
Disability leave	57 (28.6)	36 (34)	21 (22.6)	
Retired	65 (32.7)	28 (26.4)	37 (39.8)	
Part time	16 (8)	9 (8.5)	7 (7.5)	
Homemaker	6 (3)	3 (2.8)	3 (3.2)	
Full time	46 (23.1)	25 (23.6)	21 (22.6)	
Temporarily unemployed	9 (4.5)	5 (4.7)	4 (4.3)	
Self-report weekly PA[f] (m-GLTEQ[g]), median (IQR)				
MVPA[h] minutes	45.0 (0-150.0)	60.0 (0-180.0)	40.0 (0-135.0)	.74
Resistance PA minutes	0 (0-21.25)	0 (0-15.0)	0 (0-30.0)	.21
Cancer characteristics				
Cancer type, n (%)				N/A
Breast	108 (54.3)	54 (50.9)	54 (58.1)	
Lung	24 (12.1)	12 (11.3)	12 (12.9)	
Digestive	15 (7.5)	10 (9.4)	5 (5.4)	
Gynecological	14 (7)	9 (8.5)	5 (5.4)	
Genitourinary	12 (6)	8 (7.5)	4 (4.3)	
Other	26 (13.1)	13 (12.3)	13 (14)	
Advanced cancer, n (%)	47 (23.6)	25 (23.6)	22 (23.7)	N/A
Current treatment, n (%)				
Status				N/A
On treatment	108 (54.3)	61 (57.5)	47 (50.5)	
After treatment	91 (45.7)	45 (42.5)	46 (49.5)	
Type				N/A
Surgery	38 (19.1)	21 (19.8)	17 (18.3)	
Chemotherapy	12 (6)	8 (7.5)	4 (4.3)	
Radiation	42 (21.1)	21 (19.8)	21 (22.6)	
Hormone therapy	2 (1)	2 (1.9)	0 (0)	
Biological therapy	34 (17.1)	24 (22.6)	10 (10.8)	
Other	34 (17.1)	24 (22.6)	10 (10.8)	

[a] INT: intervention.

[b] CTR: waitlist control.

[c] *P* values were estimated using independent 2-tailed *t* tests for continuous variables and chi-square tests for categorical variables.

[d] N/A: not applicable.

[e] A currency exchange rate of CAD $1=US $0.74 is applicable.

[f] PA: physical activity.

[g] m-GLTEQ: modified Godin Leisure Time Exercise Questionnaire.

[h] MVPA: moderate-to-vigorous physical activity.

Adherence to the Intervention Components: App Use and App Support Provided

App use information and a summary of the technical support provided for the app are presented in Table 3 and Figure S1 in Multimedia Appendix 1. Upon downloading the app in week 2, intervention group participants used the app for a median of 10.3 (IQR 1.3-22.9) weeks of a possible 23 weeks during the study period, with 52% (47/90) of participants using the app for at least 12 weeks. Approximately two-thirds (mean 66.3%, SD 37.2%) of app use was via a mobile device. Attendances at the first and second introductory workshops were 66% (70/106) and 50% (53/106), respectively. Participants reported 45 technical issues requiring 25.6 total hours of study team support to resolve.

Table 3. App use, workshop attendance, and app support provided.

	INT[a] (n=106)
App use, median (IQR)	
Weeks (out of 23)	10.3 (1.3-22.9)
Entries per week	9.6 (4.4-17.8)
Activities per week	9.5 (3.4-19.7)
Symptoms tracked per week	20.4 (7.8-42.0)
Introductory workshop attendance, n (%)	
Workshop 1	70 (66)
Workshop 2	53 (50)
Technical issues reported (n=45), n (%)	
Resolved via email	24 (53.3)
Resolved via Zoom	21 (46.7)
Time required to resolve	
Total hours	25.6
Total minutes	1535
Minutes per issue	34.1
Minutes per user	14.5

[a] INT: intervention group.

Primary Outcome: Self-Report MVPA Minutes

Self-reported weekly MVPA minutes at baseline, week 12 (after EXCEL), and week 24 (after PA maintenance period) are shown in Figure 2 and Table 4. In the intervention group, median MVPA minutes per week were 60.0 (IQR 0.0-180.0) at baseline, 240.0 (IQR 117.5-378.75) at week 12, and 205.0 (87.5-330.0) at week 24. In the waitlist control group, median MVPA minutes per week were 40.0 (IQR 0.0-135.0) at baseline, 225.0 (IQR 102.5-352.5) at week 12, and 160 (IQR 55.0-180.0) at week 24. There were no between-group differences in weekly MVPA minutes at any time point (Table 4; *P*=.64-.90).

Figure 2. Boxplot of self-reported weekly moderate-to-vigorous physical activity (MVPA) minutes at baseline, week 12, and week 24. Black dots represent individual participants. m-GLTEQ: modified Godin Leisure Time Exercise Questionnaire.

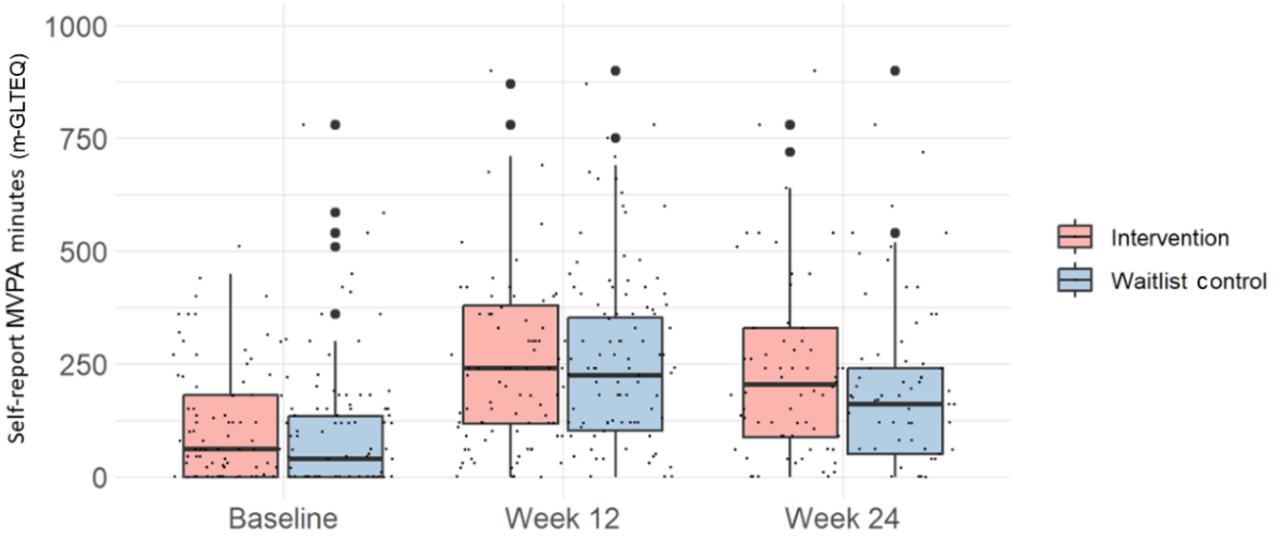


Table 4. Self-reported weekly moderate-to-vigorous physical activity minutes of the participants (n=199) at baseline, week 12, and week 24.

Time point	Intervention		Waitlist control		P value[a]
	Values, median (IQR)	Values, n (%)	Values, median (IQR)	Values, n (%)	
Baseline	60.0 (0.0-180.0)	105 (52.8)	40.0 (0.0-135.0)	91 (45.7)	.90
Week 12	240.0 (117.5-378.75)	96 (48.2)	225.0 (102.5-352.5)	82 (41.2)	.66
Week 24	205.0 (87.5-330.0)	68 (34.2)	160.0 (55.0-180.0)	71 (35.7)	.64

[a] *P* values for between-group differences at baseline, 12, and 24 weeks were calculated using unpaired 2-tailed *t* tests. *P* values <.05 were considered statistically significant as per the a priori cutoff.

Analyses via linear mixed modeling using data from all time points (Table 5) indicated a significant effect of time (week 12: mean 90.5%, SD 11.6% increase in self-report weekly MVPA minutes relative to baseline; week 24: 66.5%, SD 12.3% increase in self-report weekly MVPA minutes relative to baseline; $F_{2,289}$=65.8; P<.001) but not group ($F_{1,163}$=0.09; P=.76) or group by time ($F_{2,289}$=0.14; P=.87). Education and income were included as fixed effects in the model to control for significant between-group baseline differences in these factors. No other demographic factors showed strong correlations with self-report weekly MVPA minutes to warrant inclusion in the model. A second linear mixed model focusing on the PA maintenance period between 12 and 24 weeks showed similar results, with a significant overall effect of time (week 24: mean −26.0%, SD 11.4% decrease in self-report MVPA minutes per week relative to week 12; $F_{1,140}$=7.78; P=.006) but not group ($F_{1,147}$=0.22; P=.64) or group by time ($F_{1,139}$=0.26; P=.61; Table S2 in Multimedia Appendix 1). Exploratory analyses, with intervention group participants stratified by weeks of app use (highest, middle, and lowest thirds), indicated that intervention effectiveness did not differ between user subgroups (Table S2 in Multimedia Appendix 1). Sensitivity analyses confirmed that the mixed modeling results were robust to the presence of outliers and intervention noncompliance. The intracluster correlation of MVPA minutes with exercise class cluster was 0.008 at baseline, 0.025 at week 12, and 0.011 at week 24, indicating the limited effects of clustering (ie, classes) on the primary outcome.

Table 5. Linear mixed modeling results for weeks 0-24 (full intervention period)a.

	F test (*df*)	*P* value[b]
Group	0.09 (1,163)	.76
Time	65.8 (2,289)	<.001
Education	1.19 (4,162)	.32
Income	1.16 (5,164)	.33
Group × time	0.14 (2,289)	.87

[a] Logarithm (modified Godin Leisure Time Exercise Questionnaire moderate-to-vigorous physical activity minutes) ~ group × time + education + income + (1|participant).

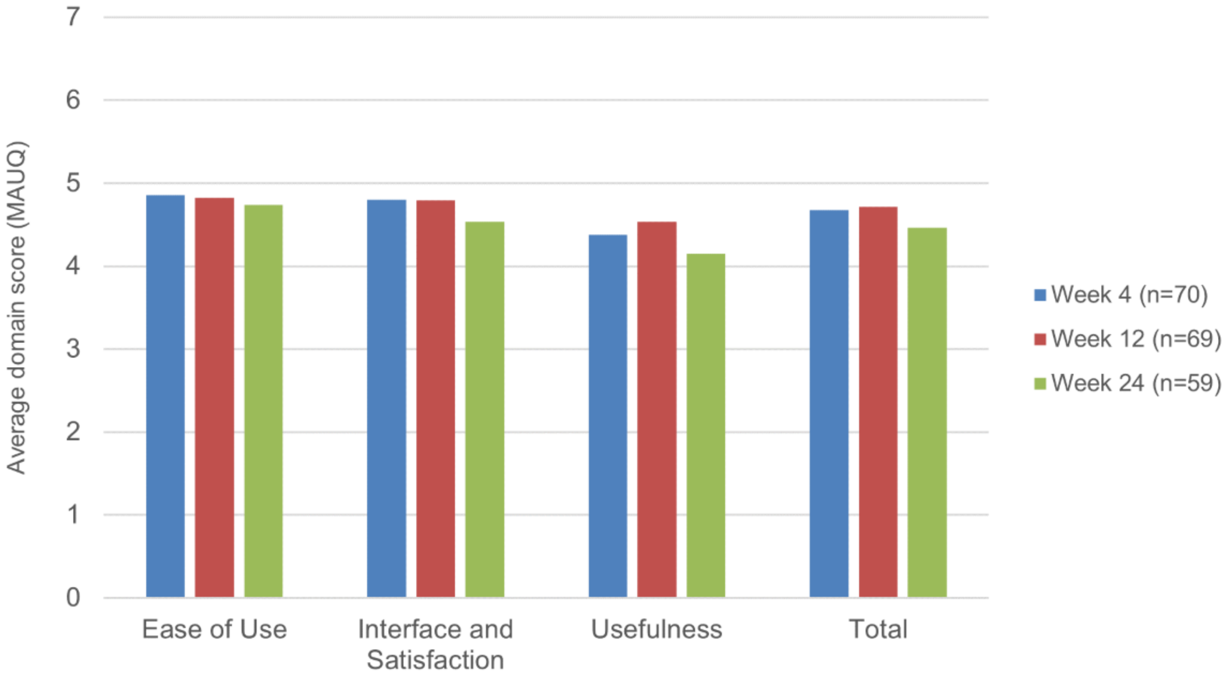
[b] All *P* values were calculated via the linear mixed model using Wald *F* tests with Satterthwaite approximation for denominator df. *P* values <.05 were considered statistically significant as per the a priori cutoff.

Secondary and Exploratory Outcomes

Mobile App Usability Ratings

Figure 3 summarizes the MAUQ ratings for the app at 3 time points: first impressions at week 4, after the EXCEL exercise program period at week 12, and after the PA maintenance period at week 24. On average, participants gave Zamplo moderate ease of use (4.7-4.9 out of 7), interface and satisfaction (4.5-4.8 out of 7), and usefulness (4.2-4.5 out of 7) scores.

Figure 3. Participant-reported Mobile App Usability Questionnaire (MAUQ) scores over time.



Objective MVPA Minutes and Daily Steps

Owing to resource constraints, objective Garmin PA data were collected only for 55.3% (110/199) of participants, with 48.2% (96/199) recording valid data for an average of 14.7 (SD 9.1) weeks (intervention: average 16.8, SD7.9; waitlist control: average 13.1, SD 9.6). Of these, 46% (44/96) were in the intervention group, whereas the remaining 54% (52/96) were in the control group. Among this participant subset, the intervention and control groups did not differ with regard to demographics, except for higher income in the intervention group (P=.03); nor did they differ on baseline m-GLTEQ MVPA minutes (P=.80). An overview of the group averages for objective MVPA minutes and steps measured each week during the study period is provided in Figure S2 in Multimedia Appendix 1. Average daily steps during the 12-week exercise class period were 7345 (SD 2888) and 6219 (SD 2960) for the intervention and control groups, respectively. During the PA maintenance period (weeks 12-24), the average daily steps were 7995 (SD 2876) for the intervention group and 6159 (SD 2954) for the control group. There were no significant differences between groups for Garmin daily steps during the first 5 weeks. However, the intervention group had significantly higher daily steps than the waitlist control group during weeks 6 to 7, 9 to 12, 14 to 18, 20 to 21, and 23 (P=.048 to <.001; Figure S2 in Multimedia Appendix 1). During these weeks, the average daily steps in the intervention group were between 1200 and 3010 steps higher than those in the waitlist control group. There were no significant differences in Garmin MVPA minutes at any time point.

Discussion

Principal Findings

This study provides novel insights into the effectiveness of an app-based self-monitoring intervention in supporting PA maintenance after a 12-week exercise oncology program among rural and remote individuals living with and beyond cancer. Most previous eHealth exercise oncology interventions have recruited urban populations and did not examine postintervention PA maintenance [23]. Study participants in both the intervention and waitlist control groups increased their self-report weekly MVPA minutes directly after the 12-week exercise program and maintained significant increases at 24 weeks relative to baseline, indicating the positive impact of the EXCEL exercise oncology program. Additional support via the self-monitoring app did not improve self-report weekly MVPA during the PA maintenance period. Exploratory analyses indicated that app use may have contributed to significantly higher step counts during the later stages of the exercise class period and over half of the PA maintenance period.

Although the app included behavior change techniques (eg, self-monitoring and goal setting) linked to effective PA behavior change in oncology [8,10,47], its lack of additive impact on PA within this study may have been in part due to the effects of the EXCEL exercise program, which includes behavior change components that the app largely modeled. In addition, there was decreased app use, especially during the PA maintenance period. Specifically, the EXCEL exercise and educate program features behavior change techniques such as goal setting and barrier management, which were sufficient for supporting PA maintenance at 3 months after EXCEL [24]. Thus, there may have been limited potential for the self-monitoring app to further improve PA maintenance, especially within the first 12 weeks after EXCEL.

These results differ from some prior eHealth PA maintenance interventions for populations with cancer [48,49]. For example, an intervention containing telephone-based health coaching and tailored SMS text messages after an exercise oncology intervention was shown to improve PA maintenance [48]. However, the more intensive the health coaching and text messaging intervention was, the shorter the maintenance period was, and a lack of PA maintenance in the control group (highlighting potential differences in the effectiveness of the initial exercise programs provided by these studies to support PA maintenance) in the study by Gell et al [48] may contribute to the contrasting findings. However, other technology-based PA interventions in oncology also reported no significant intervention effects on PA maintenance, despite using a combination of technology and other supports (eg, phone counseling and printed materials) [50,51]. Research to date highlights that more resource-intensive interventions are not always better, with varied individual needs and preferences for eHealth PA maintenance support.

Notably, nearly 50% of the intervention group participants in this study stopped using the app before the PA maintenance period, indicating significant ease of use challenges, a lack of perceived value, or both [52]. For individuals with prior PA experience, as was the case for many participants in the present sample, and those who are already receiving behavior change support within EXCEL, the use of a self-monitoring app such as Zamplo may have limited utility. Research shows that the continued use of eHealth in behavior change interventions is driven by participants' perceived value of the intervention [53]. In addition, low eHealth literacy scores among participants may have led to greater challenges with using the app. App improvements that are tailored to meet user needs and integrate evidence-based PA maintenance behavior change techniques (eg, graded tasks and action planning) may enhance intervention engagement and potentiate the intervention's effectiveness in supporting PA maintenance [10]. For example, although the app included the ability to chat one to one with other participants, further social functionality (eg, team PA challenges and group messages) may improve app engagement and support behavior change [54,55]. Tailoring and optimizing eHealth components will be especially important for interventions targeting rural and underserved populations, who often face greater PA barriers, including less social support [56].

Whereas no intervention effects on MVPA maintenance were observed, daily step counts collected via Garmin devices were significantly higher in the intervention group for extended periods, including more than half of the PA maintenance period. This points to a potential positive impact of app-based self-monitoring on daily steps. These effects may be clinically relevant, exceeding the minimal important difference of approximately 1000 steps noted in prior chronic disease research [57,58]. Although MVPA is typically associated with greater health benefits, increased step counts may also contribute to improvements in physical and psychosocial well-being in oncology [1,59,60]. These findings speak to the value of measuring PA across varying intensities and using both objective and subjective PA measures to comprehensively examine the potential effects of technology-supported exercise oncology interventions. However, positive intervention effects on daily steps can only be seen as preliminary, given that objective PA data were not captured for all participants and that data availability was greatly reduced during the final weeks of the PA maintenance period.

Strengths and Limitations

This study has several strengths, including a large sample size coupled with a linear mixed modeling approach, leading to robust analyses of intervention effectiveness for supporting PA maintenance based on all the available data. Given the smaller sample sizes, single-arm designs, and limited measurement of PA maintenance in many previous eHealth exercise oncology intervention studies, this study adds significantly to the existing literature [23]. However, the participant sample was biased toward a subset of the population with cancer with above-average baseline PA, well-being, and socioeconomic status, with an overrepresentation of White female patients with a breast cancer diagnosis. Therefore, the results of this study may not be generalizable to other populations with cancer. Although the measurement of subjective and objective PAs painted a more comprehensive picture of PA behaviors herein, PA self-reporting is prone to recall and social desirability biases, and only a subset of participants received trackers owing to financial and logistical constraints. Furthermore, despite the intracluster correlations indicating no significant effects of class clusters on the primary outcome, future work may consider randomly assigning participants to class sites to reduce potential selection bias. In this EXCEL effectiveness-implementation trial, this level of randomization was not possible, as participants joined web-based class sites based on geographic location and class timing preferences. These are important considerations for interpreting the PA outcomes of this study. Finally, the selected app was designed for populations with cancer and tailored to participant needs via user-centered codevelopment [28]. The codevelopment process also prompted the integration of behavior change techniques that are linked to effective PA behavior change (eg, prompts or cues and feedback) into the app [28,29,47,61]. Tailoring technology to participant needs and integrating evidence-based behavior change techniques are valuable steps to enhance engagement and potential effectiveness in eHealth interventions [61-63]. Despite this theory-informed co-design process, using an existing app limited the customizability of the tracking experience specific to PA. As highlighted by the technical issues, decreased use over time, and lack of effects on MVPA maintenance, further improvements to the existing app or the development of newer, more effective mobile apps or other eHealth tools may be required to better support PA maintenance in this participant population.

Future Work

Qualitative data from participant interviews conducted at 24 weeks were used to better understand participants' perspectives on the ease of use and potential value of the current self-monitoring app to support PA maintenance. These results will provide further insights into the potential impact of app-based self-monitoring in exercise oncology, address important research gaps (ie, what works, for whom, and why), and help inform future eHealth exercise oncology interventions.

Beyond this study, additional work is needed to examine the potential of eHealth for exercise maintenance. Given the limited impact of the present app, future eHealth exercise oncology studies may want to use other PA-specific apps such as WalkOn, which has been shown to increase weekly steps among individuals with breast cancer, or Heal-Me, an app designed to support health behavior change among older populations living with chronic diseases [64,65]. Future research can leverage alternative trial designs (eg, sequential multiple assignment randomized trials and preference-based trials) to build knowledge on what eHealth interventions best support PA maintenance, as well as the *how* and *why* of their effectiveness [7,66,67]. The results of such studies can inform the development of tailored eHealth interventions for supporting PA maintenance across various populations with cancer. Importantly, codevelopment with potential users, to maximize the ease of use and personal relevance, and researchers, to ensure that the technology draws upon the best evidence in PA maintenance, is recommended to develop highly effective eHealth tools [68-71].

Conclusions

In this study, a self-monitoring app-based intervention did not improve MVPA maintenance among remote and rural populations with cancer after they completed a supervised web-based exercise oncology program. Participants in both the intervention and waitlist control groups maintained significant increases in MVPA at 24 weeks, indicating that the 12-week EXCEL exercise program alone supported MVPA maintenance in the present sample. Objective PA data from a subset of participants highlighted the potential positive effects of the app on daily steps during the PA maintenance period. Future work should examine the impact of eHealth on PA maintenance in those who may require more PA behavior change support. In addition, research is warranted on the long-term PA maintenance effectiveness (ie, beyond 6 months) and optimal components for eHealth exercise oncology interventions.

Acknowledgments

This research received no specific grants from any funding agency in the public, commercial, or not-for-profit sector. The larger Exercise for Cancer to Enhance Living Well (EXCEL) study was funded by the Canadian Institutes of Health Research, Canadian Cancer Society, and Alberta Cancer Foundation. The authors would like to thank Thompson Luu for his help with data management during the recruitment phase and Andy Pohl for support with data processing and analyses.

All authors declared that they had insufficient or no funding to support open access publication of this manuscript, including from affiliated organizations or institutions, funding agencies, or other organizations. JMIR Publications provided article processing fee (APF) support for the publication of this article.

Data Availability

The data sets generated or analyzed during this study are available from the corresponding author upon reasonable request.

Authors' Contributions

ME, MHM, MLM, and SNC-R conceived the study. ME and SNC-R developed the protocol. ME and JD coordinated the participant recruitment and flow throughout the study. ME and CWW processed the data for analyses. ME, CWW, GC, and SNC-R performed the data analyses. ME and SNC-R wrote the first draft of this manuscript. All authors reviewed, edited, and approved the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Additional baseline and outcome data.
[DOCX File , 98 KB - cancer_v9i1e47187_app1.docx]

Multimedia Appendix 2
CONSORT-eHEALTH checklist V 1.6.1.
[PDF File (Adobe PDF File), 12430 KB - cancer_v9i1e47187_app2.pdf]

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Abbreviations

eHLQ: eHealth Literacy Questionnaire
ESAS: Edmonton Symptom Assessment System
EXCEL: Exercise for Cancer to Enhance Living Well
FACIT-F: Functional Assessment of Chronic Illness Therapy-Fatigue
FACT-Cog: Functional Assessment of Cancer Therapy-Cognitive Function
FACT-G: Functional Assessment of Cancer Therapy-General
MAUQ: Mobile App Usability Questionnaire
m-GLTEQ: modified Godin Leisure Time Exercise Questionnaire
MVPA: moderate-to-vigorous physical activity
PA: physical activity
QoL: quality of life
RCT: randomized controlled trial
REDCap: Research Electronic Data Capture

Edited by T de Azevedo Cardoso; submitted 10.03.23; peer-reviewed by M Swartz, PhD, MPH, RD, LD, L Edbrooke, A Gao; comments to author 31.05.23; revised version received 03.07.23; accepted 26.07.23; published 07.09.23.

Please cite as:
Ester M, Wagoner CW, Dreger J, Chen G, McDonough MH, McNeely ML, Culos-Reed SN
Effectiveness of a Self-Monitoring App in Supporting Physical Activity Maintenance Among Rural Canadians With Cancer After an Exercise Oncology Program: Cluster Randomized Controlled Trial
JMIR Cancer 2023;9:e47187
URL: https://cancer.jmir.org/2023/1/e47187
doi:10.2196/47187
PMID:37676714

Original Paper

Feasibility of a Health Coach Intervention to Reduce Sitting Time and Improve Physical Functioning Among Breast Cancer Survivors: Pilot Intervention Study

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Abstract

Background: Sedentary behavior among breast cancer survivors is associated with increased risk of poor physical function and worse quality of life. While moderate to vigorous physical activity can improve outcomes for cancer survivors, many are unable to engage in that intensity of physical activity. Decreasing sitting time may be a more feasible behavioral target to potentially mitigate the impact of cancer and its treatments.

Objective: The purpose of this study was to investigate the feasibility and preliminary impact of an intervention to reduce sitting time on changes to physical function and quality of life in breast cancer survivors, from baseline to a 3-month follow-up.

Methods: Female breast cancer survivors with self-reported difficulties with physical function received one-on-one, in-person personalized health coaching sessions aimed at reducing sitting time. At baseline and follow-up, participants wore the activPAL (thigh-worn accelerometer; PAL Technologies) for 3 months and completed physical function tests (4-Meter Walk Test, Timed Up and Go, and 30-Second Chair Stand) and Patient-Reported Outcomes Measurement Information System (PROMIS) self-reported outcomes. Changes in physical function and sedentary behavior outcomes were assessed by linear mixed models.

Results: On average, participants (n=20) were aged 64.5 (SD 9.4) years; had a BMI of 30.4 (SD 4.5) kg/m^2; and identified as Black or African American (n=3, 15%), Hispanic or Latina (n=4, 20%), and non-Hispanic White (n=14, 55%). Average time since diagnosis was 5.8 (SD 2.2) years with participants receiving chemotherapy (n=8, 40%), radiotherapy (n=18, 90%), or endocrine therapy (n=17, 85%). The intervention led to significant reductions in sitting time: activPAL average daily sitting time decreased from 645.7 (SD 72.4) to 532.7 (SD 142.1; β=–112.9; *P*=.001) minutes and average daily long sitting bouts (bout length ≥20 min) decreased from 468.3 (SD 94.9) to 366.9 (SD 150.4; β=–101.4; *P*=.002) minutes. All physical function tests had significant improvements: on average, 4-Meter Walk Test performance decreased from 4.23 (SD 0.95) to 3.61 (SD 2.53; β=–.63; *P*=.002) seconds, Timed Up and Go performance decreased from 10.30 (SD 3.32) to 8.84 (SD 1.58; β=–1.46; *P*=.003) seconds, and 30-Second Chair Stand performance increased from 9.75 (SD 2.81) to 13.20 completions (SD 2.53; β=3.45; *P*<.001). PROMIS self-reported physical function score improved from 44.59 (SD 4.40) to 47.12 (SD 5.68; β=2.53; *P*=.05) and average fatigue decreased from 52.51 (SD 10.38) to 47.73 (SD 8.43; β=–4.78; *P*=.02).

Conclusions: This 3-month pilot study suggests that decreasing time spent sitting may be helpful for breast cancer survivors experiencing difficulties with physical function and fatigue. Reducing sitting time is a novel and potentially more feasible approach to improving health and quality of life in cancer survivors.

(JMIR Cancer 2023;9:e49934) doi:10.2196/49934

KEYWORDS

physical function; sedentary behavior; quality of life; activPAL; health coaching; cancer survivors; physical functions; breast cancer; survivors; quality of life; sitting time; physical activity; walking; exercise; fatigue; sitting

Introduction

Background

As there are over 4 million female breast cancer survivors in the United States, with numbers increasing yearly [1], finding strategies to improve physical function and overall survivorship quality of life is a paramount public health issue. Behavioral interventions to improve breast cancer survivors' physical function and quality of life have typically focused on physical activity and increasing minutes of moderate to vigorous physical activity (MVPA) [2]. Despite the effectiveness of increasing physical activity to improve physical function and quality of life [3,4], not all survivors are able to make these behavioral changes. In particular, some breast cancer survivors have poor physical function that would make achieving the recommended level of MVPA [5] an unrealistic and potentially unsafe goal. Focusing on decreasing sedentary behaviors, such as prolonged sitting time, may be a more appropriate and attainable behavioral target for breast cancer survivors with worse physical health.

Sedentary behavior among breast cancer survivors is associated with increased risk of cancer recurrence, lower quality of life, and premature mortality [6-8]. Sedentary behavior is any waking behavior done in a sitting, reclining, or supine position and characterized as an energy expenditure ≤1.5 metabolic equivalents [9]. Cancer survivors spend over 9 hours a day being sedentary and are more sedentary than individuals without a cancer history [10-12]. Among breast cancer survivors, long sitting bouts (≥20 min in duration) are associated with worse physical function [1,13,14] and lower quality of life [15].

Sedentary behaviors such as sitting and reclining result in decreased muscle activation and are associated with sarcopenia and subsequent physical and functional decline [9,11,16]. Decreasing sitting time has been shown to be effective in increasing postural muscle activation with improved physical and mental health benefits [17-19]. However, there is limited research on decreasing sitting time in breast cancer survivors; most studies on sedentary behaviors have used combined sedentary and physical activity interventions [20,21]. Furthermore, it is unknown what impact reducing sitting time has on physical function and quality of life of cancer survivors [22-26]. Given the growing number of breast cancer survivors with physical function limitations affecting their quality of life, there is a pressing need to develop effective and feasible sedentary behavior interventions. Therefore, we designed Rise, a 3-month, theory-based intervention aimed to reduce sitting time and improve physical function and quality of life among female breast cancer survivors with physical function limitations.

Objectives

The primary aim of this pilot study was to determine the feasibility of enrolling and retaining breast cancer survivors who reported some physical function limitations into a 3-month intervention to reduce sitting time. The secondary aim was to investigate if the intervention could reduce objectively measured sitting time via activPAL (a thigh-worn accelerometer; PAL Technologies). The tertiary aim was to examine the preliminary impacts of the intervention on objectively and self-reported physical function and multiple aspects of quality of life from baseline to 3 months. We also solicited qualitative participant feedback on the Rise intervention and suggestions for future improvements.

Methods

Participants and Design

Participants were recruited between February and May 2022, from individuals who agreed to be contacted for future research studies and from those who were not eligible for an ongoing physical activity intervention trial [27]. Trained recruiters described this study's activities and confirmed eligibility over the phone before potential participants were scheduled for their first in-person study visit. The target enrollment (n=20) was based on available funding. All participants provided written informed consent. Participants were then enrolled in a 1-arm feasibility trial of a 3-month intervention to reduce sitting time. The trial was registered with ClinicalTrials.gov (NCT05260723). Data were collected from February through August 2022 in San Diego, California, United States.

Eligibility

Eligible women (1) were breast cancer survivors diagnosed at stages 1-4, (2) received chemotherapy, radiation, immunotherapy, or endocrine therapy as part of their breast cancer treatments, (3) were at least 1 year after active treatment (eg, chemotherapy), (4) were sedentary (defined as 7 h or more of sitting time per d on at least 4 d as measured by the activPAL), and (5) had a T-score of less than 50 on the Patient-Reported Outcomes Measurement Information System (PROMIS) physical function measure. Exclusion criteria were (1) medical condition that interferes with ability to safely stand or stay balanced, (2) other cancer diagnosis that occurred after their breast cancer diagnosis, (3) stage 4 breast cancer with brain metastases or less than 12 months life expectancy, and (4) unable to commit to a 3-month study.

Ethical Considerations

The University of California, San Diego institutional review board approved all study procedures (IRB # 171548). Informed consent and the ability of participants to opt out were provided to all participants. All data were stored on a secure HIPAA (Health Insurance Portability and Accountability Act)–compliant database, REDCap (Research Electronic Data Capture; Vanderbilt University), at the University of California, San Diego [28]. Participants received a US $25 gift card for completing baseline measures and a US $50 gift card for the 3-month final assessment.

Measurement Procedures

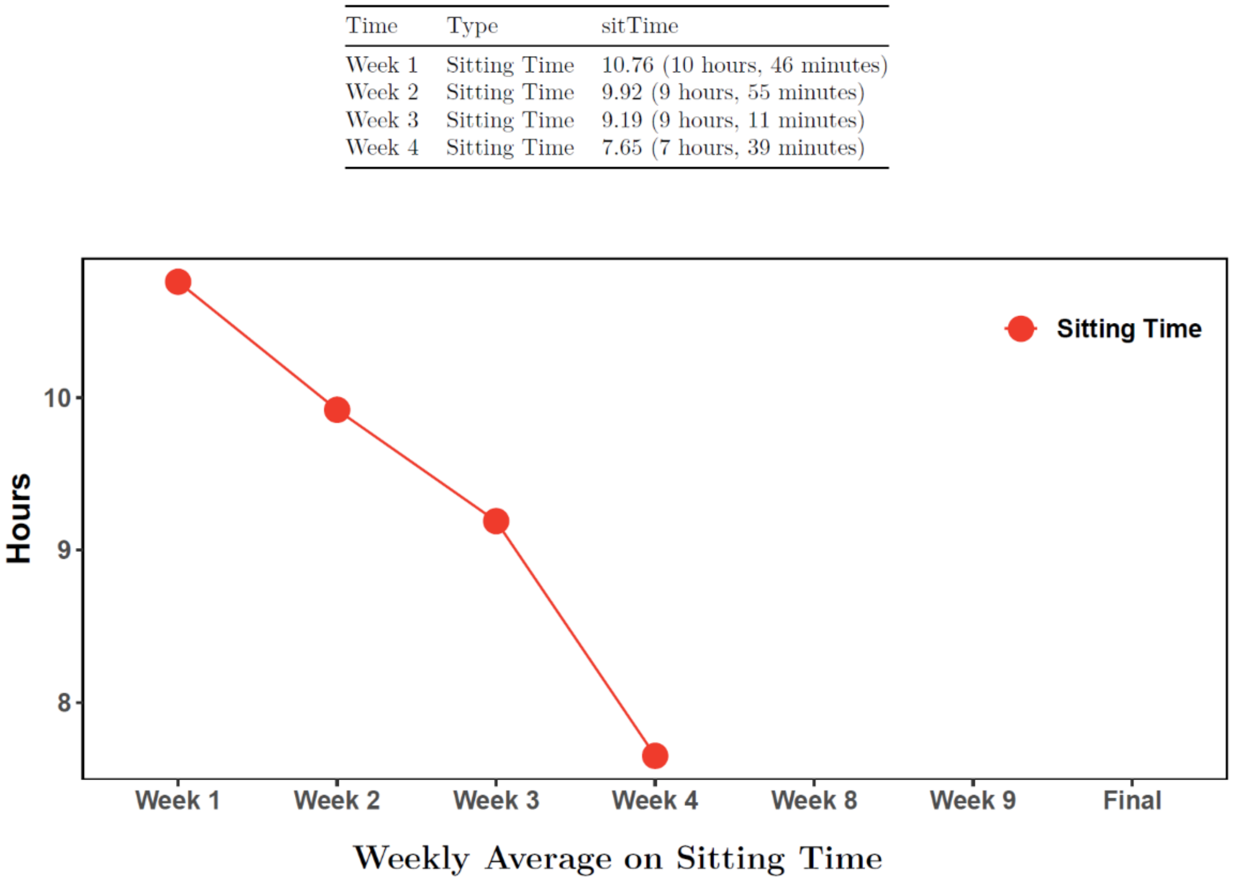
Interested and eligible women were scheduled and consented. At the in-person baseline visit, height and weight were taken and three physical function tests were completed: (1) 4-Meter Walk Test, (2) Timed Up and Go (TUG), and (3) 30-Second Chair Stand. At the end of the baseline visit, participants were given a thigh-worn accelerometer (activPAL) to measure sedentary behaviors and a hip-worn accelerometer (ActiGraph GT3X+; ActiGraph LCC) to measure physical activity. Participants were asked to wear both devices for 24 hours continuously for 7 days and to bring the devices to the second visit. Between the baseline and second visits, participants also completed web-based surveys, including self-reported measures of quality of life. At the second visit, data from the activPAL were screened for sitting time eligibility, which was a minimum of 4 days of wear with greater than 7 h/d of total sitting time on >50% (n=4) of days worn. Participants who met all the eligibility criteria were then started in the Rise intervention. All baseline measures were repeated at the 3-month final assessment.

Intervention

The Rise intervention consisted of 7 individual, personalized health coaching sessions over the course of 3 months. The intervention was delivered by 2 health coaches trained in motivational interviewing. The 5 in-person sessions were 60 minutes each (weeks 1, 2, 3, 4, and 8) and conducted at University of California, San Diego Moores Cancer Center in La Jolla, California, while the two 30-minute sessions (weeks 6 and 11) were conducted remotely via telephone or Zoom (Zoom Video Communications) per the participant's preference. Intervention topics were modeled from a sitting less intervention aimed to reduce sitting time in postmenopausal women [29] and adapted for breast cancer survivors. Adaptations included modifying the educational materials and health coach sessions to reflect how the goal of decreasing sitting time may improve health-outcomes and minimizes the risk of cancer recurrence [20].

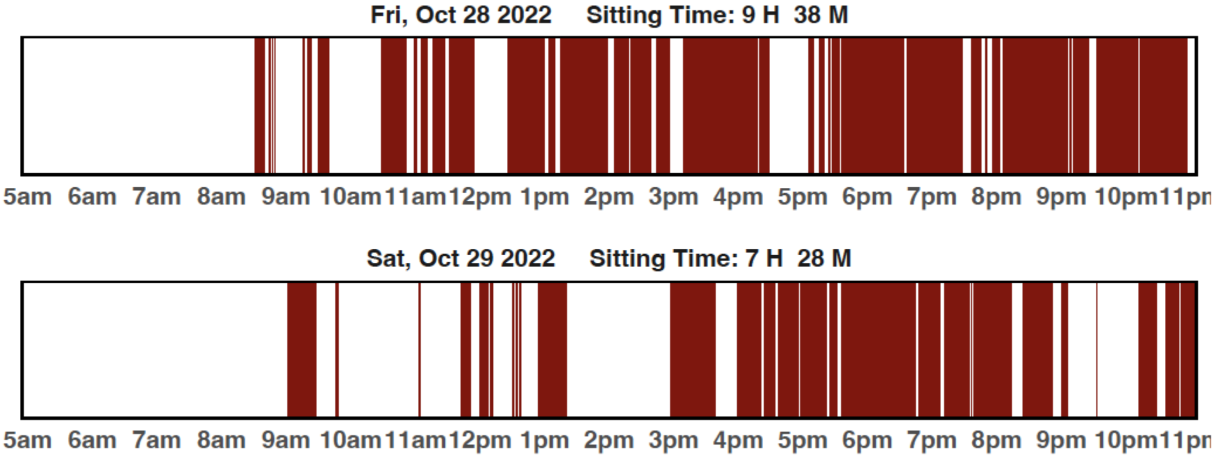
The sitting less intervention components are based on habit formation [30-33] and the social cognitive theory [34], which can be mapped to behavioral strategies found to be important by Michie et al [35]. Sitting is a highly automatic behavior and breaking it up requires conscious recognition to promote the formation of different habits [36]. Unlike traditional physical activity interventions, where participants may be able to plan a walk into their day and track physical activity at the daily level with a pedometer, reducing and interrupting prolonged sitting requires more intense self-monitoring and specific goal-oriented feedback [34]. Particularly important are prompts and environmental cues to continually help participants become more conscious of sitting behaviors [37]. As part of the Rise intervention, participants were asked to wear the activPAL on their thigh continuously for weeks 1-4 and again during week 7 to receive feedback on their sitting time (Figures 1 and 2) to promote self-monitoring to support habit formation. Figure 1 is an example feedback report provided to participants. It shows the average sitting time each week they wore the activPAL so that participants can see how their sitting time changes across the intervention. Participants were encouraged to gradually reduce daily sitting time to achieve a 120-minute reduction in sitting time per day from their baseline. Figure 2 is an example feedback report provided to each participant that shows their day-level activPAL data. The red bars indicated their sitting time and white bars indicate when they were in an upright position (eg, standing and walking). Waking and sleep time were adjusted for and displayed as complete white sections to the left of the first red bar. Using both activPAL graphs, the health coach supported participants to set goals with a specific action plan for the upcoming weeks. To further support behavior change, a variety of prompts and environmental cues were provided, including a standing desk or table, timer, cue cards, and a wrist-worn device (ie, Lintelek watch) to prompt breaks from sitting.

Figure 1. Sample feedback graph from a participant’s activPAL data of their average weekly change in sitting time.



Time	Type	sitTime
Week 1	Sitting Time	10.76 (10 hours, 46 minutes)
Week 2	Sitting Time	9.92 (9 hours, 55 minutes)
Week 3	Sitting Time	9.19 (9 hours, 11 minutes)
Week 4	Sitting Time	7.65 (7 hours, 39 minutes)

Figure 2. Sample feedback graphs from a participant’s day-level activPAL data. Red indicated sitting occurred and white bars indicated upright positions (eg, standing and walking).



Measures

Feasibility

Feasibility was measured via the recruitment, adherence, and retention outcomes. Adherence and retention rates were measured as the percentage of participants that (1) completed all 7 health coach sessions and (2) completed the 3-month final assessment.

Objective Measure of Sedentary and Physical Activity Behaviors

The activPAL, a triaxial thigh-worn accelerometer, was used to objectively measure sedentary behaviors and stepping pattern at baseline and 3-month assessments. Event files from the activPAL were extracted via the CREA classification algorithm (version 8; PALanalysis), which was set to require ≥4 second for a new posture to be registered and generated sleeping time for removal from analysis. Minutes spent in various sedentary behaviors (ie, sitting, standing, sit to stand transitions, and stepping time) were derived from continuously recorded data

[38,39]. The activPAL has been validated with good reliability and validity [40-42] for measuring sedentary behavior and stepping pattern in community-dwelling older adults [43].

The ActiGraph GT3X+, a triaxial hip-worn research grade accelerometer, was used to objectively measure MVPA minutes. Sufficient ActiGraph wear time was classified as at least 5 days with 600 minutes (10 h/d) or 3000 minutes (50 h) across 4 days. Wear time validation was analyzed via Choi et al [44] 2011 guidelines and processed with ActiLife software (ActiGraph LCC). ActiGraph data were processed with low frequency extension and aggregated to 60-second epochs via established Freedson et al [45] MVPA cutoff points defined as 1952 or more counts per minute (3.00-7.00 metabolic equivalents). ActiGraph has been validated [46] with good reliability [47] for measuring MVPA in adults under free-living conditions.

Physical Function Outcomes

Objective physical function outcomes were measured with the 4-Meter Walk Test, TUG, and 30-Second Chair Stand. The 4-Meter Walk Test consisted of measuring their normal walking pace for 4 meters, with the time recorded from when they began walking to when the first foot crossed the 4-meter line. Participants performed the test twice and the faster time was used. This measure of gait speed has excellent interrater, intrarater, and test-retest reliability and convergent validity among community-dwelling older adults [48]. The TUG measured the amount of time it took to get up from a chair, walk 3 m down a path, turn 180 degrees around a cone, walk back, and sit down. Participants performed the test twice and the faster time was used. It has established validity and test-retest reliability in older cancer survivors [49]. The 30-Second Chair Stand measured how many full sit-to-stand repetitions the participant completed in 30 seconds. Participants performed the test once. It has excellent interrater and test-retest reliability and criterion validity in community-dwelling older adults [50]. Self-reported physical function was measured using the PROMIS Physical Function scale. This measure uses computer adaptive testing, which was developed to measure a full range of functions, minimizing ceiling and floor effects [51].

Quality of Life Outcomes

Depression, anxiety, fatigue, sleep, and pain were assessed through the PROMIS cancer scales for depression, anxiety, fatigue, sleep, and pain interference that were developed for cancer survivors and are administered using computer adaptive testing [52,53]. These measures have been shown to be responsive to intervention and prospective studies in cancer survivors [54,55].

Intervention Feedback

The acceptability of the intervention was assessed via web-based satisfaction surveys regarding various components of the Rise intervention, barriers and facilitators outside of the program contributing to reducing sitting time, and satisfaction with the intervention tools. Satisfaction with the intervention tools was rated on a Likert-type response covering topics about how helpful the features from the intervention were on a 5-point scale ranging from 1 (not at all helpful) to 5 (extremely helpful) and how much they liked the features ranging from 1 (disliked a lot) to 5 (liked a lot). Barriers and facilitators contributing to reducing sitting time and various components of Rise were gathered via both closed and open-ended written questions to assess parts of the program that participants felt were the most and least helpful in reducing their sitting time. Open-ended written questions also asked about ways to improve the intervention and to better address the needs of cancer survivors.

Statistical Analysis

Descriptive statistics were used to describe participant demographics and breast cancer characteristics. Except where stated otherwise, continuous variables were presented in mean (SD), categorical variables were presented as number (n) and percent (%), and the statistical type I error (α-level) was set at .05. Feasibility was calculated as the percentage of participants that (1) completed all 7n health coach sessions and (2) completed the 3-month final assessment compared to the baseline enrollment (n=20). Linear mixed models (LMM) with participant-level random intercept were fitted by repeated measures of outcome and fixed effects of the visit. LMM analyses were performed to investigate the intervention effect on physical function, PROMIS, sedentary behavior, and physical activity measures from baseline to the 3-month assessment. The coefficient (β) is an estimation of intervention effect from the baseline to the 3-month visit. All analyses were performed in R statistical programming (R Foundation for Statistical Computing) [56] language and LMM was implemented in R package *nlme* [57,58].

Results

Participant Characteristics

The participants' average age was 64.5 (SD 9.4; range 51-78.3) years, and their BMI averaged 30.4 (SD 4.5; range 22.4-38.0) kg/m^2. In total, 15% (n=3) of the participants identified as Black, 20% (n=4) as Hispanic or Latina, and 55% (n=14) as non-Hispanic White, with 60% (n=12) having a college degree or higher. On average, time since diagnosis was 5.8 (SD 2.2) years with 40% (n=8) treated with chemotherapy, 90% (n=18) having received radiation, and 85% (n=17) were prescribed endocrine hormone therapy (see Table 1 for complete descriptive statistics).

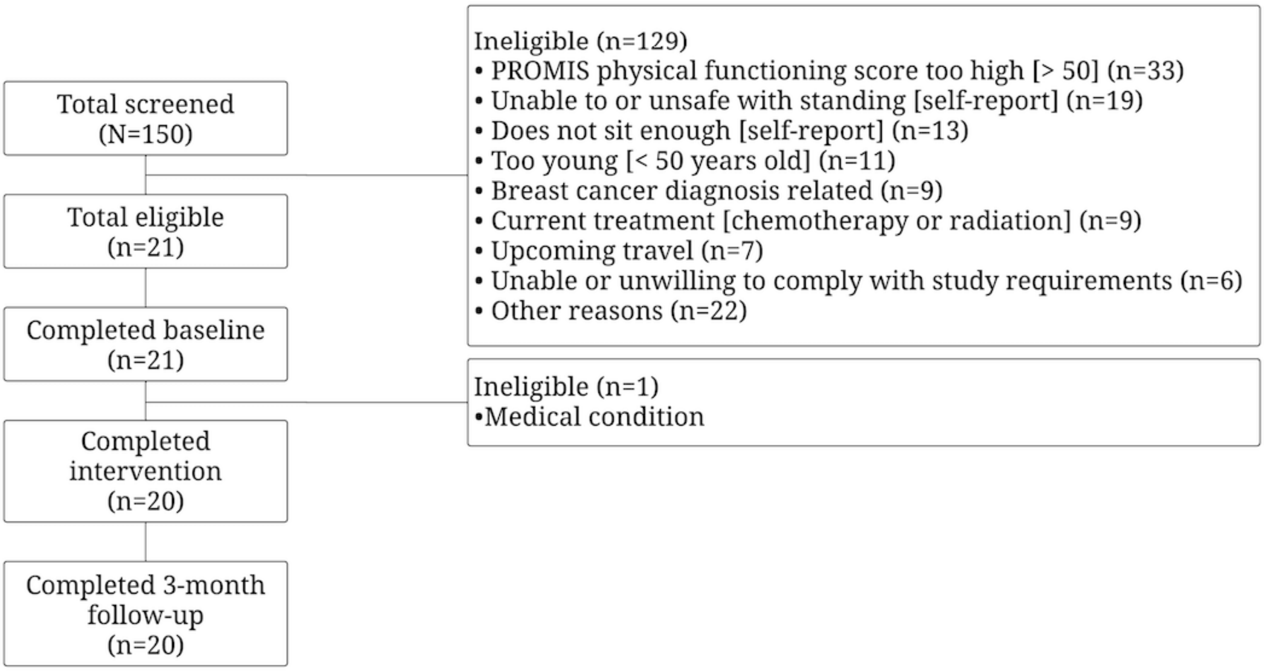
Table 1. Participant demographics (n=20).

Characteristics	Value
Age (y), mean (SD)	64.5 (9.4)
BMI (kg/m^2), mean (SD)	30.4 (4.5)
Education, n (%)	
Some college or less	8 (40)
College graduate	5 (25)
Graduate degree	7 (35)
Marital status, n (%)	
Divorced or separated or widowed	10 (50)
Living with partner	8 (40)
Never married	2 (10)
Ethnicity, n (%)	
Hispanic or Latina	4 (20)
Non-Hispanic or Latina	16 (80)
Race, n (%)	
Black	3 (15)
White	14 (55)
More than 1 race	2 (10)
Other	1 (20)
Cancer stage, n (%)	
Stage 1	12 (50)
Stage 2	6 (30)
Stage 3	1 (5)
Stage 4	1 (5)
Hormone therapy, n (%)	
Currently taking	8 (40)
Previously took	9 (45)
Not prescribed	3 (15)
Surgery type, n (%)	
Lumpectomy	15 (75)
Mastectomy	5 (25)
Time since diagnosis (y), mean (SD)	5.8 (2.2)
Received chemotherapy, n (%)	8 (40)
Received radiation, n (%)	18 (90)

Enrollment and Feasibility

Participants were predominantly recruited via previous research study lists and telephone-screened to determine eligibility. The CONSORT (Consolidated Standards of Reporting Trials) diagram (Figure 3) showed that out of 150 women who were screened for eligibility, 21 were eligible and enrolled into this study. The most common ineligibility reasons included PROMIS physical functioning score being too high (>50; n=33), being unable to or unsafe when standing (n=19), and self-reported not enough time spent sitting (n=13). At the baseline visit, 21 women were deemed eligible. However, an a priori decision was made to exclude 1 participant from analyses due to a heart attack that occurred 2 weeks into this study. The final data set for all analyses includes 20 participants. Adherence to this study was high; all 20 participants completed all 7 intervention sessions and the 3-month final assessment resulting in a 100% (n=20) retention rate.

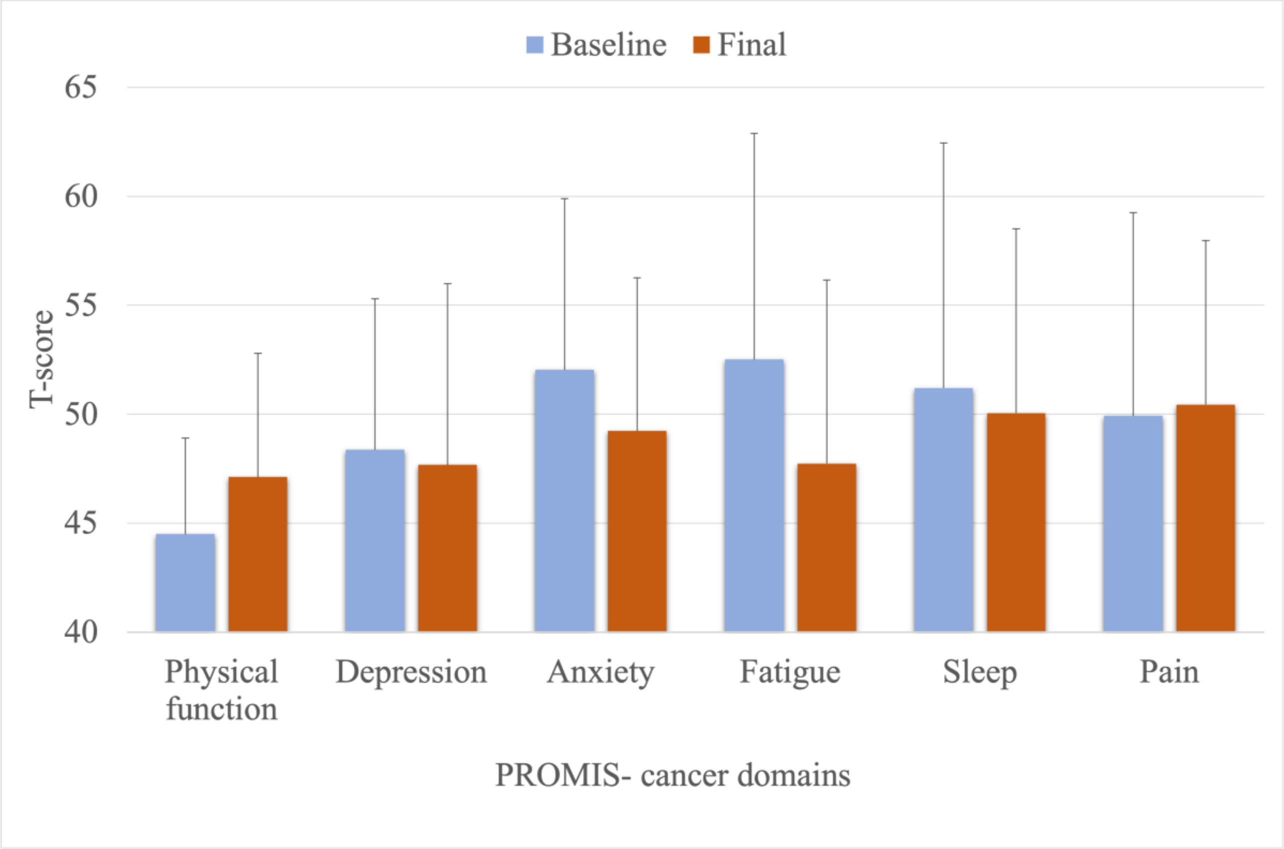
Figure 3. CONSORT (Consolidated Standards of Reporting Trials) diagram. PROMIS: Patient-Reported Outcomes Measurement Information System.



Changes in Sedentary Behaviors and Physical Activity

Daily sitting time and long sitting bouts (bout length 20 min) both significantly decreased from baseline to the final 3-month visit (Figure 4). Average daily sitting time decreased from 645.7 (SD 72.4) min/d to 532.7 (SD 142.1; β=–112.9; *P*=.001) min/d, and average daily long sitting bouts decreased from 468.3 (SD 94.9) min/d to 366.9 (SD 150.4; β=–101.4; *P*=.002) min/d. Average daily standing time significantly increased from 219.3 (SD 63.9) min/d to 300.3 (SD 117.5; β=80.8; *P*=.005) min/d. Average daily stepping time increased from 81.3 (SD 34.3) min/d to 98.6 (SD 51.6) min/d (β=17.2, *P*=.052). Neither sit-to-stand transitions (β=–3.4; *P*=.13) nor daily MVPA (β=.11; *P*=.97) significantly changed over time.

Figure 4. Quality of life outcomes (mean and SD were presented by visit). PROMIS: Patient-Reported Outcomes Measurement Information System.



Physical Function Outcomes

All 3 objective physical function tests showed significant improvements (Table 2). The 4-Meter Walk Test mean time decreased from 4.23 (SD 0.95) seconds to 3.61 (SD 0.53; β=–.63; *P*=.002) seconds, the TUG mean time decreased from 10.30 (SD 3.32) seconds to 8.84 (SD 1.58; β=–1.46; *P*=.003) seconds, and the 30-Second Chair Stand mean number of sit-to-stand transitions increased from 9.75 (SD 2.81) transitions to 13.20 (SD 2.53; β=3.45; *P*<.001) transitions. Participants also self-reported improvements in physical function and fatigue. Mean score of the PROMIS physical function measure increased from 44.59 (SD 4.40) to 47.12 (SD 5.68; β=2.53; *P*=.05), indicating improved physical function. Mean score of the PROMIS fatigue decreased from 52.51 (SD 10.38) to 47.73 (SD 8.43; β=–4.78; *P*=.02), indicating reductions in fatigue. However, no significant changes were reported for anxiety (β=–2.81; *P*=.17), depression (β=–.69; *P*=.61), sleep (β=–1.16; *P*=.64), or pain (β=.52; *P*=.80).

Table 2. Physical function outcomes.

Physical function	Baseline, mean (SD)	Final, mean (SD)	β, LMM[a] estimated intervention effect (SE)	*P* value
4-Meter Walk Test (s)	4.2 (0.95)	3.61 (.53)	–.63 (.17)	.002
Timed Up and Go (s)	10.3 (2.32)	8.84 (1.58)	–1.46 (.42)	.003
30-Second Chair Stand (number of stands)	9.75 (2.81)	13.20 (2.53)	3.45 (.65)	<.001

[a] LMM: linear mixed model.

Acceptability and Feedback of the Intervention

Of the 18 (90%) out of 20 participants who completed this study's feedback questionnaire, all participants (18/18, 100%) reported they were satisfied or very satisfied with the overall intervention. The majority of the participants (17/18, 94%) were motivated or very motivated to sit less throughout the intervention. Many enjoyed the various aspects of the intervention with 1 participant noting, "coaching was terrific, especially the 1st 3 weeks breaking the old patterns." Participants were also asked to expand on ways that this study can better address breast cancer survivors' needs. Most participants did not have any specific suggestions; however, 1 indicated wanting "more info on how to reduce and deal with brain fog."

Regarding the total number of coaching sessions, of the 18 participants, 14 (78%) thought it was just the right amount while 2 (11%) reported they were a few too many sessions and 2 (11%) reported there were not enough sessions. For the first remote session, 8 were conducted via phone and 10 via Zoom. For the second remote session, 9 were conducted via phone and 9 via zoom. Of the 18 participants who responded, 11 (61%) found the number of in-person versus Zoom or phone sessions to be the right amount while 6 (33%) would have liked less in-person and more Zoom or phone sessions and 1 (6%) would have liked more in-person and less Zoom or phone sessions. When asked to expand on the improvements to the program 1 participant indicated, "I would have liked the program to last longer," while another expressed, "Probably less in person visit and more zoom call."

A variety of tools were offered to the participants to support behavior change. Some of the tools were used in-session with their health coach (ie, goal setting with coach, goal tracking log, personalized graph of sitting time, and the workbook) and some for use on their own outside of sessions (ie, wrist device, manual timer, and standing desk or tray). All participants (18/18, 100%) indicated that the personalized graphs were quite or extremely helpful. All participants also reported that at least 1 of the in-session or at home intervention tools listed above were helpful or extremely helpful with achieving their goal to sit less. For example, 1 participant shared that the personalized activPAL graphs of siting time were the most helpful part of the intervention: "The personalized graphs are a big stimulus to keep working on reducing sitting time. Understanding the energizing feeling by sitting less." A few participants expressed that they would have liked to have worn the activPAL device more frequently because of the personalized graphs. Feedback on tools used outside of sessions were more mixed with the standing desk or tray being the most helpful and wrist device the least helpful. As there is no currently available wrist device that can detect sitting time, participants found the device used to be inaccurate and reported, "Sometimes it was beeping to [tell me to] move when I was moving." However, participants still expressed interest in using a wrist device with the suggestion, "I would try to find a better wrist device!" Several participants identified joint pain as a challenge they experienced in trying to change their behavior. However, they also shared some of the benefits they felt from sitting less, including "Standing more, I discovered help me be more steady on my feet. I like that!"

Overall, the feedback from participants on the intervention was very positive. In total, 12 (67%) of the 18 participants reported they were very likely to continue to work on reducing sitting time, 5 (28%) were somewhat likely to continue reducing sitting time, and 1 (6%) indicated that they were very unlikely to continue working on reducing sitting time. For example, 1 participant stated, "I'm so glad I was asked to participate in this study and can't wait to tell my Oncologist about it."

Discussion

Principal Findings

This study highlights the feasibility of retention and adherence in a 3-month sedentary behavior intervention to reduce sitting time in breast cancer survivors. Retention and adherence were extremely high, with all 20 (100%) participants attending all 7 health coaching sessions and the final 3-month assessment. The intervention was associated with decreased sedentary behaviors, an improvement in objective and subjective measures of physical function, and decreased self-reported fatigue. Feedback from the participants indicated high acceptability with all participants who responded (18/18, 100%) indicating they were satisfied or very satisfied with Rise and found the personalized graphs helpful in changing their sitting habits.

Despite having a highly intensive in-person intervention, this study's retention and adherence rates were very high with 100% (n=20) adherence and 0% (n=0) attrition. Although participants were very adherent, feedback highlighted participants' desire to have fewer in-person sessions and to use more frequent remote coaching, via Zoom or phone. The high retention and adherence may have been related to our participants being highly educated and being on average more than 5 years after diagnosis [59]. However, previous research in patients with cancer has found that lower physical function contributed to higher attrition rates [59,60]. Our focus on a simple and feasible behavioral target may have supported retention in the current trial despite reported lower levels of physical functioning.

Sedentary behaviors of daily sitting time and long bouts of sitting significantly decreased by over 100 min/d on average. These significant changes are consistent, but slightly higher, than other 3-month sedentary behavior interventions which showed objective decreases in daily sedentary behaviors ranging from 36.6-72.2 min/d [26,61-63]. Participants did not significantly change sit-to-stand transitions, stepping time, nor MVPA, which is inconsistent with other studies [26,62,63]. Unlike the other studies, our intervention only focused on sitting time and did not include information on behavioral targets for any of these other behaviors. Our intervention focusing on sitting less and only impacting sitting time is consistent with previous research that has shown the distinct nature of different sedentary behaviors and the need to specifically target different behaviors, such as sit-to-stand transitions in order to change them [64]. Importantly, the lack of significant changes in stepping time and MVPA suggest that the benefits participants experienced over the 3-month intervention were not due to changes in physical activity but may have been due to reducing sitting time. This strengthens the support for focusing on sitting time to improve cancer survivorship.

Key findings of this study were that physical function and fatigue significantly improved. The improvement in physical function is consistent with sedentary behavior interventions in older adults without cancer [24,25]. As cancer survivors experience faster declines in physical function than their noncancer counterparts [6,65-67], these promising findings bolster support for targeting sedentary time in behavioral interventions for cancer survivors. The relationship between fatigue and sedentary behaviors has not been consistent across studies [7,68,69]. However, our results align with a study of objectively assessed sedentary time that found associations with improved fatigue duration at a 6-month follow-up [10]. It is important to note that the improvements in physical function and fatigue occurred without a concurrent increase in MVPA, suggesting that a sedentary behavior intervention can be effective without requiring patients to exercise. Furthermore, the use of objective measures in addition to patient-reported outcomes [70] adds to the dearth of literature surrounding sedentary behavior and breast cancer survivors.

Feedback from our multipronged intervention had overall high acceptability of the wearable devices and intervention materials. The multiple behavior components is consistent with prior studies, including our own work, suggesting that in addition to providing a device, accountability and feedback regarding the wearable tracker data are critical to the success of physical activity interventions [26,29,63,71,72]. While participants liked the thigh-worn activPAL and the accuracy of those graphs and devices, they did not like the wrist-worn tracker used for prompting standing. There were consistent recommendations for finding a more accurate wrist device. Unfortunately, existing commercial devices such as Fitbit (Fitbit LLC) and Apple Watch (Apple Inc) use the lack of steps to trigger alerts to stand, similar to the devices used for this study, and would have similar issues of incorrect alerts. With greater attention on the ill effects of sedentary behavior, we hope that future wearable devices will have better technology for identifying prolonged sitting as the likability of a wearable device has been found to increase adherence and usage in cancer survivors [73]. Finally, participants enjoyed the overall number of sessions but suggested an increased ratio of remote to in-person sessions. These reflections support changes seen across health behavior interventions as the COVID-19 pandemic has created opportunities for increased uptake and acceptability of remote care delivery among cancer survivors [74].

Limitations

Although this was designed as a feasibility pilot study, important limitations to the findings include the small sample size, participants may not be representative of the broader breast cancer population, the lack of a control arm, and the short intervention period. As this was a pilot study, we did not control for multicomparisons in determining statistical significance. The use of multiple intervention components makes us unable to determine what aspects were most effective for behavior change. Future trials using a multiphase optimization strategy framework is important for supporting effective and cost-effective strategies to support uptake and maintenance of sitting less. Despite these limitations, this study also includes several strengths, including the use of objective measures of sedentary behaviors and physical function, being one of the first studies for breast cancer survivors to focus solely on sedentary behavior (without an exercise component), enrolled participants with low to average physical function, and had 100% (n=20) compliance and 0% (n=0) attrition over a 3-month period. The results provide important and necessary feasibility data for a future trial to assess the efficacy of the Rise intervention in an adequately powered study.

Conclusions

Sedentary behavior interventions may support improved physical function among breast cancer survivors. In particular, the focus on solely decreasing sitting time without changes in MVPA is highly promising for the many breast cancer survivors who cannot safely or feasibly increase MVPA. These pilot results provide support for an adequately powered and longer trial. Future iterations of the intervention should include more remote and less in-person sessions, more accurate sedentary behavior wearable trackers, and assess maintenance of sedentary behavior change beyond the intervention period. Given the rapidly growing rates of breast cancer survivors in the US, the use of wearable technology and continued development of low-barrier sedentary behavior interventions is crucial in improving overall quality of life in cancer survivors.

Acknowledgments

This study was funded by the University of California, San Diego Academic Senate (grant RG104379) and the Herbert Wertheim School of Public Health (HWSPH) Women's Health and Reproductive Justice program. HKN was supported by the TEAM ABBY Gives St Baldrick's Foundation Scholar Award and the National Heart, Lung, and Blood Institute of the National Institutes of Health (award K23HL163456).

Data Availability

The data sets generated or analyzed during this study are available from the corresponding author on reasonable request.

Authors' Contributions

Conceptualization was by RMT, AZL, and SJH. Data curation was done by RMT, LD, and ES. Formal analysis was performed by RWZ, CL, and LN. Funding acquisition was obtained by AZL and SJH. Project administration was by RMT. Supervision was done by LN, AZL, and SJH. Writing of the original draft, its review and editing was done by RMT, RWZ, HKN, LN, LD, ES, and SJH.

Conflicts of Interest

None declared.

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Abbreviations

CONSORT: Consolidated Standards of Reporting Trials
HIPAA: Health Insurance Portability and Accountability Act
LMM: linear mixed model
MVPA: moderate to vigorous physical activity
PROMIS: Patient-Reported Outcomes Measurement Information System
REDCap: Research Electronic Data Capture
TUG: Timed Up and Go

Edited by T de Azevedo Cardoso; submitted 30.06.23; peer-reviewed by M Lopez-Pentecost, S Pedersen; comments to author 09.11.23; revised version received 16.11.23; accepted 23.11.23; published 19.12.23.

Please cite as:
Tam RM, Zablocki RW, Liu C, Narayan HK, Natarajan L, LaCroix AZ, Dillon L, Sakoulas E, Hartman SJ
Feasibility of a Health Coach Intervention to Reduce Sitting Time and Improve Physical Functioning Among Breast Cancer Survivors: Pilot Intervention Study
JMIR Cancer 2023;9:e49934
URL: https://cancer.jmir.org/2023/1/e49934
doi:10.2196/49934
PMID:38113082

Original Paper

Using Text Messages and Fotonovelas to Increase Return of Home-Mailed Colorectal Cancer Screening Tests: Mixed Methods Evaluation

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Abstract

Background: Colorectal cancer (CRC) is currently the second leading cause of cancer-related deaths in the United States; however, it is mostly preventable with appropriate screening and is often treatable when detected at early stages. Many patients enrolled in an urban Federally Qualified Health Center (FQHC) clinic were found to be past due for CRC screening.

Objective: This study described a quality improvement (QI) project to improve CRC screening rates. This project used bidirectional texting with fotonovela comics and natural language understanding (NLU) to encourage patients to mail fecal immunochemical test (FIT) kits back to the FQHC.

Methods: The FQHC mailed FIT kits to 11,000 unscreened patients in July 2021. Consistent with the usual care, all patients received 2 text messages and a patient navigator call within the first month of mailing. As part of a QI project, 5241 patients who did not return their FIT kit within 3 months, aged 50-75 years, and spoke either English or Spanish were randomized to either usual care (no further intervention) or intervention (4-week texting campaign with a fotonovela comic and remailing kits if requested) groups. The fotonovela was developed to address known barriers to CRC screening. The texting campaign used NLU to respond to patients' texts. A mixed methods evaluation used data from SMS text messages and electronic medical records to understand the impact of the QI project on CRC screening rates. Open-ended text messages were analyzed for themes, and interviews were completed with a convenience sample of patients to understand barriers to screening and impact of the fotonovela.

Results: Of the 2597 participants, 1026 (39.5%) in the intervention group engaged with bidirectional texting. Participating in bidirectional texting was related to language preference (χ^2_2=11.0; P=.004) and age group (χ^2_2=19.0; P<.001). Of the 1026 participants who engaged bidirectionally, 318 (31%) clicked on the fotonovela. Furthermore, 54% (32/59) of the patients clicked on the fotonovela and responded that they loved it, and 36% (21/59) of patients responded that they liked it. The intervention group was more likely to get screened (487/2597, 18.75%) than those in usual care (308/2644, 11.65%; P<.001), and this pattern held, regardless of demographic subgroup (sex, age, screening history, preferred language, and payer type). Interview data (n=16) indicated that the text messages, navigator calls, and fotonovelas were well received and not unduly invasive. Interviewees noted several important barriers to CRC screening and offered suggestions for reducing barriers and increasing screening.

Conclusions: Texting using NLU and fotonovela is valuable in increasing CRC screening as observed by the FIT return rate for patients in the intervention group. There were patterns in which patients did not engage bidirectionally; future work should investigate how to ensure that populations are not left out of screening campaigns.

(JMIR Cancer 2023;9:e39645) doi:10.2196/39645

KEYWORDS

colorectal cancer screening; texting campaign; patient navigation; fotonovela; fecal immunochemical test kit; FIT kit; screening; cancer; colorectal cancer; CRC; bidirectional texting; health text messaging; health promotion; participation; fotonovela; comics

Introduction

Background

Colorectal cancer (CRC) is the second leading cause of cancer-related deaths in the United States, accounting for an estimated 53,200 deaths in 2020 [1]. CRC is mostly preventable with appropriate screening and can be treated successfully (5-year survival rate of approximately 90%) when detected at early stages and the cancer is localized [1]. One screening tool for CRC is the fecal immunochemical test (FIT) kits, which have shown promise in increasing screening rates [2]. A yearly FIT is a recommended screening method for asymptomatic adults aged ≥45 years who are at an average risk of CRC [3]. Findings from a Participatory Research to Advance Colon Cancer Prevention pilot study showed that patients with no prior history of CRC screening are more likely to respond to more intensive communication modalities [4] and that some unscreened populations may require multiple outreach and education modalities and touchpoints [5].

The Federally Qualified Health Center (FQHC) that conducted this project has a majority of patients who are Hispanic or Latin American. Hispanic and Latin American people are less likely to be diagnosed at an early stage than non-Latin White people and more likely to be diagnosed with advanced disease. Barriers to CRC screenings can include health beliefs or cultural linguistic barriers (eg, I feel fine, do not need it, it is embarrassing, and it is unpleasant) [6]. In the state of California, where the FQHC is located, Medi-Cal is the State's version of Medicaid, a benefit program in the United States that pays for medical services for patients with a low-income status. By serving patients with Medicaid, the FQHC supports increasing access to health care and addressing health equity.

A visual narrative approach using fotonovelas—comics that impart a particular message, or short stories—has been piloted with a wide range of users and is narrowing the health equity gap for Spanish speakers and underserved or marginalized populations [7,8]. However, it has typically been used by programs to increase knowledge about screenings and vaccinations [7-10], rather than to directly increase screening rates.

Texting campaigns have been successfully used for health promotion purposes [11] to motivate behavioral change. However, few studies have addressed the effectiveness of texting in supporting CRC screening and colonoscopy preparation [12]. Some studies have used texting campaigns to send one-way text message reminders and educational content to patients [13-15], but few studies have used bidirectional texting, in which the system is built for patients to reply to the initial text messages and receive automated responses from the texting platform [5,16-18].

Objectives

The goal of this quality improvement (QI) project was to evaluate the impact of tailored SMS text messaging and fotonovela visual stories on patients who remained unscreened in returning FIT kits after the FQHC's initial outreach attempts. This project sought to understand the success factors, challenges, barriers, and patient experiences to support program improvement.

Our bidirectional texting plus fotonovela intervention builds on established research as well as our own patient-centered research to understand and address patient barriers to behavioral change [4]. The aim of this paper was to report on texting campaign engagement and CRC screening in the context of patient characteristics in the usual care group compared with the intervention group. The QI project includes (1) bidirectional texting that tailors responses to better address individual barriers and (2) the fotonovela visual component that incorporates learnings about patient barriers to build a compelling story. Additional information about how the fotonovelas were created and how natural language understanding was used can be found in a separate study [19].

Methods

Patient Population

The QI project was conducted at an FQHC that served approximately 300,000 patients in a large urban environment in California. Per usual care, the FQHC mailed FIT screening kits (n=11,000) to unscreened patients in July 2021. All patients received a text message before the mailing, including a link to an instructional video on completing the FIT kit (ie, a primer text message), a follow-up text message reminding them to complete the FIT kit (ie, reminder text message), and a call from a patient navigator about receiving and completing their FIT within the first month of mailing if the patient had not yet sent it. 12 weeks after the kits were mailed, approximately 60% of the patients outreached did not return the FIT. The nonresponder group (5241 patients, aged 50-75 years, and who spoke either English or Spanish) was enrolled in the QI project to try a novel approach to increase screening rates. A total of 374 patients were excluded because they did not have a valid mobile phone number in the electronic health records.

Randomization of Nonresponders

Patients were randomized to either the usual care group (no further intervention beyond usual care) or the intervention group (4-week SMS text messaging campaign with a visual story [also called a comic or fotonovela] and the opportunity to request a replacement FIT kit if needed). The randomization was conducted by mPulse Mobile (a third-party texting service) using a Microsoft Excel (Microsoft Corporation) randomizer function and then verified using 2-tailed *t* tests of the mean values of the usual care group versus the intervention group. Patients were block randomized by binary sex (male or female), age group (50-60 and 61-75 years), and prior screening history (Table 1). Screening history was categorized as never screened (never completed a CRC screening), very inconsistent (previous CRC screening was >24 months ago), or inconsistent (CRC screening occurred 12-24 months prior). Language preference (Spanish or English) was used as an inclusion criterion (excluding members who preferred a different language).

Table 1. Demographics of usual care and intervention patients after randomization.

Randomization variables	Usual care (n=2644)	Intervention (n=2597)	*P* value
Female, n (%)	1446 (54.69)	1405 (54.1)	.67
Average age (years), mean (SD)	60 (6.2)	60.2 (6.2)	.30
Aged 50-60 years, n (%)	1494 (56.51)	1479 (56.95)	.74
Aged 61-75 years, n (%)	1150 (43.49)	1118 (43.05)	.74
CRC[a] screening history, n (%)			
Inconsistent	614 (23.22)	603 (23.2)	.99
Very inconsistent	800 (30.26)	787 (30.3)	.97
Not screened	1230 (46.52)	1207 (46.5)	.97
Other important variables			
Population whose preferred language is Spanish, n (%)	1670 (63.16)	1599 (61.6)	.23
Insurance payer, n (%)			
Commercial	227 (8.58)	211 (8.1)	.55
Medi-Cal	1748 (66.11)	1671 (64.3)	.18
Medicare	373 (14.11)	431 (16.6)	.01
Nonmanaged care	114 (4.31)	115 (4.4)	.84
Uninsured	182 (6.88)	169 (6.5)	.59
SDOH index[b], n (%)	2371 (17.8)	2330 (18.5)	.15
Very low impact	22 (0.93)	28 (1.2)	.36
Low impact	82 (3.46)	91 (3.9)	.42
Medium impact	224 (9.45)	240 (10.3)	.33
High impact	560 (23.62)	555 (23.8)	.87
Very high impact	1483 (62.55)	1416 (60.8)	.21
Missing SDOH, n (%)	273 (10.32)	267 (10.28)	.96

[a] CRC: Colorectal cancer.

[b] A Social Determinants of Health (SDOH) index score (0-100) for each patient was generated, where 0 represents a low-needs census tract and 100 represents a high-needs area. Briefly, 5 SDOH bands were used: very low impact (0-20), low impact (20-40), medium impact (40-60), high impact (60-80), and very high impact (80-100), as well as a group of unknown SDOH impact if addresses were not recognized by the system.

QI Project to Increase Colon Cancer Screening

The 4-week series of text messages was designed and implemented using mPulse Mobile to remind and encourage patients to return their FIT kit. All text messages were in the patient's preferred language (English or Spanish) at a sixth-grade reading level or lower. If they responded, natural language understanding was used to trigger appropriate automated replies (Multimedia Appendix 1). The series of messages entailed the following:

1. Week 1 was tailored to prior screening history and promoted CRC screening literacy. For those who had never been screened, the message included a comment about "Do it for your peace of mind and your health!" For those that were inconsistent or very inconsistent, the message was modified to say, "We know you've completed colon cancer screening before- but you are due now. We'll check back in about a week."
2. Week 2 addressed barriers to screening by asking: "If you haven't done it yet, please tell us if any of these reasons apply" and then followed up with automated conversational responses specific to the barriers the patient reported. The provided reasons included: "1. I'm not sure why I need it"; "2. I feel fine, and I don't have any pain or symptoms"; "3. I'm too busy right now"; "4. I'm scared about the results"; and "5. It's embarrassing to do it and then mail it back." Patients could reply using numeric responses (1-5) or use their own words to share why they had not returned the FIT kit.

3. Week 3 asked patients to click on a link to view a “comic about FIT kits and why you should get it done soon.” Clicking on the link loaded a fotonovela in the mobile browser tailored to their sex and language preferences. Characters within the fotonovela talked about the FIT kit, addressed myths and misconceptions, highlighted the need for self-care and the dangers of procrastination, and emphasized the value of prevention for individuals and their families (Figure 1).
4. Week 4 reminded patients to complete and return the FIT kit, and the patients who replied that they had mailed it in were told what to expect next if their result was normal versus abnormal (ie, blood in stool). Those who had not yet sent it were reminded of the final time: “Do try to get this done as soon as possible. It’s quick and easy, and you will be protecting yourself against colon cancer.”

Figure 1. Fotonovela example “Do It for Me” aimed at English-speaking men and English-speaking people of unknown sex.

Many of the automated text messages contained questions with close-ended responses that the patients could text back (Multimedia Appendix 1). In addition, patients could text back in their own words, and those responses were handled using rules and basic natural language processing and monitored using mPulse Mobile. For example, if a patient texted “what is a FIT kit?” or “why do I need a FIT kit?” they received an automated response saying “A FIT is a quick and easy test to find blood in your stool (poop) that you might not be able to see. If you have hidden blood, we ask you to get a colonoscopy. This looks for any growth that we can remove before they turn into colon cancer.” The message also provided the FQHC’s phone number in case they had further questions or required support. Similarly, in instances where patients were familiar with the test but did not believe it was necessary and replied, “I feel fine” or “I don’t need the test,” the intervention built knowledge and health literacy by texting back, “It turns out most people with colon cancer feel healthy and have no symptoms. And most people with colon cancer also have no family history of the disease. This is a quick and easy way to find out if there are any problems.” Again, they were reminded that they could call the FQHC and were provided with the phone number to feel free to ask any questions about why they needed to complete the test.

When patients requested a new FIT kit or replied that they did not receive the FIT kit, an automated text message asked them to request one at their next visit, and mPulse Mobile provided the patients’ information back to the FQHC so they could mail a new FIT kit to them (n=200). If a patient opted out by replying “STOP” or “WRONG” at any point, they received no further text messages. A patient could engage and later decide to opt out. If a patient texted “Help,” then the automated response included the phone number to the FQHC’s patient service center.

In combination with the automated responses via text messages, fotonovelas were created to address barriers found in the literature such as procrastination, lack of self-care, lack of time, embarrassment about the process, and fear of results [20-25]. Fotonovelas were written in both Spanish and English, and each version contained a cast of either men or women for a total of 4 different fotonovelas. They contained a story about someone encouraging a friend to complete their FIT, explaining why it is important to do so, and normalizing the process. The fotonovela comes with a call to action for patients to use the kit that they received in the mail (Figure 1).

Quantitative Data Analysis and Data Sources

There were 2 data sources: one from the FQHC based on electronic medical record data and one from mPulse Mobile. The data from the 2 sources were linked using a unique identifier common in both data sets. The data were transferred via secure file transfer options. All quantitative data from texting outreach and electronic medical records were analyzed using R (R Foundation for Statistical Computing). The *t* tests of the mean values of screening completion rates were used to test the difference between the intervention and usual care groups, as well as to verify the distribution of demographic characteristics. Differences in texting engagement and clicking on the fotonovela by population characteristics were tested using chi-square statistics for categorical variables. Logistic regressions were run for clicking the fotonovela (no=0, yes=1) and for being screened (no=0, yes=1) to consider covariates that could be related to each of these 2 key outcomes. Differences in FIT results (normal, abnormal, erroneous [ie, FIT needs to be repeated, or no FIT returned]) in the 2 groups (usual care vs intervention) were tested using chi-square statistics for categorical variables.

CRC Screening Completion

CRC screening completion and results were determined by running a report querying the electronic medical records 2 months after the intervention to capture completion based on CRC screening performed by the patient (eg, colonoscopy, FIT). If a patient’s record was updated to indicate that a colonoscopy or another screening method had been performed within the appropriate time frame, they were considered screened. Blood in the stool sample indicated an abnormal result for the FIT kit.

Covariates

Demographic variables of interest (sex, age, prior screening history, and language preference) were collected from the electronic medical records. Additional variables of interest included insurance payer (commercial, Medi-Cal, Medicare, nonmanaged care, and uninsured), and the Social Determinants of Health (SDOH) index.

The SDOH index was derived from 10 Census-datapoint factors such as unemployment and percent of the population who completed high school (range 0-100, where 0 represents low-needs census tract and 100 represents high-needs area). The index was developed by mPulse Mobile [26] and was used to create 5 bands of need: very low impact, low impact, medium impact, high impact, and very high impact. It provides a granular view of the population at the United States census tract level and can be used to highlight neighborhoods where there might be a higher incidence of unmet social needs and an increased likelihood of health inequities. The SDOH index was included to monitor whether disparities were being mitigated or worsened.

Engagement in Bidirectional Texting and Fotonovela

mPulse Mobile tracked 2 engagement process measures: whether a patient replied to a text message and whether a patient clicked on the fotonovela. Patients who responded to at least one text message (ie, participated in a bidirectional text exchange) were considered “engaged.” If they responded, but at some point opted out, they were considered “engaged but opted out.” Patients who did not respond to any text message were considered “not engaged.” It was not possible to track whether the patient viewed the fotonovela, only whether they clicked the text message link to the fotonovela (yes or no).

Barriers to Screening and Impact of Fotonovela

The data were collected both through the texting program as well as by interviews. Through the texting program, patients were asked whether they received the FIT kit in the mail (yes or no). Patients received a text message asking what they thought about the fotonovela and were given the options of “didn’t like it,” “it was okay,” “liked it,” and “loved it.” They were also asked whether the fotonovela would affect their behavior regarding screening in the coming week. Patients’ free-text responses via text message were reviewed to determine whether they completed the FIT, the barriers they experienced in completing the FIT, enjoyment of the fotonovela, and whether the fotonovela would affect their behavior. When possible, open-ended responses were recoded to fit into one of the options provided. Responses that did not fit into the options provided were reviewed for themes, which were analyzed alongside the interview themes.

In addition, phone interviews were conducted to gather feedback on the QI project. A convenience sample of 144 patients was selected to be outreached. The numbers were split evenly among English speakers and Spanish speakers, and there were 4 groups within each language group: patients receiving usual care who completed the FIT, patients receiving usual care who did not complete the FIT, patients receiving a bidirectional automated texting campaign who did not complete the FIT, and patients receiving a bidirectional automated texting campaign who completed the FIT. Potential interviewees were sent text messages up to 3 times, with an invitation to participate in a phone interview. Of the 144 patients, 119 (82.6%) did not respond to the text invitations and 2 (1.4%) declined to participate. A total of 16 patients were interviewed, and an additional 6 patients were scheduled but did not complete the interview. Interview questions were regarding barriers, facilitators, and motivators for completing the FIT kit. Participants in the intervention group were also asked about their perceptions of the fotonovela and what role it played in deciding whether to complete the FIT. Data regarding user experience were themed using emergent coding methods [27].

Ethics Approval

The QI project was reviewed and determined to not involve research and therefore was exempted by the Kaiser Permanente Washington Human Subjects Review Office. Patients who agreed to be interviewed as part of the QI project received a US $25 Amazon, Starbucks, or Target gift card incentive (patients chose which gift card they would like).

Results

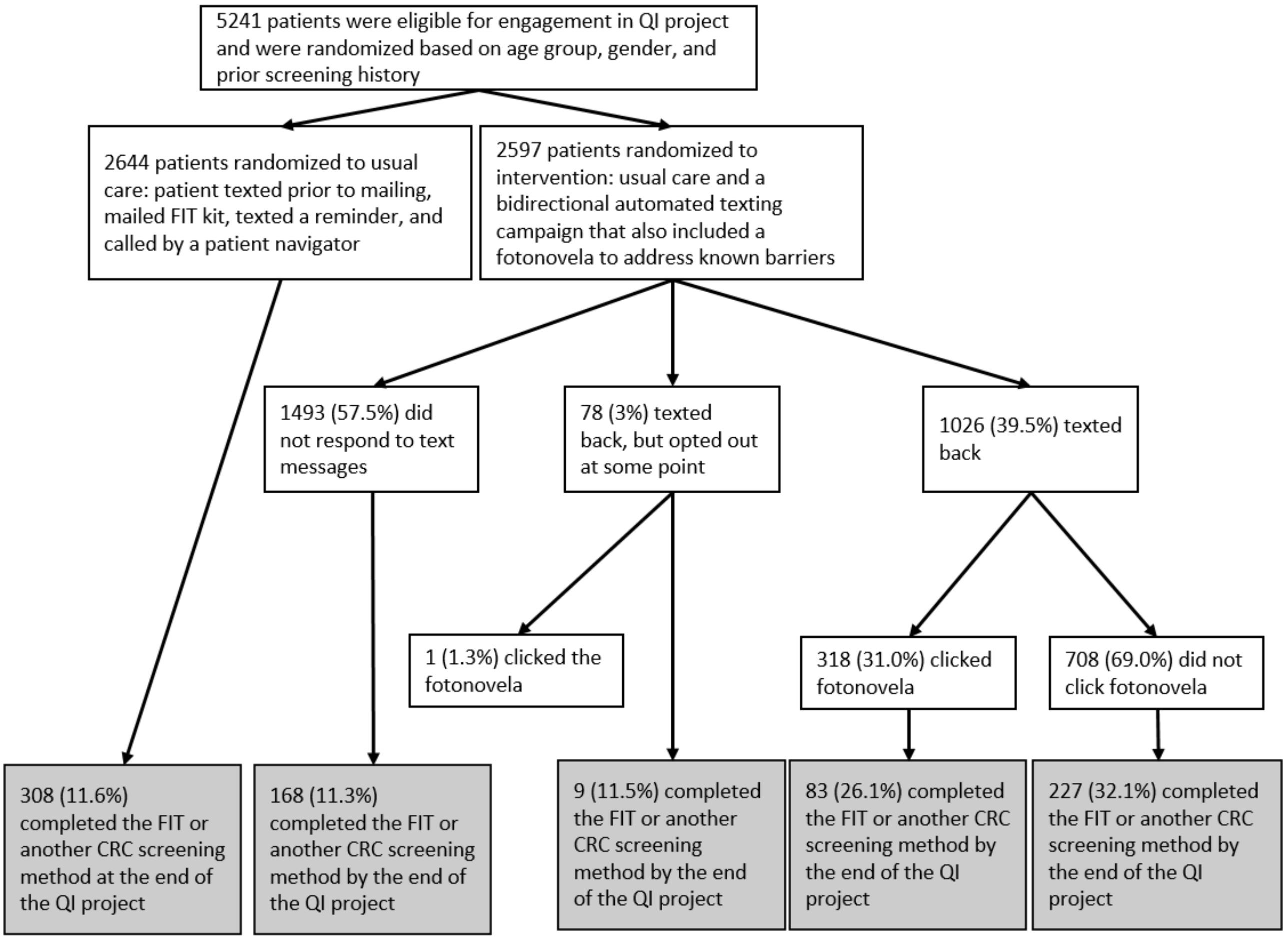
Randomization

The *t* tests found no statistical difference between the usual care and intervention groups in the following variables: binary sex, age group, and prior CRC screening history (Table 1). In addition, the intervention and usual care groups had similar distributions of payer types, Spanish language preference, and SDOH index distribution even though they were not randomization variables. The percent of patients receiving Medicare differed between the usual care (373/2644, 14.11%) and intervention (431/2597, 16.6%; *P*=.01) groups. Across both the intervention and usual care groups, >40% had never been screened for CRC. Approximately two-thirds of the patients in each group had Medi-Cal insurance (1748/2644, 66.11% in usual care and 1671/2597, 64.34% in intervention).

Engagement Through Bidirectional Texting

Approximately 39.51% (1026/2597) of the patients in the intervention group engaged in bidirectional texting. More than half (1493/2597, 57.49%) of the patients in the intervention group did not engage in text messages and 3% (78/2597) texted back “STOP” or “WRONG” and opted out (1 patient opted out after engaging; Figure 2).

Figure 2. Engagement of patients in the intervention. CRC: colorectal cancer; FIT: fecal immunochemical test; QI: quality improvement.



Engagement was statistically related to language preference (n=2597; χ^2_2=11.0; *P*=.004); age group (n=2597; χ^2_2=19.0; *P*<.001); prior screening history (n=2597; χ^2_4=14.8; *P*=.005); insurance type (a greater proportion of those who engaged had commercial insurance than those who did not engage or engage but opted out; n=2597; χ^2_8=27.4; *P*<.001); and SDOH index band, where those who engaged had a higher SDOH index score (n=2330; χ^2_8=20.4; *P*=.009; Table 2).

Table 2. Demographics of patients by engagement category.

Variable	Did not engage (n=1493)	Engaged, but opted out (n=78)	Engaged via text message (n=1026)	Chi-square tests of association (*df*; n=2597)	*P* value
Sex (binary), n (%)	783 (52.44)	42 (53.85)	580 (56.53)	4.1 (2)	.13
Age (years), mean (SD)	60.7 (6.4)	60.7 (6.3)	59.3 (5.8)	19 (2)	<.001
CRC[a] screening history, n (%)				14.8 (4)	.005
Inconsistent	316 (21.16)	12 (15.38)	275 (26.8)		
Very inconsistent	466 (31.21)	22 (28.21)	299 (29.14)		
Never screened	711 (47.62)	44 (56.41)	452 (44.05)		
Spanish as preferred language, n (%)	927 (62.09)	34 (43.59)	638 (62.18)	11.0 (4)	.004
Insurance payer, n (%)				27.4 (8)	<.001
Commercial	95 (6.36)	5 (6.41)	111 (10.82)		
Medi-Cal	969 (64.9)	44 (56.41)	658 (64.13)		
Medicare	265 (17.75)	15 (19.23)	151 (14.72)		
Nonmanaged care	70 (4.69)	3 (3.85)	42 (4.09)		
Uninsured	94 (6.3)	11 (14.10)	64 (6.24)		
SDOH index band[b] (n=2330), n (%)				20.4 (8)	<.009
Average SDOH index	1343 (80.3)	70 (73.9)	917 (78.5)		
Very low impact	12 (0.89)	2 (2.86)	14 (1.5)		
Low impact	50 (3.72)	6 (8.57)	35 (3.8)		
Medium impact	121 (9.01)	13 (18.57)	106 (11.6)		
High impact	313 (23.31)	13 (18.57)	229 (25)		
Very high impact	847 (63.07)	36 (51.43)	533 (58.1)		
Missing SDOH, n (%)	150 (10.05)	8 (10.26)	109 (10.6)	20.4 (8)	.009

[a] CRC: colorectal cancer.

[b] An Social Determinants of Health (SDOH) index score (0-100) for each *patient* was generated, where 0 represents a low-needs census tract and 100 represents a high-needs area. Briefly, 5 SDOH bands were used: very low impact (0-20), low impact (20-40), medium impact (40-60), high impact (60-80), and very high impact (80-100), as well as a group of unknown SDOH impacts if addresses were not recognized by the system.

Engagement Through Clicking Fotonovela Link

Of those who engaged in the bidirectional texting, just less than one-third (319/1026, 31.09%) clicked on the fotonovela link (Figure 2). All but one of the 319 patients who clicked on the fotonovela participated in bidirectional texting without opting out.

For those who engaged in bidirectional texting, there was no association between clicking on the fotonovela and the following variables: binary sex, preferred language, prior CRC screening history, or the SDOH index band (Table 3). Those aged 61-75 years were less likely to click on the fotonovela than those aged 50-60 years (odds ratio=0.67; *P*=.02). Those who did not reply to a text message asking whether they received the FIT kit in the mail were more likely to click on the fotonovela than those who texted “yes” that they did receive the FIT kit in the mail (odds ratio=2.08; *P*<.001). Those with Medicare were more likely to click on the fotonovela than those with commercial insurance (odds ratio=1.91; *P*=.04). Those who engaged but opted out were much less likely to click on the fotonovela than those who engaged (odds ratio=0.02; *P*<.001). These results were consistent with the chi-square analyses for the categorical variables (data not shown).

Table 3. Logistic regression predicting whether patients click on the fotonovela in the text message among the patients who engaged via bidirectional texting.

Characteristics	Estimate (SE)	*z* value	*P*>|z|	Odds ratio (95% CI)
Intercept (reference)	−1.31061 (0.3671)	−3.57	<.001	0.27 (0.13-0.55)
Male (reference: female)	0.19289 (0.14868)	1.297	.19	1.21 (0.91-1.62)
61-75 years age band (reference: 50-60)	−0.40128 (0.17102)	−2.346	.02	0.67 (0.48-0.93)
Screening history (reference: inconsistent)				
Never screened	−0.01094 (0.19379)	−0.056	.95	0.99 (0.68-1.45)
Very inconsistent	0.13551 (0.19741)	0.686	.49	1.15 (0.78-1.69)
Spanish as preferred language (reference: English)	−0.29278 (0.15853)	−1.847	.06	0.75 (0.55-1.02)
Self-reported receiving FIT[a] kit in mail (reference: no)				
Unknown	0.73073 (0.20698)	3.531	<.001	2.08 (1.40-3.15)
Yes	−0.38366 (0.27363)	−1.402	.16	0.68 (0.40-1.16)
Payer type (reference: commercial)				
Medi-Cal	0.32849 (0.26085)	1.259	.21	1.39 (0.84-2.35)
Medicare	0.66074 (0.32341)	2.043	.04	1.94 (1.03-3.68)
Nonmanaged care	0.03194 (0.48414)	0.066	.95	1.03 (0.39-2.62)
Uninsured	0.45208 (0.40198)	1.125	.26	1.57 (0.71-3.45)
SDOH[b] band (reference: high impact, 60-80)				
Very low impact (0-20)	0.075 (0.57664)	0.13	.90	1.08 (0.33-3.32)
Low impact (20-40)	−0.47331 (0.43174)	−1.096	.27	0.62 (0.26-1.41)
Medium impact (40-60)	0.06829 (0.2553)	0.268	.79	1.07 (0.65-1.76)
Very high impact (80-100)	−0.02755 (0.17733)	−0.155	.88	0.97 (0.69-1.38)
Engaged, but opted out (reference: engaged via bidirectional texting)	−3.77899 (1.01261)	−3.732	<.001	0.02 (0.00-0.11)

[a] FIT: fecal immunochemical test.

[b] SDOH: Social Determinants of Health.

Patient-Reported Impact of Fotonovela

During the fourth week of the SMS text messaging campaign, 20.7% (66/319) of the patients who participated in bidirectional texting and clicked on the fotonovela responded to a text message query regarding their enjoyment. Of the 59 people who gave a specific rating, 32 (54%) said they loved it, 21 (36%) said they liked it, 6 (10%) said that it was okay, and none said that they did not like it. There were 7 other comments to the text asking the patient to rate the fotonovela, 3 of which were requesting another FIT kit and 1 that was someone saying they were getting a follow-up colonoscopy. Furthermore, 44% (29/66) said that they were more likely to complete the FIT kit after seeing the fotonovela (37 people said that it would not affect their behavior).

Of the 10 interviewees who received the fotonovela, 6 (60%) recalled receiving it and 4 (40%) of them indicated it was helpful (Table 4).

Table 4. Barriers to, success factors of, and suggestions for increasing screening from 16 patient interviews.

Category and theme (n=16)	Illustrative quotes from interviews	Patient suggestions for improvement
Barrier: I kept forgetting to do it or did not have it in the bathroom (n=9)	“I kept forgetting until I was already in the bathroom.”	Add a note to place in the bathroom upon receipt.
Barrier: I was busy and did not prioritize it (n=7)	“It takes time to do, and I don’t want to take the extra 10 or 15 minutes to figure out what to do and how to mail or whatever.”	Add an incentive if returned within X number of days, such as a US $5 gift card or entry into a raffle
Barrier: I lost it or did not remember receiving it (n=5)	“My husband picks up the mail, and I don’t know where he put it, but I requested another one when they ([navigator] called, and did it then.”	Include a text with a link to request another kit.
Barrier: It can be difficult or stressful, especially for first time users (n=6)	“The first time I had no idea what to do. They used generic words like ‘open the bag’ what bag? It’s many pieces and lot to read.”	Offer a walk-through at clinic visits; text an offer to request a navigator call if needed, particularly for those who have never completed one.
Barrier: I felt embarrassed to do it (n=2)	“Smearing poop on paper is just weird.”	Acknowledge awkwardness; make it clear that you do not touch fecal material.
Barrier: Did not realize they needed to do it every year (n=2)	“I did it last year and it was negative, so I thought I was good to go, I didn’t know it was an every year thing.”	Include the word “annual” to make the desired frequency clearer.
Success factor: Having the kit mailed to do at one’s convenience in the home (n=15)	“I really like getting mailed kits; it’s much better than doing it at the clinic. I like having the time to sit and read and do it on my own with privacy for something like this.”	Mail kits every year the same month—make it a routine part of care at this clinic.
Success factor: Phone call from patient navigator (n=10)	“Keep having someone call us because that always makes me feel guilty and then I’ll do it. A text I can ignore more easily.”	Add an additional call, especially if another kit is mailed out.
Success factor: Clear instructions with pictures (n=9)	“I didn’t quite get what to do, and the instructions were long and overwhelming. Could you do them in Spanish?”	Consider a video or more pictures, less generic language; keep in mind those who do not read English well.
Success factor: Text Reminders (n=6 out of 10 in intervention group)	“It’s nice to get the text reminder because then the message is there to see when you have time, even if you are busy when it comes in.”	Keep sending text reminders as-is; add texts offering to mail another KIT and texts offering phone support.
Success factor: Fotonovela (n=4 out of 6 who received it)	“The fotonovela made me reflect that I shouldn’t wait, I should not be even more late in doing it!”	Text 1 panel to pique interest and make people more likely to click on the link
Success factor: Family members reminder (n=3)	“My spouse kept bugging me to do it. I know it’s important but it’s just not something you think about doing, I kept putting it off.”	Continue to highlight family in materials—this is something that patients value.

CRC Screening Completion

If patients returned the FIT kit or underwent colonoscopy, they were considered successfully screened. Patients in the intervention group were significantly more likely to be screened (18.8% screened) compared with those in the usual care group (11.6%; 95% CI for the difference between means was 5.2%-9.0%; *P*<.001; Table 5). This pattern was observed in all demographic subgroups (Table 5). For those who returned the FIT kit, the usual care group had 5.1% (23/448) abnormal results, whereas the intervention group had 2.9% (18/617) abnormal results. FIT results were statistically related to group (N=5241; χ^2_3=43.3; *P*<.001).

Table 5. Screening rates at end of the quality improvement (QI) project for usual care and intervention groups by subgroup.

Percent screened at end of QI project by subgroup	Usual care (n=2644), n (%)	Intervention (n=2597), n (%)	Difference of means (95% CI)	*P* value
Overall	308 (11.6)	487 (18.8)	5.2 to 9.0	<.001
Sex				
Male (n=2390)	1198 (10.7)	1192 (16)	2.6 to 8.1	<.001
Female (n=2851)	1446 (12.4)	1405 (21.1)	5.9 to 11.3	<.001
Age groups (years)				
50-60 (n=2973)	1494 (9.3)	1479 (17.7)	6 to 10.9	<.001
61-75 (n=2268)	1150 (14.7)	1118 (20.1)	2.3 to 8.5	<.001
CRC[a] screening history				
Inconsistent (n=1217)	614 (20.8)	603 (32.3)	6.6 to 16.4	<.001
Very inconsistent (n=1587)	800 (9.9)	787 (15.4)	2.2 to 8.8	<.001
Never screened (n=2437)	1230 (8.2)	1207 (14.2)	3.5 to 8.5	<.001
Preferred language				
English (n=1972)	974 (7.4)	998 (13.1)	3.1 to 8.4	<.001
Spanish (n=3269)	1670 (14.1)	1599 (22.3)	5.5 to 10.8	<.001
Payer type				
Commercial (n=438)	227 (15.9)	211 (27.5)	3.9 to 19.3	.003
Medi-Cal (n=3419)	1748 (10.2)	1671 (16.5)	4 to 8.5	<.001
Medicare (n=804)	373 (19.6)	431 (26)	0.6 to 12.2	.03
Nonmanaged care (n=229)	114 (9.6)	115 (15.7)	−2.7 to 14.7	.17
Uninsured (n=351)	182 (5.5)	169 (14.2)	2.4 to 15	.007
SDOH[b] index				
Very low impact (n=590)	295 (9.1)	295 (7.1)	−18.1 to 14.2	.81
Low impact (n=713)	355 (7.3)	358 (11)	−5 to 12.3	.40
Medium impact (n=1004)	497 (11.2)	507 (17.9)	0.4 to 13.2	.04
High impact (n=1655)	833 (10.4)	822 (18.9)	4.4 to 12.7	<.001
Very high impact (n=3439)	1756 (12.4)	1683 (19.6)	4.6 to 9.9	<.001

[a] CRC: colorectal cancer.

[b] SDOH: Social Determinants of Health.

There were large differences in screening rates by demographic variables of interest that were consistent for both intervention and usual care groups (Table 5; logistic regression for the intervention group is provided in Table 6). Men were less likely than women to be screened at the end of the QI project (odds ratio=0.73; *P*=.008). Those with no screening history were less likely to be screened than those with an inconsistent screening history (odds ratio=0.39; *P*<.001). Those with a very inconsistent screening history were also less likely to be screened than those with an inconsistent screening history (odds ratio=0.43; *P*<.001). Those who preferred to speak Spanish were more likely to be screened than those who preferred to speak English (odds ratio=1.75; *P*<.001). Those who self-reported having received the FIT kit in the mail were more likely to be screened than those who self-reported not receiving the FIT kit in the mail (odds ratio=2.85; *P*<.001). Those who engaged (ie, texted bidirectionally) were more likely to be screened than those who did not (odds ratio=3.07; *P*<.001).

Table 6. Logistic regression predicting whether patients will be screened at the end of the QI project among the intervention group (n=2597).

Characteristics	Estimate (SE)	*z* value	*P*>|*z*|	Odds ratio (95% CI)
Intercept (reference)	−1.88102 (0.3954)	−4.757	<.001	0.15 (0.07-0.33)
Male (reference: female)	−0.31112 (0.11705)	−2.658	.008	0.73 (0.58-0.92)
61-75 years age band (reference: 50-60)	−0.04095 (0.13063)	−0.313	.75	0.96 (0.74-1.24)
Screening history (reference: inconsistent)				
Never screened	−0.94208 (0.14654)	−6.429	<.001	0.39 (0.29-0.52)
Very inconsistent	−0.84281 (0.1467)	−5.745	<.001	0.43 (0.32-0.57)
Spanish as preferred language (reference: English)	0.55926 (0.13444)	4.16	<.001	1.75 (1.35-2.28)
Self-reported receiving FIT[a] kit in mail (reference: no)				
Unknown	0.20309 (0.21754)	0.934	.35	1.23 (0.81-1.89)
Yes	1.0462 (0.24531)	4.265	<.001	2.85 (1.77-4.64)
Engagement (reference: did not engage)				
Engaged	1.12186 (0.1485)	7.554	<.001	3.07 (2.29-4.11)
Engaged, but opted out	−0.0411 (0.41879)	−0.098	.92	0.96 (0.39-2.05)
“No” to “clicked fotonovela” (reference: “yes”)	0.1012 (0.17063)	0.593	.55	1.11 (0.79-1.55)
Payer type (reference: commercial)				
Medi-Cal	−0.26009 (0.19647)	−1.324	.19	0.77 (0.53-1.14)
Medicare	0.31875 (0.23302)	1.368	.17	1.38 (0.87-2.18)
Nonmanaged care	0.05858 (0.35283)	0.166	.87	1.06 (0.52-2.09)
Uninsured	−0.07765 (0.32092)	−0.242	.81	0.93 (0.49-1.72)
SDOH[b] band (reference: high impact, 60-80)				
Very low impact (0-20)	−0.6958 (0.77029)	−0.903	.37	0.50 (0.08-1.83)
Low impact (20-40)	−0.29288 (0.37916)	−0.772	.44	0.75 (0.08-1.83)
Medium impact (40-60)	0.08399 (0.21889)	0.384	.70	1.09 (0.70-1.66)
Very high impact (80-100)	0.0275 (0.13852)	0.199	.84	1.03 (0.79-1.35)

[a] FIT: fecal immunochemical test.

[b] SDOH: Social Determinants of Health.

Patients in the intervention group who did not engage (95% CI for difference between means was –2.4% to 1.6%; *P*=.70) or opted out had very similar rates of screening compared with the usual care group (95% CI for difference between means was −7.5% to 7.2%; *P*=.97; Figure 2). Patients in the intervention group who bidirectionally engaged had greater screening rates than those who engaged but opted out (95% CI for difference between means was 10.9%-26.4%; *P*<.001) or than those who did not (95% CI for difference between means was 15.7%-22.2%; *P*<.001). Those who clicked on the fotonovela had a statistically greater percentage screened at the end of the QI project compared with those who did not click the fotonovela (95% CI for the difference between means was 3.2%-13.4%; *P*=.001). When only looking at patients who engaged in bidirectional texting (n=1026), those who did not click on the fotonovela had slightly higher screening rates than those who did click on the fotonovela (95% CI for difference of means was 0%-11.9%; *P*=.05).

Barriers, Success Factors, and Suggestions for Increasing Screening Rates

In program week 2, the text messages queried the patients whether they had completed the FIT kit. If they had not completed the FIT kit or did not respond, they were asked about the barriers they were facing to complete the FIT kit. A total of 303 people responded to this question, 75 (24.7%) of whom replied “none” and 183 (60.4%) did not select a barrier from the list. Of those who chose a specific barrier from the list (n=45), the majority (19/45, 42%) said, “I feel fine, and I don’t have any symptoms.” The next highest selections were “I’m not sure why I need it” (n=10) and “I’m too busy right now” (n=10). Five people said that it was “embarrassing to do it and then mail it back,” and 1 person said, “I’m scared of the results.”

For those interviewed, the greatest motivator for returning the FIT kit was the patient navigator phone call, with the text message reminders and the fotonovela playing a smaller role (Table 4). The most common barrier reported by the 16 interviewees was simply forgetting to complete the FIT kit (9/16, 56%), followed by not wanting to take the time (7/16, 44%), followed by losing it or not remembering having received one (5/16, 31%).

Of the 16 interviewees, 15 (94%) cited mailing FIT kits to one’s home as a strong preference for going into the clinic, and they suggested that they continue doing this annually, with a more explicit offer via text message to request another kit to be mailed out if it was never received or lost. The simple instructions with pictures were specifically cited by 56% (9/16) of respondents as helpful. The 4 people who had trouble with instructions were all people who preferred the Spanish language, and 3 of them suggested more pictures and a video tutorial available via a weblink. Getting reminders via both phone and text message were both noted as helpful and unintrusive; none of the 16 people interviewed said they wanted to stop getting text messages or calls, and that having the option to text “stop” was sufficient. Patients had several suggestions for increasing motivation, including better advertising with a return date, adding an incentive in the form of a small gift card, or entry into a raffle. Finally, interviewees suggested offering more support, especially for first-time FIT kit users, such as the offer to walk through it at an upcoming clinic visit (Table 4).

Discussion

Screening Completion Among Usual Risk FQHC Patients

The QI project sought to use tailored texting with fotonovela comics to boost return rates for the FIT screening kit mailing campaign. Overall, the intervention group had a greater proportion of patients successfully screened at the end of the QI project compared with the usual care group, and this pattern was maintained for all demographic subgroups. This difference was driven by the significant increase in screening for the patients in the intervention group who engaged in texting, regardless of whether they clicked on the fotonovela. Women, Spanish speakers, and those with inconsistent screening histories (compared with very inconsistent or never screened histories) were more likely to be screened at the end of the QI project. The campaign was acceptable to the patients, although there were still many suggestions for further improvement. The effect seen here (7.2%) is stronger than what is known about the impact of text messages on CRC screening (0.6%-3.3% for CRC) [28] and similar to the effect of sharing a fotonovela booklet (7.1%) [29].

Engaging FQHC Patients in CRC Screening

These results amplify the need to ensure that patients aged 61-75 years and those without insurance are not being left out of health promotion campaigns and a general need to continue to tailor materials and campaigns to maximize engagement and impact. There were clear differences in engagement by demographics; age and insurance status were related to both whether the patient would engage via bidirectional texting and whether they would click the fotonovela link. In addition, language, screening history, and SDOH needs were related to whether the patient would engage via bidirectional texting (although not in whether they clicked the link to the fotonovela).

In the study population, having half of the patients living in high or very high impact SDOH band areas drove the decisions for developing and tailoring the behavioral motivational messaging and the fotonovelas. Findings from previous research conducted with patients from this FQHC [5] provided information on known barriers to health behaviors that the team applied to frame and present information in culturally relevant formats. In the bidirectional texting program, 11.67% (303/2597) of the patients responded with a barrier to completing the FIT. These patient-reported barriers generally aligned with those noted in the literature: not knowing testing was necessary and lack of information [4,24,30,31], as anticipated in the automated responses to patient-reported barriers. Of note, a few test-specific barriers were noted, suggesting that materials accompanying the FIT addressed concerns about handling stool and other considerations that arise during the completion of a fecal test. Future work should investigate the timing of when it is most impactful to have the bidirectional texting program relative to when the FIT kits were mailed out.

Our results also showed the highest engagement via bidirectional texting for patients in the highest (greatest need) SDOH bands, indicating that these populations were open to communication. However, of the patients who did not engage in bidirectional texts, almost two-thirds were in the very high impact band. Of those who engaged but opted out, just more than half were in the very high impact band. It remains an important factor in future outreach strategies to tailor engaging and impactful ways of providing health services, especially when multiple social needs are unmet.

Implications for Future QI

Although bidirectional texting appears beneficial, the platform and expertise it requires come at an additional cost for services that not all FQHCs may be able to afford; therefore, it would be useful to conduct a future campaign with the unidirectional texting that is more likely to be available to FQHCs and other clinics looking to boost CRC screening rates. A cost-benefit analysis of usual care compared with bidirectional texting with fotonovelas would also be useful to help determine which method to use in the long term. Similarly, although fotonovelas did not increase screening above and beyond bidirectional texting, it is possible that they would produce a boost beyond unidirectional texting, and this should be explored. Once created, fotonovelas do not incur substantial additional cost to use one-way texting blasts. Future exploration is needed to identify ways to encourage people to click on the fotonovela link.

The American Cancer Society recently updated the guidelines to reduce the recommended age to begin CRC screening from 50 to 45 years [32]. Health systems will need to explore ways to effectively reach out to younger patients who have not historically been screened. This may be more of a challenge, as previous research has found that patients are more likely to complete the FIT kit via mail if they have done once before [4], and younger patients might not be aware of the guidelines or feel that they are too young to worry about CRC.

With the COVID-19 pandemic resulting in decreased in-person clinical visits and pushing traditional interactions to telehealth, the FQHC is exploring how to best use text message and other phone-based promotions, communications, and programs to reach patients. Fotonovelas have historically been a print resource [33] but are less accessible to patients if they are only available in the clinics. The FQHC is exploring incorporating materials from this campaign to support patients in scheduling and preparing for colonoscopy, and other ways to use texting to reach patients for a broader range of clinical and social health needs over a longer term. It is also critical to continue to identify equity-centered methods that are useful and accessible for Hispanic and Latin American patients and other marginalized communities [34]. Newer technologies have the potential to significantly reduce the structural barriers to care.

Limitations

The QI project tested whether the tailored text messages with fotonovela led to higher FIT kit return rates compared with usual care. However, when monitoring fotonovela link clicks, we found that those who clicked on the link did not have greater screening rates than those who merely engaged with texts without clicking. This finding could imply that the texting rather than the fotonovela was driving the increased screening in the intervention versus usual care groups or that the people likely to complete the FIT did so before receiving the fotonovela in week 3 of the intervention. In addition, it is possible that patients, despite not engaging, read the text messages, and those texts served as reminders for them to complete screening; the QI project could not attribute those screenings to the program components.

The interviews were a small, nonrandom convenience sample of clinical patients, with interviewees being, by definition, more engaged. Therefore, their feedback was viewed by the FQHC as potential ideas to explore, rather than definitive success factors and critical improvements. Similarly, the texted survey responses were a small nonrepresentative sample of responses, and although the data generally supported the findings from other methods in terms of barriers and enjoyment level of the fotonovela, it should not be considered definitive in nature, as selection bias was likely at play.

Owing to lags in data use agreement paperwork, the interviews were conducted over 2 months after the program ended and roughly 6 months after the FIT kits were originally mailed. This time lag may have affected the patients’ willingness to engage in interviews and their recall of the text messages and fotonovela.

The FQHC previously reported that 6.9% of the patients completing FIT had an abnormal result (ie, blood in the stool) [5]. In the current QI project, the usual care group FIT abnormal result rate (5.1%) compared with that of the intervention group (2.9%) suggests the importance of providing multimodal screening. This finding suggests that the usual care group had a higher baseline rate of abnormal results.

Conclusions

Texting with automated conversational responses to those with a prior screening history appears to be valuable in increasing CRC screening. Patients were open to multiple contacts about their screening; a significant number of patients from all demographics engaged and returned FIT kits; and the vast majority of people who engaged with the campaign had positive or neutral responses, with very few indicating a negative impact. Intervention participants had moderately greater rates of returning FIT kits than those receiving usual care. Future work should tease out the differential impact of bidirectional texting versus unidirectional texting, and future campaigns could also attempt to address additional barriers raised by patients in the QI project. Finally, despite the success of this campaign, numerous patients remained unscreened, underscoring the need for continued education and multilevel interventions to reduce barriers to CRC screening.

Acknowledgments

The authors would like to thank Eric Goemer for assistance with the manuscript preparation and proofreading. The authors would also like to thank the patient navigators, the care team, and the patients who shared their stories. The authors acknowledge the California Health Care Foundation for their financial support for the quality improvement project and the evaluation.

Data Availability

The data sets generated during or analyzed during this study are available from the corresponding author upon reasonable request.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Texting workflows.
[PPTX File , 4361 KB - cancer_v9i1e39645_app1.pptx]

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Abbreviations

CRC: colorectal cancer
FIT: fecal immunochemical test
FQHC: Federally Qualified Health Center
NLU: natural language understanding
QI: quality improvement
SDOH: Social Determinants of Health

Edited by A Mavragani; submitted 10.06.22; peer-reviewed by T Lam, G Donovan; comments to author 22.09.22; revised version received 27.10.22; accepted 14.11.22; published 07.03.23.

Please cite as:
Levitz CE, Kuo E, Guo M, Ruiz E, Torres-Ozadali E, Brar Prayaga R, Escaron A
Using Text Messages and Fotonovelas to Increase Return of Home-Mailed Colorectal Cancer Screening Tests: Mixed Methods Evaluation
JMIR Cancer 2023;9:e39645
URL: https://cancer.jmir.org/2023/1/e39645
doi:10.2196/39645
PMID:36881466

Original Paper

Developing an e-Prehabilitation System of Care for Young Adults Diagnosed With Cancer: User-Centered Design Study

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Abstract

Background: A diagnosis of cancer in adolescence or young adulthood can pose many different and unique challenges for individuals, as well as their families and friends. Drawing on the concept of prehabilitation, the provision of high-quality, accessible, timely, reliable, and appropriate information, care, and support for young adults with cancer and their families is critical to ensure that they feel equipped and empowered to make informed decisions relating to their treatment and care. Increasingly, digital health interventions offer opportunities to augment current health care information and support provision. Co-designing these digital health interventions can help to ensure that they are meaningful and relevant to the patient cohort, thereby maximizing their accessibility and acceptability.

Objective: This study had 4 primary interlinked objectives: understand the support needs of young adults with cancer at the time of diagnosis, understand the potential role of a digital health solution to assist in the delivery of prehabilitation for young adults with cancer, identify appropriate technologies and technological platforms for a digital prehabilitation system of care, and develop a prototype for a digital prehabilitation system of care.

Methods: This was a qualitative study using interviews and surveys. Young adults aged 16 to 26 years diagnosed with cancer within the last 3 years were invited to participate in individual user-requirement interviews or surveys. Health care professionals specializing in the treatment and care of young adults with cancer and digital health professionals working in the industry were also interviewed or completed a survey. Consensus feedback interviews were conducted with 3 young adults and 2 health care professionals after the development of the first generation of the prototype app.

Results: In total, 7 individual interviews and 8 surveys were completed with young adults with a range of cancer diagnoses. Moreover, 6 individual interviews and 9 surveys were completed with health care professionals, and 3 digital health professionals participated in one-on-one interviews. A prototype app with the working name of Cancer Helpmate was developed based on these collective participant data. Overall, feedback from participants across the data collection activities suggests that the concept for the app was positive during these developmental stages. Further insightful ideas for the app’s future development were also identified.

Conclusions: Young adults with cancer and health care professionals are responsive to the need for more digitally driven services to be developed. Further development of an app such as Cancer Helpmate, which incorporates key features and functionalities directly informed by users, could help to augment the support provided to young adults with cancer.

(JMIR Cancer 2023;9:e41441) doi:10.2196/41441

KEYWORDS

digital health; human factors; user-centered; prehabilitation; young adults; cancer

Introduction

Prehabilitation

More than 1.3 million adolescents and young adults (YAs)—individuals aged 15 to 39 years—were newly diagnosed with cancer globally in 2019 [1]. In the United Kingdom, where YAs with cancer are referred to as “teenagers and young adults” and are typically aged 15 to 24 years, <1% of new cancer cases are diagnosed in this population, making it a relatively rare illness [2]. However, it is well established that the cancer burden as well as experiences of treatments and their associated side effects can present different challenges when compared with those involving an older population [1] because of physical, psychosocial, educational, and financial challenges associated with a cancer diagnosis and treatment at this particular developmental life stage [3-5]. A diagnosis of cancer at any point will always cause some biographical disruption to an individual, but during adolescence and young adulthood in particular, there can be substantial disruption to developmental milestones, education, career, relationships, self-esteem, body image, and identity [6]. By definition, life experience will be shorter in YAs, and therefore opportunities to develop and rehearse robust coping strategies will generally be more limited [4,7].

Research has highlighted the importance of providing specialized information, care, and support to and for YAs and their families at the time of cancer diagnosis [8,9]. Attention is rightly focused on the psychological well-being and resilience of YAs, with some evidence suggesting that developing resilience in the initial stages of a cancer diagnosis and treatment may aid longer-term coping [3]. In this regard, there has been a move toward delivering interventions—physical, diet, and psychosocial—in the interim period between diagnosis and treatment commencement. This concept is now commonly described as prehabilitation [10].

Historically, prehabilitation efforts focused on maximizing a patient’s physical fitness (eg, for surgery), with the aim of having a positive impact on survival, coping skills, and patient-reported outcomes during and after treatment [11-15]. However, the concept of prehabilitation in the context of cancer care has gathered momentum and is now recognized as an increasingly important area of cancer supportive care provision. In the United Kingdom, in November 2020 [16], MacMillan Cancer Support published guidance advocating the use of prehabilitation (both for physical and psychological needs) in the management of, and support for, people living with cancer. The report specifies a series of prehabilitation principles, with 3 key benefits from the inclusion of prehabilitation in cancer care provision identified. These were as follows: (1) personal empowerment and a sense of control for the patient, (2) physical and psychological resilience and improved quality of recovery from treatment, and (3) a positive impact on long-term health through positive changes in behavior [16]. This guidance advocates for prehabilitation to coexist within the rehabilitation pathway from either the point of diagnosis or even before the diagnosis in some cases so that people diagnosed with cancer can be best prepared, physically and mentally, for treatments and later stages of the cancer pathway [16]. However, the development of tailored prehabilitation interventions and associated supportive care services for patient populations such as YAs with cancer is in its infancy.

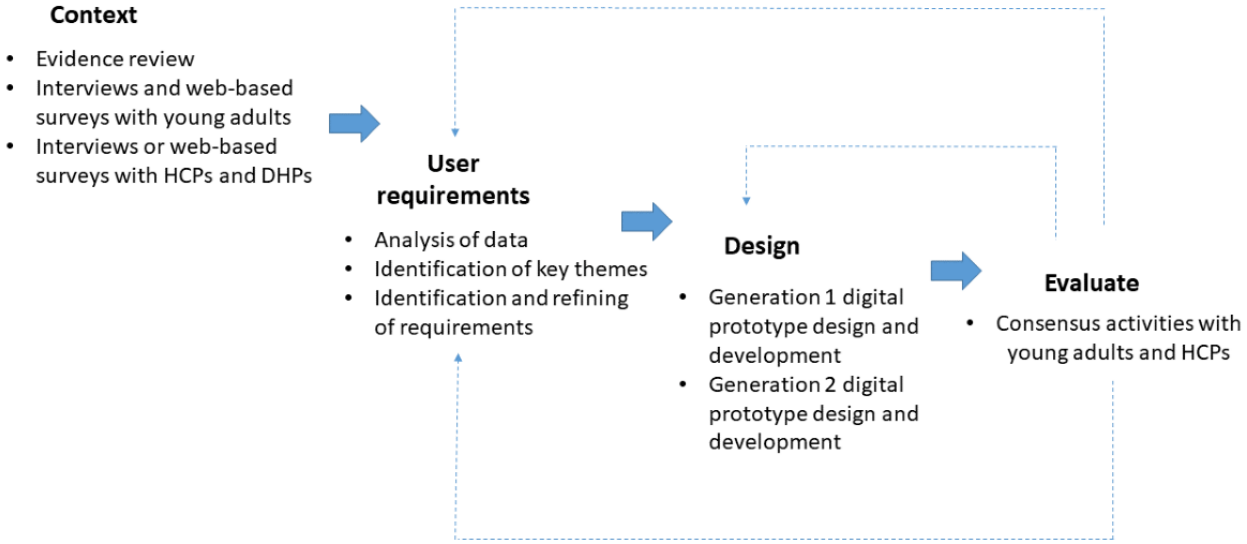
User-Centered Design Processes for Developing Prototype Digital Health Interventions

User-centered design processes are those defined by collaborative, cooperative, and cocreation methods; thus, they lend themselves well to the development of new interventions that are responsive to and meet the needs of target populations. Therefore, a user-centered design backdrop, set within the rapidly evolving digital health agenda, enables researchers to explore opportunities to tackle current and future health care challenges via technology-based interventions. The uptake of digital health interventions, including those that use technologies such as websites, mobile apps, and wearables, has accelerated in recent years, particularly in the period from 2020 to 2022 during the global COVID-19 pandemic [17-19]. Assumptions of data literacy among YAs and their access to and use of technologies in health care contexts [20] present opportunities to better identify meaningful technology-based interventions in health care provision for YAs with cancer [21,22].

User-centered design methodologies are invaluable in identifying and designing acceptable and appropriate interventions for target populations [23]. They afford some flexibility, are typically iterative in nature, and allow for critical contextual insights to inform and direct the design, development, and evaluation of digital solutions and interventions through their 3 typically classified categories of inspection, testing, and inquiry [24]. Thus, applying a user-centered design approach to the development of a mobile phone app to support prehabilitation in YA cancer care has the potential to help improve the experiences of this patient cohort.

This paper presents an overview of the user-centered design process in the development of a prototype mobile phone app (working name: *Cancer Helpmate*) to support prehabilitation experiences of YAs diagnosed with cancer (Figure 1). This paper reports on the contextual understanding of YAs’ diagnosis experiences and pathways of care, and the initial user-centered development rounds of a digital solution focused on addressing these needs.

Figure 1. The user-centered design process. DHP: digital health professional; HCP: health care professional.



Methods

Study Design

This was a qualitative user-centered design project. The protocol paper for this project has been published previously [25]. To ensure that the prototype product design and purpose were meaningful and informed directly by users' requirements and experiential insights, the research team recruited key stakeholders, including YAs with cancer, health care professionals (HCPs), and digital health professionals (DHPs), to the study.

Ethics Approval

The study received full ethics approval from the Yorkshire and the Humber–Bradford Leeds Research Ethics Committee in the United Kingdom (17/YH/0352) and was endorsed by the University of Strathclyde Ethics Committee shortly thereafter. Local research and development management approval (GN17ON664) was received for the study, as was approval from the participating cancer hospital before study commencement. No financial or incentive payments were made for participation.

Recruitment

YA Participants

Using purposive sampling, YAs aged 16 to 26 years diagnosed with cancer up to 3 years but no less than 4 weeks before participation at the time of recruitment were invited to participate in this study by the YA cancer team at the partner cancer hospital. HCPs from the cancer team identified and approached potential YA participants either in person or via email by reviewing clinic lists, caseloads, and databases. Potential participants were introduced to the study by the cancer team through age-appropriate study information, provided in written and video formats on a study-dedicated website. YAs interested in participating were asked to complete a consent-to-approach form or contact the research team directly with their contact details. The research team then contacted the YAs to discuss participation and confirm eligibility to participate.

A range of self-referral recruitment methods were also used to recruit YAs to the study, including placing advertisement posters and postcards around university buildings and the hospital's clinics, recruitment-orientated posts on a dedicated project Twitter account, development and use of a dedicated project website, and contacting YA-specific support groups. If YAs were interested in participating in the study after learning of it via one of these self-referral channels, they contacted the research team directly via the study email address or completed a screening survey on the study website to confirm their eligibility. The research team followed up with the individual thereafter to review and confirm participation.

Recruitment was more challenging than anticipated, even with the simultaneous activation of the aforementioned recruitment strategies. In response, an additional recruitment strategy was implemented after an ethics protocol amendment. In addition to the existing strategies, a member of the research team established a presence at the YA clinics at the cancer hospital. This visibility enabled potential participants to have a face-to-face introductory dialogue with the researcher about the study immediately after initial introduction from the HCP, and this strategy helped to enhance recruitment.

HCP and DHP Participants

Researchers purposively identified and directly approached HCPs with experience of working with YAs with cancer. DHPs—individuals with experience of developing and deploying digital health solutions and interventions within National Health Service, industry, and academic contexts—were also approached directly by the research team to offer their perspectives as domain experts.

Inclusion criteria for each of the participant groups are summarized in Textbox 1.

Textbox 1. Participant inclusion criteria.

- Teenagers and young adults (YAs)
  - Aged 16 to 26 years
  - Diagnosed with cancer up to 3 years but no less than 4 weeks before participation
  - Receiving or received services by National Health Services Scotland or [hospital name]
  - Sufficiently proficient in English to be able to participate in data collection activities
- Health care professionals
  - Member of the teenagers and YAs cancer team or multidisciplinary team involved in the provision of care to YA with cancer
  - Have experience working with YA who have or have had a diagnosis of cancer
  - Sufficiently proficient in English to be able to participate in data collection activities
  - Able to provide informed consent
- Digital health professionals
  - Professionals with experience of working in the digital health space within National Health Service, industry, and academic contexts
  - Sufficiently proficient in English to be able to participate in data collection activities
  - Able to provide informed consent

Data Collection Activities

This study used the concept of user-centered design—an iterative approach to product design and development that evolves through cycles of contextual understanding, requirements capture, design and development, and evaluation—and qualitative data collection activities to address the study objectives. This is illustrated in Figure 1, which has drawn inspiration from the user-centered design framework as advocated by the Interaction Design Foundation [26].

Stream 1: Interviews or Web-Based Surveys With YAs

Individual interviews or web-based surveys were completed by YAs who were currently or previously diagnosed with cancer to develop an understanding of the issues they experienced before and upon diagnosis. The interviews lasted between 46 and 60 minutes, and survey completion time ranged from 4 to 45 minutes. The aim was to recruit up to 20 YAs who met the inclusion criteria to participate in the first stage of data collection via these 2 data collection strategies.

Within the interviews and surveys, YAs were asked about their experiences regarding the following aspects:

- The experiential impact of cancer diagnosis within the context of the following themes:
  - Practical
  - Family
  - Emotional
  - Social
  - Physical
- Current cancer information provision
- Suggestions for the role of technology to support YAs newly diagnosed with cancer

Stream 2: Interviews or Web-Based Surveys With HCPs and DHPs

In stream 2, which ran concurrently with stream 1, we provided HCPs and DHPs with specific participant information sheets and invited them to participate in one-on-one interviews or complete a web-based survey to explore their preferences for the content and delivery of the system. Upon consent, the interviews lasted for approximately 60 minutes. The aim was to recruit up to 21 individuals, with 2 to 3 representatives from each professional group, including nursing, oncology and hematology, psychology, physiotherapy, occupational therapy, social work, and youth support, as well as professionals working with digital health solutions and interventions from health care, industry, and academic settings.

Within these interviews and surveys, HCPs and DHPs were asked about the following topics:

- Their experiences of information provision before initiation of YA cancer treatment
- Preferences and requirements for the e-prehabilitation resources and materials
- Preferences for the technology system
- The role of an e-prehabilitation system in assisting in the prehabilitation care offered

Stream 3: Prototype Design and Development

Data gathered in streams 1 and 2 informed the user and system requirements for the first generation of the prototype. A medium- to high-fidelity prototype of a web-based mobile app that could be viewed and evaluated by users was developed at the end of the first development cycle (ie, generation 1 of the product).

Stream 4: Consensus Activities

In stream 4, we sought feedback from participants on the generation 1 medium- to high-fidelity prototype developed in stream 3 so that we could review our interpretation and development of the prototype derived from our user requirements, experience, and insights.

We did this by creating environments—paper and digital—for participants (YAs and HCPs) to access and comment on the medium- to high-fidelity prototype. Where this was not possible, we distributed an electronic version of the prototype by email along with a link to a web-based survey and asked for comments and feedback. Participation in stream 4 was optional for both YA and HCP participants.

Data Analysis

Interviews were audio recorded and transcribed verbatim using an external transcriber. Transcripts were merged with field notes and outputs of brainstorming activities. During the analysis, 2 researchers (LM and KM) drew upon the research objectives and identified and developed themed categories to guide the data analysis. NVivo (version 12; QSR International), a qualitative analysis software package, was used to support the data analysis activities.

Data were analyzed using a thematic analysis approach because this is useful for answering questions about the salient issues for a particular group of respondents or for identifying typical responses [27]. For reliability and validity purposes, 2 researchers (LM and KM) coded a subsample of transcripts and field notes separately and then cross-checked them together. The remaining transcripts and field notes were coded by researcher KM.

Results

Streams 1 and 2: Participant Demographics

YA Participants

In stream 1, a total of 7 YAs participated in interviews with a member of the research team. The mean age of the YAs at the time of participation was 21.7 (SD 3.2) years, and their mean age at the time of cancer diagnosis was 20.5 (SD 2.8) years. Most of the YAs (5/7, 71%) received their treatment in the specialist YA cancer ward at the partner cancer hospital in Scotland, and all participants received chemotherapy as part of their treatment, with surgery (4/7, 57%) and radiotherapy (1/7, 14%) also being received. All participants received a pack of information materials provided by the clinical nurse specialist at the time of diagnosis. Other information resources used by the YAs at this time included websites (6/7, 86%), social media (3/7, 43%), and personal blogs (1/7, 14%). Participant demographics from the sample who participated in the interviews are outlined in Table 1.

The web-based survey contained a set of initial screening questions to facilitate immediate completion by those YAs who met the inclusion criteria. In total, 17 YAs started the web-based survey, but the initial screening questions identified the following concerns: 1 (6%) was too old, 2 (12%) did not fit the diagnosis criteria, and 1 (6%) did not complete the screening survey. Of the remaining 13 YAs who were eligible to complete the remainder of the main web-based survey, only 8 (62%) actually continued beyond the screening survey. Of these 8 YAs, 6 (75%) completed the web-based survey, whereas 2 (25%) only partially completed it. Specific demographic data beyond the eligibility screening criteria (aged 16-26 years, diagnosed with cancer 1-36 months ago, and treatment commenced 1-36 months ago) were not collected.

Questions asked within the web-based survey were open-text questions, and the free-text qualitative data from the survey participants (n=8) were integrated with the interview data in stream 3.

Table 1. Young adult interview demographic information (N=6[a]).

Variable	Values
Current age (years), mean (SD)	21.7 (3.2)
Age at diagnosis (years), mean (SD)	20.5 (2.8)
Sex, n (%)	
Male	3 (50)
Female	3 (50)
Education level, n (%)	
Higher or A level or SVQ3[b]	2 (33)
Advanced higher or certificate of higher education	2 (33)
Honors degree	1 (17)
Master's degree	1 (17)
Employment status, n (%)	
Full time	3 (50)
Part time	2 (33)
Seeking work or student	1 (17)
Relationship status, n (%)	
Single	4 (67)
Living with partner	2 (33)
Cancer type, n (%)	
Sarcoma	1 (17)
Testicular cancer	1 (17)
Lymphoma[c]	4 (67)
Period elapsed since diagnosis (months), n (%)	
3 to 5	1 (17)
6 to 9	1 (17)
12 to 24	4 (67)
Treatment received, n (%)	
Surgery	4 (67)
Radiotherapy	1 (17)
Chemotherapy	6 (100)
Receiving cancer treatment currently, n (%)	
Yes	1 (17)
No	5 (83)
Where participants received most of their treatment, n (%)	
Regional cancer center	5 (83)
Teenage Cancer Trust ward at regional cancer center	4 (67)
Local hospital	1 (17)
Information resources used at diagnosis, n (%)	
Print	6 (100)
Pack of materials provided by clinical nurse specialist	6 (100)
Websites	6 (100)
Social media	3 (50)

Variable	Values
Blogs	1 (17)

[a] Overall, 7 young adults were recruited, but 1 (14%) did not complete the demographic form.

[b] SVQ3: Scottish Vocational Qualification level 3.

[c] n=2: Hodgkin lymphoma, n=1: Burkitt lymphoma, and n=1: non-Hodgkin lymphoma.

HCP and DHP Participants

In stream 2, of the 15 HCP participants, 6 (40%) participated in interviews, and 9 (60%) completed a survey. In addition, 3 DHPs participated in interviews. In terms of the HCP interview participants, psychology, oncology, and allied health professions disciplines were represented, and the mean experience in their current role was 8.7 (SD 5) years, whereas the mean experience working with YAs with cancer was 5.1 (SD 5.7) years. Half (3/6, 50%) of the HCP interview participants had received specialist training for working with YAs with cancer. Further participant demographics are outlined in Table 2. The free-text qualitative data from the 9 surveys completed by HCPs were integrated with the interview data in stream 3.

Table 2. Health care professional (HCP) and digital health professional (DHP) interview demographic information (N=8[a]).

Variable	Values
Age (years), n (%)	
25 to 34	1 (13)
35 to 44	5 (63)
45 to 54	2 (25)
Profession, n (%)	
HCP	6 (75)
DHP	2[a] (25)
Sex, n (%)	
Male	4 (50)
Female	4 (50)
Education level, n (%)	
PhD	4 (50)
Medical degree	1 (13)
Master’s degree	1 (13)
Honors degree	2 (25)
HCP experience in current role (years), mean (SD)	8.7 (5)
HCP experience working with YAs[b] with cancer (years), mean (SD)	5.1 (5.7)
DHP experience in current role (years), mean (SD)	2.8 (1.3)
DHP experience working with YAs with cancer (years), mean (SD)	5.5 (1.5)
Specialist training to work with YAs with cancer, n (%)	
Yes	3 (38)
No	5 (63)

[a] Overall, 3 digital health professionals were recruited, but 1 (33%) did not complete the demographic form.

[b] YA: young adult.

Stream 3: Synthesis of Qualitative Data

The identified main and supporting subthemes identified deductively during data analyses of the collective interviews and surveys are summarized in Textbox 2. These themes and subthemes are further elaborated on in the following sections; evidence is provided with embedded key quotations for illustrative purposes.

Textbox 2. Main and supporting subthemes from interviews.

- Needs of young adults at diagnosis
  - Diagnosis experience
  - Life disruption
  - Physical and psychological impact of cancer diagnosis
  - Information provision and delivery
- The role of technology to support prehabilitation in young adults with cancer
  - Understanding prehabilitation for young adults with cancer
  - Barriers and facilitators for technology use
  - Design and delivery of an e-prehabilitation system of care for young adults with cancer

Needs of YAs at Diagnosis

Diagnosis Experience

YA narratives illustrated that the period from initial symptomatic presentation to a confirmed cancer diagnosis was long and often lasted many months. YAs described this as a confusing and worrying time. There were some observed similarities among participants in this regard (ie, multiple presentations to a general practitioner and repeated referrals for tests with different specialists before receiving a definitive cancer diagnosis). From there, active treatment commenced at pace:

> *[T]he build-up to getting diagnosed was extremely long. I'd been ill since about before Christmas, and I kept going to the doctor's and getting blood tests, and they were presenting me as anemic, and then I was having iron tablets, iron supplements, and then I went to get my blood tests again and it didn't improve, and because of the timescale of me travelling...my doctor like referred me to hematology really quick, and then that's what happened, but for months, I was actually meant to get my tonsils removed, they put it down to that; I was meant to get a tonsillectomy this month...but it took months to diagnose it, but once it was diagnosed, it was extremely fast.* [YA001, 17 years old, female]
>
> *So it was quite a shock, because I never really thought, well, I went in with a sore stomach and came out with cancer! It's a bit of a strange scenario. So...yeah, it was a little bit daunting.* [YA002, 20 years old, male]

Life Disruption

YAs' narratives revealed the different aspects of their lives disrupted by their cancer diagnosis, including relationships with friends and family, school and university, work, finances and planned holidays, and life experiences. YAs spoke about some of the challenges of maintaining friendships when they were not feeling well enough to engage in social activities. Participants spoke candidly about the impact of their diagnosis on their social networks and expectations of friends:

> *I think my relationship with my friends, at the beginning, it was different to the way it was throughout treatment, at the beginning: I wanted my friends around all the time, and then throughout treatment, I was just kind of, I was too tired to really socialize, and then after treatment, I think they were all under the impression as well that I would just like go back to the normal way of things and be going out at the weekends and things like that, but it was still like a hard transition to feeling normal again.* [YA007, female]

HCPs also acknowledged the range of impacts and life disruptions a diagnosis of cancer can have on a YA's life; many identified issues similar to the following reflections:

> *Psychological challenges e.g. shattered assumptions about the future, mood/anxiety issues, body image concerns, fears of various treatment procedures, fears of dying. Relationship issues e.g. difficulties in intimate relationships, worries about how parents are coping, worries about how to tell friends re their diagnosis. Practical concerns e.g. interference with work/study/life plans, limiting ability to travel/see the world, financial worries. Worries about various symptoms and how they will cope e.g. nausea, pain, fatigue. Spiritual concerns where relevant.* [HCP survey participant 05]

Physical and Psychosocial Impact of Cancer Diagnosis

Given the emphasis on physical and mental health during prehabilitation, the interviews explored the physical and psychological impacts of a diagnosis of cancer on YAs. Most of the participants discussed the physical symptomatic impacts of a cancer diagnosis and treatments, including fatigue, nausea, diarrhea, pain, and weight changes. Hair loss, a physical manifestation of some cancer treatments, also had considerable psychological impacts because the anticipation of losing their hair caused considerable anxiety for YAs:

> *Every time I'd go to sleep, I'd be anxious to wake up in the morning to see if it [hair] had fallen out or not. Every time I went for a bath, I'd dread it, because it would all come out.* [YA001, 17 years, female]

YAs spoke with honesty about the initial shock and disbelief of being diagnosed with cancer. For some of the YAs, understanding their diagnosis information was compounded by the overwhelming amount of cancer-related information provided by their clinical team. Participants noted how this information could vary from focusing on expected treatment-related side effects to potential decisive life-course decisions such as fertility choices:

> *It's more just like it's such a short amount of time to understand anything. Like understanding the fact alone that you have cancer, because it's such a big word when you're not really involved with it...it's such a big, scary word—so it's just getting to terms with the fact that that's what's wrong with you, and then trying to understand how serious or like how treatable it is so quickly, as well, that's quite big.* [YA003, 25 years old, female]
>
> *And I think it's really important to think not just about physical side effects in their own right, but the psychological impact of a physical side effect, so how does it feel emotionally to feel so fatigued all the time? How does it affect your body image if you lose your hair, for example, or if your weight and muscle mass changes? It's thinking kind of about the emotional impact of the physical symptoms: I think that's kind of one step that's sort of missed out sometimes, so there's all of those things.* [HCP002]

Information Provision and Delivery

YAs and HCPs perceived current information provision at diagnosis to be very good; an information pack of written materials was provided as standard to YAs at the time of diagnosis from the participating hospital site. However, YAs repeatedly commented that the nature and presentation format of this information "can be very overwhelming, it is a lot of new information to take on-board in such a short space of time" (YA survey participant 01). As a result, engagement with the aforementioned materials was limited to the window between diagnosis and treatment commencement:

> *It was just kind of like information just thrown at you, and a lot of kind of leaflets, there were other books, but I couldn't get my head round it, it wasn't something you could take a read of.* [YA005, 26 years old, male]
>
> *At the beginning, I got this massive like pack of leaflets and pamphlets, and it was just too much literature that I didn't read it all, just because it was so much: it was kind of overwhelming and I didn't really know what I wanted to find out about.* [YA007, female]
>
> *They [information pack] were alright. Some of them, one of them was quite childish, one of the books. I always remember one being quite childish.* [YA001, 17 years old, female]

It was apparent that accessing accurate and reliable information drove some of the YAs to seek out their own information, predominantly from well-known cancer charity websites, social media, or blogs. However, there was a substantial gap in information provision–related experiences shared by peers:

> *Yeah, that was me going out and looking for it myself. The only thing that I was given was the leaflets and the websites, and the websites were great, but I would always look for more! I wanted to hear more and hear what other people were going through, and that's when I started to hunt for the blogs and even these, not chat rooms, forums and things, like they were really helpful too: hearing how other people cope.* [YA004, 19 years old, female]
>
> *I feel that there is a lot of information out there, but sometimes not in one cohesive location in a format that people find accessible.* [HCP survey participant 05]

The Role of Technology to Support Prehabilitation in YAs With Cancer

Understanding Prehabilitation for YAs With Cancer

In the interviews, most YAs and HCPs talked about the realities of a very short period between cancer diagnosis and treatment commencement. Usually, prehabilitation focuses on a prolonged period before treatment commencement and on physical fitness and physical readiness for the surgery. However, in the context of this study, the focus was placed more on facilitating psychological readiness by providing appropriate information at the time of diagnosis and making this information available throughout treatment. Providing this support digitally was perceived to be a potential enabler of this care:

> *Years ago, when this idea was kind of in my mind, what triggered that was that I was aware of young people and their families kind of saying to me, "I wish I kind of knew then what I know now," and I always think, that's important, because that could really help people in the future. But, in reality, the window was going to be too small, because between being diagnosed and starting treatment, often there isn't very much opportunity, and people are geographically spread. So, that's when we were looking at an electronic format.* [HCP001]

Facilitators and Barriers for Technology Use

All YAs interviewed spoke about the role and presence of technologies such as mobile phones and the internet in their everyday lives, especially in relation to seeking information relative to their cancer experience, treatments, and side effects. Technology was perceived to have a positive role in health care, particularly in facilitating access to information and support:

> *I think the benefit to them [apps] is particularly if you're encouraging somebody to do some sort of self-monitoring, I think most people have got their mobile phone on their person 24/7, so there's definitely a benefit to that, versus if you give somebody like a diary, they're not going to really have that about with them, so then you miss information.* [HCP002]
>
> *Yeah, I think it probably would help, because then you've got—especially if it's a more kind of central place to get information, it's more, like a lot of the*

> *sites that are there will link to other sites more, but then quite often you'll find that you'll be going back and forward between the same kind of sites, whereas if you've got somewhere central you can go that kind of gives you more specific information or, yeah, something like that.* [YA002, 20 years, male]

Accessibility was also identified as a facilitator for using technology to support YAs; providing the same amount of information in an app or website as in a written format was considered by YAs to be more accessible and less overwhelming:

> *Yeah. Something that's like accessible. A big pile of papers is accessible, if you want to go through all the information, but not necessarily everybody does, and I know now, even for everything in my life, if I'm looking for information on something, I'm on my phone, like I'm looking for something that's going to give me information on it straight away...So, it makes sense to just have another app or another website that just has, it just fulfils another need for people who have questions.* [YA003, 25 years, female]

YAs described using an app on their phone as easier than going through printed materials when they were feeling nauseous or fatigued because it requires less effort to *scroll* than sift through multiple papers. They also highlighted that having a single app where all the information was collated would reduce the overlap of information, which they often found was the case with leaflets and books from multiple sources. This would also provide the ability to filter the information so that the user is able to access the information most relevant to them and their situation, which can be done much more quickly electronically than with paper formats.

Design and Delivery of an e-Prehabilitation System of Care for YAs With Cancer

The preferred form of an e-system suggested by all participants was a mobile app that could be used on both iOS and Android devices. The participants identified system features and functionalities as well as design and delivery. A repeated theme was the need for the app to be personalized to the user in some way. Suggestions around personalization included the ability of the user to personalize how the system looked (colors, text size, and font) and the ability to personalize and tailor the information that was presented to them. Other design suggestions concerned the importance of the e-system being engaging through the use of bright colors, a catchy name, and a combination of media for the way information was presented (text, pictures, and video):

> *High quality, professionally designed, very functional app accessible on both IOS and Android. If only provided as website, there are already numerous alternatives to use. If the quality is not better than other existing resources online, TYAs [teenagers and young adults] will not use it. For most TYAs a gimmick is not required.* [HCP003]

> *I think kind of bright colors, to make it a bit more engaging, and maybe visuals, that would help, I think. I think a lot of text can be kind of overwhelming sometimes, so maybe videos of different things and images, I think that would help.* [YA007, female]

For the YAs, the most important and consistently identified functionality, alongside the provision of tailored information, was the inclusion of peer and professional experience stories. Some of the YAs spoke of self-seeking this information by accessing blogs and social media posts of other YAs. Others spoke about their desire for this sort of information to have been made available to them:

> *I don't think you necessarily want someone to come and talk to you like this, but being able to read someone's situation, I know I did that a lot...You kind of want to read that information, because you don't always know how to process what's happening, so yeah, other people's experiences definitely help...I just think it's more personal. Like a lot of the information that you get isn't personal, it's clinical.* [YA003, 25 years old, female]

> *Having someone to chat to, who has been through it before who can help provide reassurance.* [YA survey participant 07]

> *Reassurance. From professionals and people who are relatable, gone through it themselves, of similar age. One of the biggest thing that help me through my journey was meeting a girl of the same age with the same cancer but a year ahead of me. Seeing the other side helped me remain positive.* [YA survey participant 01]

Further design considerations for the app were identified during discussions with YAs about their own coping mechanisms; for example, a YA discussed some of the "self-hacks" she used to track her diagnosis and treatment pathway, including the use of lettering on light boxes and daily manual updates to the numbers on the light box. It was suggested that incorporating a digital timeline principle into the app may provide individuals with some personalized information about their forthcoming treatment pathway upon diagnosis:

> *Do you know what would also be really good? I have—I don't know if you see it over there—it's a wee light-up box, it says Hodgkin's Fighter. It used to have how many days since I've been diagnosed, but now it's 31 days until my last chemotherapy. So it's counting it down...What would be really cool is if you put in an estimated date of the last chemotherapy, and they can see that number reduce daily. That would be really cool...it could be like a timeline, so it could be like, "Oh, I was admitted for tonsillitis this day, chemotherapy postponed a week," and then it would update it for you and it would tell you how many days you had left to go. That's motivating, because I can finally see a finish line.* [YA001, 17 years old, female]

Stream 3: Prototype Design

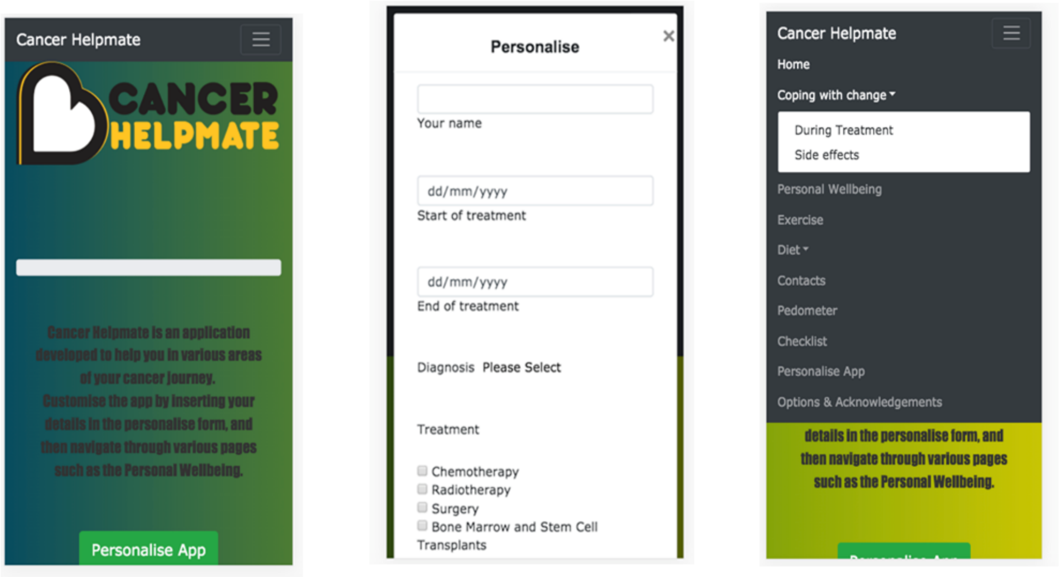
Analyzed data informed the requirements for the development of generation 1 of the medium- to high-fidelity prototype app. Table 3 summarizes these identified key user requirements for the prototype, the user-experience source, and the implementation outcome of these requirements in generation 1 of the prototype. Sample screenshots of generation 1 of the prototype are illustrated in Figures 2A to 2E. Cancer Helpmate was chosen as the working name for the product to reflect feedback from participants in the interviews and because they particularly requested that the name explicitly reference cancer as the primary purpose of the app.

Table 3. Prototype product requirements (generation 1).

Key user requirements	User-experience source	Implementation outcome (in generation 1 of Cancer Helpmate)
Cross-device product	Young adults	Mobile app developed, accessible via URL and a QR code, usable on mobile phones and tablet devices
Product can be personalized	Young adults and HCPs[a]	App interface can be personalized on registration and log-in by users by answering some brief questions on the app landing page about their specific diagnosis (Figure 2B)
Diagnosis information can be personalized on the product	Young adults	Personalizing app interface on registration and log-in means diagnostic-specific information will be presented to user, rather than generic cancer information
Treatment-related information can be personalized on the product	Young adults	Personalizing app interface on registration and log-in means information on relevant treatment-related symptoms and side effects a person may experience and how to go about seeking help is provided
Dietary information provided	Young adults	A diet function allows users to see a range of recommended healthy recipes and meals, with links to websites that will teach them how to make them at home; also has functionality for a user to log their own recipes and meals and store these in the app
Exercise information provided	Young adults	Exercise functionality includes text and links to video tutorials and demonstrations to recommended exercises for use during treatment and survivorship phases (Figure 2D)
Treatment countdown clock	Young adults	Countdown clock functionality incorporated: the user enters their expected treatment end date upon app registration, and functionality provides a clear-visual daily countdown visualization until the end of treatment
Simple pedometer function	Young adults	Simple pedometer function integrated; illustrates number of steps walked, but with drop-down menu to self-select realistic targets each day based on symptom experiences
Daily diary checklist	Young adults	Daily diary checklist functionality embedded: users can add their own self-directed tasks to a list and score them out once completed (Figure 2E)
Inclusion of reliable and trustworthy information	Young adults and HCPs	Inclusion of links to existing teenagers and young adults cancer charities and collated contact details for these organizations
Centralized information about cancer in 1 place	Young adults and HCPs	App includes menu options for information about cancer diagnoses, treatments, self-care advice, and cancer support organizations

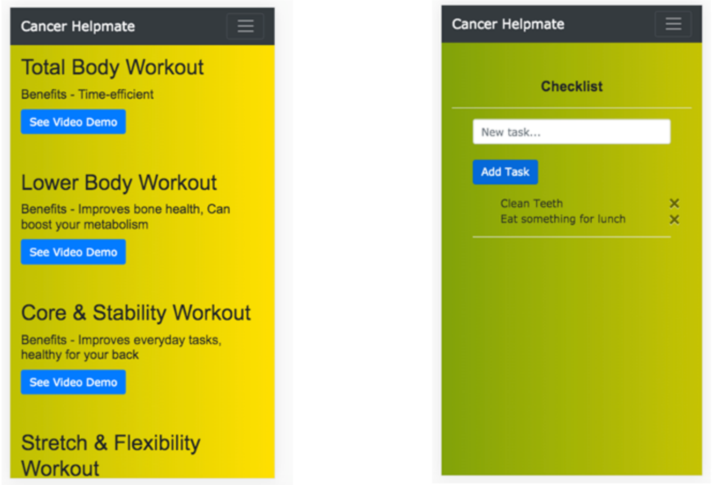
[a] HCP: health care professional.

Figure 2. Cancer Helpmate app prototype (generation 1).



Cancer Helpmate is an application developed to help you in various areas of your cancer journey. Customise the app by inserting your details in the personalise form, and then navigate through various pages such as the Personal Wellbeing.

(A) Homepage **(B) Personalisation** **(C) Menu**



(D) Exercise function **(E) Daily diary checklist**

Stream 4: Consensus Feedback Activities

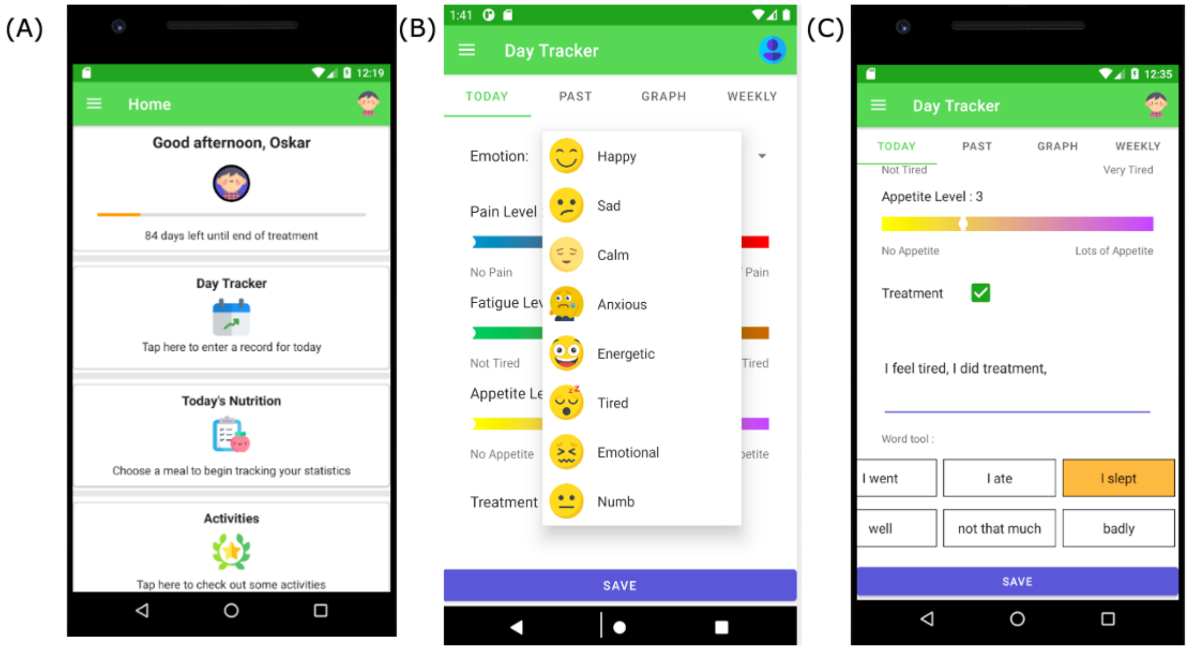
The consensus feedback activities provided us with an opportunity to not only confirm the acceptability of the features and functionalities of generation 1 of the app but also identify more features and functionalities to include in generation 2 and its subsequent design and development cycle.

The YAs (n=7) and HCPs (n=6) who participated in the study interviews were invited to provide feedback on the prototype. Of the 7 YAs, 3 (43%) participated in these consensus feedback activities (one-on-one interactions), where they reviewed the prototype with the researcher. Of the 6 HCPs, 2 (33%) participated together and provided their input collectively during their review of the prototype with the researcher. The current features, functionalities, and design of the app were reviewed, in turn, with participants asked in a *think-aloud* approach for the considered strengths and limitations of the current version of the app. During such directed conversations, participants were also asked to *think aloud* about what changes or additions would be beneficial to make to the next generation of the Cancer Helpmate app. The information was recorded by the researcher during each interaction and is summarized in Textbox 3; examples of this actioned feedback are presented in Figures 3A to 3C.

Textbox 3. Summarized feedback on generation 1 of Cancer Helpmate.

- Suggested changes and additions for generation 2 of Cancer Helpmate
    - Include section on experience of peers and way to interact with peers
    - Better use of color throughout the app (Figures 3A-3C)
    - Add function to have personal home page or bio area so that users can bookmark information relevant to them (not to be made accessible to anyone else)
    - Add functionality to link users directly with health care professionals to aid communication
    - Add function to include standard needs assessment questionnaires and share this information directly with health care professional teams (refer to Figure 3B for evolved conceptual premise of daily tracker and needs assessment)
    - Add functionality to include information and frequently asked questions relating to local cancer hospital to reduce anxiety as a new patient

Figure 3. Cancer Helpmate app prototype (generation 2). (A) Home page. (B) Daily tracker and emotions assessment. (C) Daily tracker word wall.



I feel tired, I did treatment,

Discussion

Principal Findings

This project drew upon user-centered and co-design methods to understand the experiences of YAs diagnosed with cancer. Focusing on experiences surrounding diagnosis has provided an understanding of the potential role of a digital intervention to support YAs from the point of cancer diagnosis to treatment commencement—and beyond—with a focus on psychological support and well-being. Prioritizing user-centered input to inform the development of experientially driven features and functionalities has facilitated the development of both a first- and second-generation medium- to high-fidelity prototype of an app aligned to previously identified prehabilitation benefits such as personal empowerment, physical and psychological resilience, and positive impacts on long-term health [16].

The aims and outcomes of this study are in line with local, national, and international digital health and care strategies [17] focused on empowering patients and citizens to engage and manage their own health and well-being. In the United Kingdom, in 2020, MacMillan Cancer Support established an 11-point action plan to ensure the adoption and further development of prehabilitation in cancer care [16]. This action plan focuses on points such as integrating prehabilitation into established clinical pathways; developing local and regional resources for users; developing standardized and validated measures for screening, assessment, and outcomes; and pursuing the research and business agendas.

Successful integration of digital health technologies into care provision pathways and services relies on the adoption readiness of the target end users. Previous work has illustrated that digital health technologies that are not reflective of existing health care pathways or the needs of patients and HCPs can be a preventative barrier to their routine adoption [28]. In this study, we engaged with both patients and HCPs to understand what the barriers to adoption of a new digitally driven supportive care service may be and where in the implementation pathway they may exist.

The importance of involving citizens in the design and development of new technologies and tools to ensure successful integration of digital health into care is a central tenet of digital health and care strategies [17,29]. We know that services are better adopted when co-design strategies have been embedded throughout their development cycle [23]. Involving both patients and HCPs enabled deeper understanding of the varying motivators and barriers to implementing digital solutions in daily practice. Similarly, the iterative approach allowed us to understand the needs of the YAs and HCPs and refine the design and functionality of the app accordingly [23].

This approach is consistent with that of other app development projects in similar population groups [23]. Casillas et al [23], for example, described the development and feasibility testing of an SMS text messaging system to increase adherence to, and receipt of, survivorship care in YA populations. We used a multistage co-design process involving interviews with YAs. Our system was found to be acceptable and feasible to YAs, and it was concluded that it had the potential to improve receipt of survivorship care in this population.

The findings from this project concur with those of studies of a similar nature; for example, Lea et al [30] also conducted participatory research with YAs diagnosed with cancer about their support needs and use of web-based information. The authors found that YAs use a range of social media, medical websites, search engines, charity websites, and communication platforms (eg, WhatsApp) to access information and support. No one source seemed to provide YAs with all the information they need and the ability to connect with peers with similar experiences for additional support. Our work and our Cancer Helpmate prototype app are already going some way to address some of these accessibility issues because we have applied the experiences and feedback directly of the YAs in our study to inform the co-design development of the prototype app.

Elsbernd et al [31] developed an app to support YAs who have received treatment for cancer, using a cocreation process that involved 3 creative group workshops with YAs, HCPs, and researchers. Three key features for the app were identified through this process: (1) a community forum, (2) an information library, and (3) a symptom and side effect tracker. Similar to our project, bright, warm colors were chosen by the YAs as a key design feature. Having the functionality to personalize the content presented to the user was highlighted by participants in this study, which is consistent with the findings of a qualitative study conducted by Linder et al [32], who used a computerized symptom capture tool to understand the symptoms and side effects that YAs with cancer undergoing chemotherapy experience and the self-management methods they use. The authors found that YAs often had similar symptoms and side effects but self-managed them in unique ways.

Lea et al [30] argue the case for developing effective resources collaboratively with YAs to ensure that they support the holistic needs of YAs with cancer. This is consistent with the findings from Siembida et al [33], who, after conducting a survey study among adolescents with cancer on their perceived quality of care, found that patient engagement had no impact on perceived quality of care. Instead, those adolescents who felt that providers supported their independence had a higher perceived quality of care than those who did not. This suggests that it is important to provide YAs the opportunity to give their opinion on, as well as ask questions of, and have input into, their treatment plans. Our Cancer Helpmate app is on a positive trajectory to be able to facilitate this because it contains engaging features and functionalities relevant to holistic and prehabilitative care for YAs with cancer.

Strengths and Limitations

The key strength of this project is the co-design approach with multiple stages of data collection, which prioritized the views and input of YAs, HCPs, and DHPs. Recruitment was challenging at times, but the research team persevered and identified as many different ways as possible to reach and recruit participants. A responsive approach such as this one did require submission of minor and major ethics protocol amendments during the project to reflect necessary changes to the inclusion criteria and recruitment methods, and these affected the initially conceived project timelines. It may be a limitation that more of the sample of YAs were asked to reflect on their cancer diagnosis experiences up to 3 years after diagnosis, but such is the impact of the diagnosis experience for this population that they were able to articulate and describe this with clarity and detail.

We also actively responded to recruitment challenges by delivering presentations to the clinical team, placing an advertisement in a national professional body newsletter targeting professionals working specifically with the target population, and establishing researcher presence in the YA hospital clinics to speak directly to YAs after the initial identification by, and introduction from, the clinician. This last strategy proved particularly effective because 5 (71%) of the 7 YAs recruited for a user-requirement interview were from the direct meeting with the researcher at the YA clinic. Such was the value of this recruitment strategy that it is advocated as a mechanism for other researchers working with YAs to embed within their own recruitment strategies in the future.

A notable strength of this project is the delivery of a second-generation medium- to high-fidelity prototype app that reflects the needs and requirements of the end users gathered through the multiple data collection streams in the project. However, it is acknowledged that the small sample size in relation to YAs and professionals recruited to the study could be considered a limitation in terms of representativeness of experiences and input. The reasons for these recruitment challenges in this study are not fully understood, but our responsive actions to the recruitment challenges enabled us to engage directly with our target populations. The number and range of professional roles of the clinicians who did participate are, however, somewhat representative of the size of, and multidisciplinary care provided by, the YA cancer team at the partner clinical site, although it is disappointing that there was no nurse representation in our final sample. In addition, funding requirements placed an initial geographic limitation on recruitment and consequently eligible YA participants before ethics protocol amendments allowed us to broaden recruitment scope.

Conclusions

The cancer diagnosis pathway for some YAs can be a protracted, frustrating, and anxiety-inducing experience. Upon diagnosis, pathways of care can be rapidly activated, and a YA's health status can change within hours or days. In such cases, YAs receive a substantial amount of new and important information at accelerated pace. We identified through our engagement with YAs in this study that although a range of age-appropriate, age-targeted, good-quality, and, when read, helpful information was provided to YAs from the hospital, this was predominantly delivered via traditional printed materials. Our qualitative interview and survey findings illustrated that this medium and the timing of delivery were often overwhelming for YAs, affecting negatively their engagement with the materials and information.

However, early consensus activities in this study were encouragingly positive about the need for this app; therefore, Cancer Helpmate has scope to augment information and psychosocial support services provided by YA cancer teams in the future and add to their digital service provisions.

To do this, future evaluation and implementation activities of Cancer Helpmate would be informed by, and learn from, the evolving digital health provision for similar populations. In the United Kingdom, for example, an app called Integrated Assessment Mapping has been implemented in some YA cancer services with support from the national Teenage Cancer Trust. The app allows YAs diagnosed with cancer to self-identify their needs through use of a holistic needs assessment to enable their clinical team to identify support needs based on information collected by the system [34]. Indeed, in this study too we recognize the holistic nature of supportive care but in the context of prehabilitation (including diet, exercise, self-care, and well-being) and have developed a prototype app that centralizes, and can personalize, this information for the user. Our next chapter in this program is to engage in making further developmental iterations to the product and move toward testing and evaluation with end users in community and hospital settings. In particular, we are interested in enhancing more of the app personalization components that would be selected by YAs during the onboarding process and evaluate their acceptability and utility. We also anticipate more formally evaluating the impact of written and digital information provision with this population.

Acknowledgments

The authors would like to thank all the young adults, health care professionals, and digital health professionals who participated in this study. The authors also thank the many charitable organizations who supported their recruitment efforts and activities. In addition, the authors thank the Beatson Cancer Charity for funding this research up to the prototype app development stages. The prototype app development contributions of University of Strathclyde students Mohammed Jahil (generation 1 of the app) and Andrew Hollis (generation 2 of the app) are particularly acknowledged.

Data Availability

The data sets generated and analyzed during this study are available from the corresponding author on reasonable request.

Conflicts of Interest

None declared.

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Abbreviations

DHP: digital health professional
HCP: health care professional
YA: young adult

Edited by A Mavragani; submitted 26.07.22; peer-reviewed by R Taylor, J Winterling; comments to author 24.10.22; revised version received 16.01.23; accepted 31.01.23; published 30.03.23.

Please cite as:
McCann L, Hewitt C, McMillan KA
Developing an e-Prehabilitation System of Care for Young Adults Diagnosed With Cancer: User-Centered Design Study
JMIR Cancer 2023;9:e41441
URL: https://cancer.jmir.org/2023/1/e41441
doi:10.2196/41441
PMID:36995740

Review

Evaluating Barriers and Facilitators to the Uptake of mHealth Apps in Cancer Care Using the Consolidated Framework for Implementation Research: Scoping Literature Review

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Abstract

Background: Mobile health (mHealth) solutions have proven to be effective in a wide range of patient outcomes and have proliferated over time. However, a persistent challenge of digital health technologies, including mHealth, is that they are characterized by early dropouts in clinical practice and struggle to be used outside experimental settings or on larger scales.

Objective: This study aimed to explore barriers and enablers to the uptake of mHealth solutions used by patients with cancer undergoing treatment, using a theory-guided implementation science model, that is, the Consolidated Framework for Implementation Research (CFIR).

Methods: A scoping literature review was conducted using PubMed (MEDLINE), Web of Science, and ScienceDirect databases in March 2022. We selected studies that analyzed the development, evaluation, and implementation of mHealth solutions for patients with cancer that were used in addition to the standard of care. Only empirical designs (eg, randomized controlled trials, observational studies, and qualitative studies) were considered. First, information on the study characteristics, patient population, app functionalities, and study outcomes was extracted. Then, the CFIR model was used as a practical tool to guide data collection and interpretation of evidence on mHealth uptake.

Results: Overall, 91 papers were included in the data synthesis. The selected records were mostly randomized controlled trials (26/91, 29%) and single-arm, noncomparative studies (52/91, 57%). Most of the apps (42/73, 58%) were designed for both patients and clinicians and could be used to support any type of cancer (29/73, 40%) and a range of oncological treatments. Following the CFIR scheme (*intervention*, *outer setting*, *inner setting*, *individuals*, *process*), multistakeholder co-design, codevelopment, and testing of mHealth interventions were identified as key enablers for later uptake. A variety of external drivers emerged, although the most relevant outer incentive fostering mHealth use was addressing patient needs. Among organizational factors likely to influence technology uptake, interoperability was the most prominent, whereas other providers' dimensions such as managerial attitudes or organizational culture were not systematically discussed. Technology-related impediments that could hamper the use of mHealth at the individual level were considered least often.

Conclusions: The hype surrounding mHealth in cancer care is hindered by several factors that can affect its use in real world and nonexperimental settings. Compared with the growing evidence on mHealth efficacy, knowledge to inform the uptake of mHealth solutions in clinical cancer care is still scarce. Although some of our findings are supported by previous implementation research, our analysis elaborates on the distinguishing features of mHealth apps and provides an integrated perspective on the factors that should be accounted for implementation efforts. Future syntheses should liaise these dimensions with strategies observed in successful implementation initiatives.

(JMIR Cancer 2023;9:e42092) doi:10.2196/42092

KEYWORDS

mobile health; mHealth; smartphones; mobile; oncology; cancer; implementation science; consolidated framework for implementation research; CFIR; mobile phones

Introduction

Background

Mobile health (mHealth) apps, defined by the World Health Organization as “medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants, and other wireless devices” [1], have become increasingly relevant in the health arena since the introduction of smartphones in 2007 [2]. With >6 billion smartphone users, indicating a penetration rate of >78% by the end of year 2020 [3], the number of mHealth apps has been increasing exponentially over time, leading to >351,000 mHealth apps available in the market in 2021 [4]. The COVID-19 outbreak accelerated this pattern, and mHealth provided a valid opportunity to deliver care remotely [5-7].

In oncology, mHealth apps have shown to provide benefits to patients throughout the care pathway [8-10]. Cancer treatments are complex, and mHealth apps can help patients manage their therapy more effectively and efficiently [11] by enabling better collection of patient data, remote monitoring by clinicians, patient education, and user-friendly communication tools [12]. In addition, apps have been shown to increase medication adherence, leading to reduced adverse events and increased quality of life [13,14]. This is particularly helpful for patients undergoing oral anticancer treatments, often performed in outpatient settings, whose success relies heavily on patients’ treatment compliance [15]. Overall, mHealth apps have the potential to increase patient empowerment by enhancing self-efficacy and improving patient-physician interaction [16].

Not only do individual patients benefit from using mHealth solutions, but also the broader health care system. There is a growing interest in the uptake of mHealth solutions in clinical practice because they have the potential to offer more accessible and cost-effective health care solutions [17]. Compared with conventional in-person therapies, mHealth can reduce health care costs while maintaining the same treatment quality by allowing the patient to attend follow-up appointments remotely [18,19]. By reducing commuting to and from the hospital, mHealth also holds great promise in mitigating the environmental impact of health care delivery [20], as commented by a recent study that appraised the potential environmental impact as a distinguished outcome domain of mobile medical apps [21].

The potential of mHealth is also reflected at the policy level, with an increasing number of countries gradually adopting regulatory frameworks [22]. For instance, the mHealthBelgium framework allows systemized recognition of mHealth apps as a medical device [23] using 3 validation levels depending on the safety level and socioeconomic value. Apps labeled with a level 3 status can be refunded by the National Institute for Health and Disability Insurance [24]. Similarly, in Germany, patients can apply for reimbursement of an mHealth app as a part of their statutory health insurance scheme if it is certified under Digital Health Applications (DiGA) regulation [25]. As of May 2022, the only DiGa-certified mHealth app for cancer care is CANKADO PRO-React Onco, which provides digital support to patients undergoing cancer treatment by facilitating communication with physicians and promoting patient education and empowerment [26]. In France, although some apps already receive reimbursement (eg, MOOVCARE POUMON for lung cancer telemonitoring) [27,28], the government is working on an assessment framework similar to that of the German DiGa [29]. In England, the National Institute for Health and Care Excellence developed an evidence-based standards framework for digital health technologies (DHTs), which is intended to be used by both technology developers and decision makers to inform the evidence development plans of the technology developers and commissioning of DHTs from the decision makers [30]. In this context, the European Union has recently launched a task force with the mission of harmonizing the evaluation of digital medical devices [31].

Increased interest in mHealth in cancer care has been observed in the fast-growing number of scientific publications in the past few years. However, most studies have investigated the impact of mHealth apps on patient outcomes. For instance, recent literature reviews have assessed the effect of mHealth apps on pain management in patients with cancer [32-35]. Other studies have investigated the impact of mHealth apps on patients’ quality of life, satisfaction with care, and user acceptance. However, there is limited evidence on the impact of the uptake and use of mHealth apps within the clinical setting. DHTs, including mHealth, are challenged by the phenomenon of early dropouts and abandonment [36]. To date, the implementation of mHealth apps has been analyzed less extensively. Does mHealth guarantee time and monetary savings for both patients and health care providers? Are mHealth apps used beyond the controlled study settings? In this context, implementation science is defined as “applied research that aims to develop the critical evidence base that informs the effective, sustained, and embedded adoption of interventions by health systems and communities” [37]. Through an extensive set of validated frameworks, tools, and strategies, this study investigates barriers and enablers to implementation that, respectively halt or facilitate the actual uptake of clinically proven interventions.

Objectives

Therefore, this study aimed to investigate the determinants of mHealth uptake using a theory-guided framework from implementation science, the Consolidated Framework for Implementation Research (CFIR). The CFIR was intended as a practical tool to map and interpret empirical evidence regarding factors (ie, barriers and facilitators) that could affect the implementation of mHealth in cancer care.

Methods

Study Design

This review follows the updated methodological guidance for scoping reviews [38] and the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) guidelines [39]. Scoping reviews aim to identify the main concepts, theories, sources, and knowledge gaps regarding a given topic of interest. The study protocol has not been registered. The 22-item PRISMA-ScR checklist for scoping reviews is provided in Multimedia Appendix 1.

Search Strategy

Web of Science, PubMed (MEDLINE) and ScienceDirect were consulted. The search was extended to the papers published from January 2017 to March 2022. A 5-year timeframe was deemed appropriate considering the sharp increase in the number of studies on the topic and the rapid obsolescence of previous studies. Additional relevant studies were identified by screening the bibliographies of other published reviews (snowballing).

The search strategy was defined jointly by the research team and ultimately built around 2 broad content areas, cancer and mHealth. The exact keyword string used was as follows: (cancer OR tumor OR tumour OR oncolog*) AND (mHealth OR “mobile health” OR phone OR smartphone OR app). The search was restricted to titles and abstracts in PubMed, and to titles, abstracts, and keywords in Web of Science and ScienceDirect. RefWorks [40] was used to retrieve relevant information from articles that were later exported in Microsoft Excel form for articles screening and data extraction. All papers selected for full-text reading were handled by the bibliographic reference manager, Zotero [41].

Eligibility Criteria

Only empirical study designs describing the development, evaluation (including testing), and implementation of an mHealth intervention were included. Other study types, including literature reviews, meta-analyses, conference abstracts, and clinical guidelines, were excluded. Studies were included if they focused on mHealth apps used as support for ongoing cancer therapies or management of related adverse events. Typical app functionalities included, but not limited to, enhancing patient self-monitoring, self-efficacy, or education, as well as fostering patient-clinician communication. Conversely, studies assessing mHealth apps used in other phases of the care pathway (eg, screening, diagnosis, and palliative care) were excluded. mHealth apps exclusively delivering noncore ancillary services for patients with cancer (eg, mental health, physical activity, and smoking cessation) were also out of scope. As for the target mHealth users, only adult patients undergoing cancer treatment were considered, whereas studies on cancer survivors, pediatric populations, or other targets with risky conditions or behaviors (eg, comorbidities) were excluded. Finally, studies not published in English were excluded. A detailed illustration of the inclusion and exclusion criteria is provided in Textboxes 1 and 2.

Textbox 1. Inclusion criteria for paper selection.

Study design

- Empirical studies (eg, randomized controlled trials, observational studies, pre-post studies, and qualitative designs)

App functionality

- Mobile health apps facilitating core cancer treatment delivery (eg, symptom-monitoring, tele-visit, and communication with health care professionals)

Moment of care

- Mobile health apps used as a support to ongoing cancer therapies or related adverse events

Target population

- Adult patients undergoing cancer treatment

Publication language

- English

Publication year

- From 2017 (included)

Textbox 2. Exclusion criteria for paper selection.

Study design

- Literature review, meta-analysis, conference abstract, and clinical guideline

App functionality

- Mobile health apps exclusively delivering noncore, ancillary services for cancer patients (eg, exercise programs)

Moment of care

- Other phases of the care pathway (eg, screening and prevention, diagnosis, and palliative care)

Target population

- Cancer survivors, pediatric populations, or other targets with risky conditions (eg, multimorbidities) or behaviors (eg, smokers)

Publication language

- Any other language except English

Publication year

- Before 2017

Study Selection

After double-checking a sample with a second reviewer (VA), the researcher GG screened all retrieved articles based on title and abstract, whereas full-text reading was performed by GG and VA. Disagreements regarding the inclusion of a given article were resolved by a third researcher (RT). All researchers agreed on the final selection of the studies selected for data synthesis. Owing to the variety of included studies in terms of design, objectives, and sources of evidence, no assessment of the risk of bias or methodological quality was undertaken.

Data Extraction and Analysis

Data extraction was performed in a Microsoft Excel grid. The extracted data included a general overview of the studies (eg, publication country, study objective, design, and duration), information on study participants (eg, number of participants, age, cancer type and stage, and cancer treatment), information on mHealth apps (eg, use time, app name, and main functionalities), study outcomes, and related metrics. The taxonomy by Dodd et al [42] that classifies the outcomes in medical research, was used to cluster the apps in the selected studies based on the investigated outcomes. In addition, CFIR was used to guide data collection and analysis of enablers and barriers to mHealth implementation, as well as strategies to overcome them. CFIR encompasses 5 domains and 39 constructs associated with effective implementation [43]. CFIR acts as a practical guide for systematically assessing potential barriers and facilitators when implementing innovation. CFIR integrates perspectives from different stakeholders and settings without inferring assumptions or drawing conclusions about the mechanisms of implementation, which is well suited to the heterogeneous literature to be synthesized [44]. A comprehensive explanation of the CFIR variables is provided in Multimedia Appendix 2.

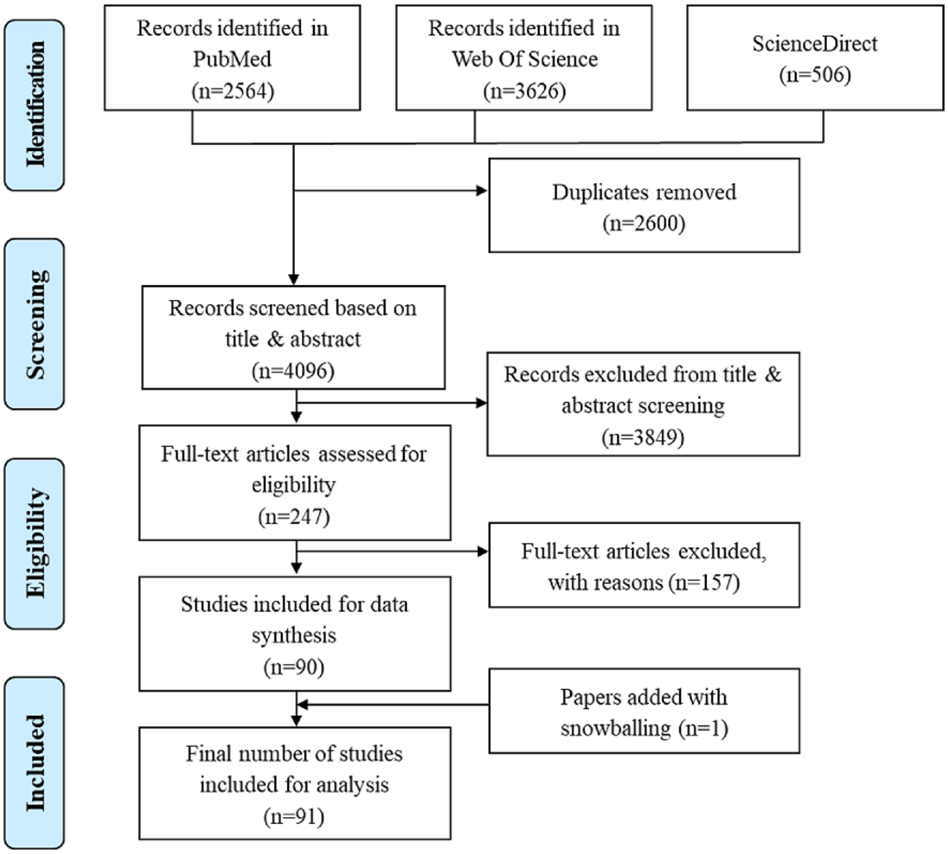
The results were summarized using mainly a narrative synthesis and organized into 2 major sections. First, an overview of the selected studies and underlying app functionalities was provided, including key statistics (eg, count and proportions) and summary characteristics when relevant. Evidence on barriers and enablers specific to mHealth implementation was then analyzed following the CFIR framework. We did not expect to find evidence on every CFIR subdomain in each selected study; therefore, data analysis was conceived as a synthesis of subsets of relevant, available observations.

Results

Review Profile

A total of 6190 papers were identified through the search (2564 records from PubMed, 3626 from Web of Science, and 506 from ScienceDirect). After duplicate removal, 3915 records remained for screening based on the title and abstract. A final number of 91 studies were included for analysis. Figure 1 describes the PRISMA flowchart [36,37].

Figure 1. PRISMA (Preferred Reporting Item for Systematic Reviews and Meta-Analyses) flowchart.



Overview of Selected Studies

Of the 91 studies, 78 (86%) [8,9,12,16,45-118] were research articles, whereas 13 (14%) [119-131] were study protocols. From 2017 to 2022, the number of published articles increased steadily over time. Almost half of the studies (43/91, 47%) were published in Europe, with Sweden (9/91, 10%), the United Kingdom (7/91, 8%), and Germany (6/91, 7%) having the highest number of publications. Outside Europe, relevant studies on mHealth in oncology were conducted in the United States (18/91, 20%), China (9/91, 10%), and South Korea (6/91, 7%).

In terms of study designs, randomized controlled trials (RCTs), including secondary analyses of RCT data, were the most common (26/91, 29%), followed by mixed-methods studies (24/91, 26%), qualitative design studies (12/91, 13%), pilot studies (11/91, 12%), other non-RCTs (7/91, 8%), pre-post studies (3/91, 3%), quasi-experimental studies (3/91, 3%), and other study designs (5/91, 6%). The majority (52/91, 57%) were single-arm studies, whereas 43% (39/91) of the studies were comparative, with 2 or multiple arms. Most of the included studies had a prospective design (84/91, 92%), 3 were retrospective, and others were combined retrospective and prospective branches (4/91, 4%).

Owing to their heterogeneous nature, the selected articles had different study durations, ranging from 2 weeks for small-scale trials to up to 2 years for larger-scale RCTs. The median sample size of the study participants was 51, ranging from a minimum of 5 to a maximum of 4475 patients.

Multimedia Appendices 3 and 4 provide an overview of the descriptive statistics and detailed study characteristics in a tabular format.

The 91 studies included for analysis describe 73 mHealth apps, of which 29 (40%) were designed for supporting any cancer types [9,12,47,48,50,54,56-58,65-69,71,73,74,76,81-83,85-88,90,91,93,105-109,111-113,116,117,121,122,125,128], followed by 17 (23%) on breast cancer [49,64,70,72,77,78,80,95-98,103,114,115,118,124,126,129-131], 5 (7%) [52,53,63,99,101,102] on gastric and colon cancer types, 3 (4%) [75,79,89,119] on lung cancer, 3 (4%) on thyroid cancer [84,100,123] type, and 2 (3%) on hematological cancer types [9,55,56,94,121]. The remaining apps (15/73, 21%) [8,16,45,46,51,59-62,92,104,110,118,120,127] covered other types of cancer, such as pancreatic, bone marrow, prostate, brain, and gynecological cancers.

Many apps did not support a specific cancer treatment (23/73, 32%) [46,51,53,62,71-74,83,84,86,88,93,95,98,99,104,105,108,112,117,118,121,124,126]. The most frequent treatment specifications were chemotherapy (15/73, 21%) [47,50,55,63,64,70,78,85,87,101,110,114-116,119,127,129,131], oral anticancer treatments (13/73, 18%) [9,48,52,56-58,65,76,80,82,90,91,94,111,122,128], radiotherapy (3/73, 4%) [54,92,120], and others (8/73, 11%) [12,16,45,59,60,66-69,75,81,89,102,106,107,113,125], which included several treatment types, such as a combination of chemotherapy and radiotherapy. Nonpharmacological treatments include surgery (8/73, 11%) [8,49,61,79,96,109,123,130] and transplantation (3/73, 4%) [77,97,100,103].

mHealth users can be patients, clinicians, a broader pool of health care professionals (HCPs), or different combinations of users. Most commonly, apps are designed for both patients and clinicians (42/73, 58%) [12,16,48-55,58,59,61,63,66,67,69,75,77,84-86,89,91-94,96,98,100,101,104-106,108,110,112-116,119,120,122-125,127-129,131], who typically access different interfaces and functionalities (eg, self-reporting function for patients, web-based dashboards with overview of patient activity for the clinicians). Only 32% (23/73) apps [8,47,60,64,65,68,70-73,76,78-83,87,88,95,97,99,102,103,107,111,121,126,130] were designed for exclusive patient use. This is the case for certain medication adherence apps that focus mainly on providing reminders to patients [65,76,79,80,82,99,111]. The remaining apps (8/73, 11%) [9,45,46,56,57,62,74,90,109,118] had diverse combinations of end users with patients, clinicians, caregivers, and pharmacologists. The app functionalities are listed in Table 1.

Table 1. Summary of app functionalities (n=73).

Characteristics of mHealth[a] apps	n (%)
App cancer targets	
Any cancer (ie, generic)	29 (40)
Breast	17 (23)
Gastric and colon	5 (7)
Lung	3 (4)
Thyroid	3 (4)
Hematological	2 (3)
Other forms of cancer	15 (21)
Cancer treatment supported	
Not specified	23 (32)
Chemotherapy	15 (21)
Oral treatment	13 (18)
Surgery	8 (11)
Radiotherapy	3 (4)
Transplantation	3 (4)
Other	8 (11)
Intended app users	
Patients and clinicians	42 (58)
Patients only	23 (32)
Patients, clinicians, and caregivers	3 (4)
Patients and caregivers	2 (3)
Other combinations	3 (4)

[a] mHealth: mobile health.

The selected studies assessed mHealth impact using a wide range of outcome metrics analyzed using the taxonomy by Dodd et al [42]. Outcomes most recurrently fall under the *Life impact* area, with 73 outcomes in the *Delivery of Care* outcome domain [8,9,12,16,45,46,48-55,57-63,65,67,70,71,73-87,90-92,94-104,107-116,119-122,128-131], 37 in *Global quality of life* [8,57,60,62,64,65,68,72,75,78,84,86,88-91,93,97,101,103,105,106,112,114,115,119-121,123-131], 16 in *Emotional functioning and well-being* [66,70,77,83,89,90,93,106,115,119,125-128,130,131], 8 in *Physical functioning* [75-77,89,101,102,105,130], and 7 in *Social functioning* [66,69,84,115,125,126,131]. Within this core area, recurring metrics were the acceptability, usability, and feasibility of mHealth apps, which could be assessed either using validated questionnaires, or qualitatively, through study-specific questionnaires or interviews. Specifically, feasibility was assessed in 41% (37/91) studies, usability in 40% (36/91) studies, and acceptability in 35% (32/91) studies.

As for the *Physiological or clinical* area, 12 outcomes are *General outcomes* [65,70,76,77,89,96,103,115,125,127,130,131] and 4 relate to *Neoplasms: benign, malignant, and unspecified* [4,77,101,112]. As for the *Resource use* area, outcomes fall under *Hospital* (n=10) [49,59,64,65,79,89,97,120,124,125], *Societal burden* (n=7) [65,77,115,119,127,128,131], and *Economic* (n=1) [126] domains. *Adverse events* related outcomes were recorded 9 times [49,53,56,57,60,78,93,108,112] and *Mortality or survival* [97] once. The outcome core areas and domains are summarized in Table 2.

Table 2. Outcomes according to the taxonomy by Dodd et al [42].

Core area *and* outcome domain	Count	Examples
Mortality or survival		
1. Mortality or survival	1	Overall survival
Physiological or clinical		
9. General outcomes	12	MDASI[a]
16. Outcomes relating to neoplasms: benign, malignant and unspecified	4	LARS[b]
Life impact		
25. Physical functioning	8	KPS[c]
26. Social functioning	7	PAM-13[d]
28. Emotional functioning and well-being	16	HADS[e]
30. Global quality of life	37	EORTC QLQ-C30[f]
32. Delivery of care	73	SUS[g]
Resource use		
34. Economic	1	Health resource use (cost)
35. Hospital	10	Reduction in unexpected visits to ED[h]
37. Societal burden	7	MSPSS[i]
Adverse events		
38. Adverse events and effects	9	CTCAE[j]

[a] MDASI: MD Anderson Symptom Inventory.

[b] LARS: low anterior resection syndrome score.

[c] KPS: Karnofsky Performance Status.

[d] PAM-13: Patient Activation Measure–13.

[e] HADS: Hospital Anxiety and Depression Scale.

[f] EORTC QLQ-C30: European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire.

[g] SUS: System Usability Scale.

[h] ED: emergency department.

[i] MSPSS: Multidimensional Scale of Perceived Social Support.

[j] CTCAE: Common Terminology Criteria for Adverse Events.

Determinants of mHealth Uptake

Intervention Characteristics

App characteristics are important predictors of intervention implementation in later stages. Regarding the *intervention source*, the literature reported that participating in the development phase increased the likelihood of later embracing the technology. Most analyzed apps have been developed collaboratively [8,53,55-58,62,72,73,75,77,87,101,103,104,107,109,114,116-118,122,127,131], often including HCPs, potential patients, and external technology partners responsible for actual software development [56,66,71,78,89,97,105,125,127,129,130]. For instance, the development of eOncoSalud was carefully planned during a series of 7 nominal consensus meetings involving a wide range of stakeholders [56]. Similarly, Konsghaug et al [80] followed an iterative and stepwise development approach, with the interactions of partners from diverse disciplines. Others followed participatory design techniques to foster stakeholder’s acceptance of the mHealth intervention, thereby increasing the likelihood of successful app implementation [73,74,90,91,95,99,104,117,118]. Perceived ease-of-use has emerged as a decisive factor for app uptake [74], and involving many actors in the development could also contribute to user-friendly interfaces (*design quality and packaging*). Satisfaction with the app design was gauged using satisfaction and usability questionnaires. Subsequent software releases and updates in app versions [64] are among the most perceived *complexities* of smartphone apps. As patient data are extremely sensitive, mHealth apps have specific data protection requirements. For instance, Giannoula et al [123] discussed data privacy and integrity (eg, cryptographed clouds, app authentication verification, and standards to transfer clinical and administrative data among software apps) and commented on the need to address data confidentiality issues from the early development phase [123]. The experimental nature of many of the study designs included in the analyses signaled the willingness to follow rigorous scientific approaches. Moreover, most studies adopted small-scale pilots to test the intervention before the roll-out (*trialability*) [66,68,80,90,91,97,102,104,119]. Nevertheless, the vast majority of included studies were noncomparative, thus hindering the possibility of assessing their *relative advantage* compared with other solutions. Being often developed for the purpose of the study, most apps were fit for the study context (*adaptability*), although incompatibility with IT systems was often mentioned as a hindering factor. Finally, practically no study has reported on the intervention development *costs* or on the economic impact of app use on the organization.

Outer Setting

The surge in the use of mHealth has attained new social needs and external policy pressures. Nearly every study stems from well-identified *patient needs and resources*, which are mostly related to a general improvement of the therapeutic pathway by means of better cancer-related symptom management [12,51,55,62,66,71,76,83,87,100,125,128], pain reduction [45,68,105,112,125], enhanced treatment adherence [48,58,65,82,91,94,111], and improved quality of life [51,99,112,124]. Another drive for mHealth uptake highlighted in the analysis was the scarcity of resources from national health systems, which pushed health care providers and policy makers to seek alternative solutions to conventional care. For instance, Zhu et al [131] reported insufficient financial commitment to health care from the government, which emerged in shortages of oncologists and the unviability of traditional face-to-face consultations. Considering recent government cost-cutting reforms, mobile-based, low-cost technologies are said to be crucial to lessening health care spending [119].

To address these newly developed needs or emerging social pressures, *external policies and incentives* have been issued to directly or indirectly foster mHealth deployment while regulating its diffusion. Broadly speaking, recent policy changes appeared to be oriented toward shaping patient care with more patient-centric service designs and posed greater attention to quality of life as opposed to only treating illnesses [74]. Examples of direct provisions can be observed in the newly issued guidelines on the facilitation of innovation diffusion by the United States Oncology Nursing Society [54], which advocates for a more individualized approach to cancer care or the need to comply with the US Health Insurance Portability and Accountability Act requirements for mHealth [52,58,87,96,110]. Provisions that strive to enhance patient-clinician communication, such as the Swedish law on patient empowerment in health care management [66] that encourages patients to participate in decision-making and to receive better knowledge about the treatment, or recommendations aimed at supporting patient self-management, such as the National Institute of Health guidelines on integrating behavioral pain interventions into cancer treatment [77], also emerged as facilitators of mHealth.

Finally, *cosmopolitanism* and *peer pressure*, namely competitive pressures to adopt an intervention because other peers are already using it, can further push the implementation process. These dimensions were not observed, as most studies only described isolated case studies and were carried out at single research centers. Only one mHealth solution has been implemented across an international network of hospitals [63,85], ASyMS, a phone-based, remote symptom monitoring system that was deployed and implemented in 13 cancer centers across 5 European countries (Austria, Greece, Ireland, Norway, and United Kingdom) [63].

Inner Setting

The inner setting refers to both structural characteristics that facilitate the implementation process and to dedicated activities activated by the recipient organizations along the way.

Structural characteristics of an organization, such as its age, size, and maturity, can significantly impact the effectiveness of mHealth interventions. Although information on these dimensions could not always be inferred from the selected papers, the type of clinical setting in which the study was being conducted was analyzed, although it did not seem discriminating.

Implementation climate is defined as the “absorptive capacity for change, shared receptivity of involved individuals to an intervention, and the extent to which use of that intervention will be rewarded, supported, and expected within their organization” [43]. In the context of mHealth apps, tensions for change resulting from perceived suboptimal situations can be observed. Patients with cancer went from being treated as in-patients to being increasingly and predominantly treated in outpatient settings. In this context, effective patient-clinician communication and facilitation with HCPs became key in the event of unforeseen symptoms and side effects, as when missing or not adequately provided, increased ED visits and hospitalization might follow [81,96]. The lack of HCPs supervision could be even more alarming in in-home administration regimens that require greater autonomy from the patients. Simultaneously, new therapeutic options are available. For instance, oral agents [9,48,52,56-58,65,76,80,82, 90,91,94,111,122] have become common today; however, their efficacy may be reduced owing to lack of adherence, erratic dosage intake, and inadequate self-management of adverse event self-management [91,122]. In addition, the growth in the uptake of mobile technologies also appeared to be connected to the need to reduce current health care spending [119]. Because of the economic implications of suboptimal medication adherence, such as increased risk of hospitalization and associated complication costs, app-based adherence interventions could mitigate this likelihood [48]. From the perspective of health care providers, mHealth could be seen as a way to make health systems more cost-effective [132]. Livingston et al [83] assessed the potential of an mHealth app in reducing the burden of screening and follow-up in busy clinics by freeing clinician time for those who need specialized follow-up [83]. According to Navarro-Alamán et al [86], managing patient symptomatology could require more than half the time spent by HCPs in monitoring the patient’s status. Shortages in health care resources were another factor that could foster the diffusion of mHealth solutions. Communicating with HCPs could be perceived as onerous [45], as pointed out in a study in which accessing well-trained pain therapists in-person appeared difficult and costly [77]. The imbalance between the number of clinicians available and the number of patients in need could be such that the latter are individually dedicated to only a few minutes of their clinician's time [50]. All these factors suggest that health care models should evolve toward more convenient solutions for patients and more cost-effective solutions for the overall health system [49].

Adopting mHealth apps is perceived as a *relative priority* within organizations. Some studies showed that physicians were aware that their ability to evaluate patients' symptoms was not optimal and acknowledged mHealth as a facilitator [64]. Not surprisingly, a survey of German health care providers showed high readiness to incorporate the use of mHealth apps into cancer treatment plans [120].

Regarding the *compatibility* of mHealth apps with the values of recipient organizations, openness from clinicians and patients to use mHealth as part of their routine could be observed [84]. Interoperability with existing IT systems and workflows was clearly preferred [87], and feasibility studies, including pilot testing, were typically used to demonstrate that an intervention could be integrated into clinical management. Interestingly, social factors, such as endorsements by trusted clinicians, likely influenced the perceived fit between an intervention and individuals [74].

Organizational incentives and rewards for using mHealth services were not systematically observed in the selected literature. Jacob et al [74] argued that app use could act as a tool to evaluate people and assign monetary rewards. A potential, yet indirect incentive was observed, which was an increased work-life balance resulting from fewer unscheduled consultations derived from correct app use [16].

Characteristics of Individuals

The likelihood of embracing a new health intervention also depends on the characteristics of the individuals who will use it. First, individuals' *knowledge and beliefs about an intervention* can be good predictors of implementation effectiveness. In the context of mHealth, age was used as a proxy for individual recipients' familiarity with and propensity to use digital health tools. In a large share of the selected papers (40/91, 44%), the observed mean age of the study participants ranged between 50 and 75 years. Nevertheless, as most participants routinely used smartphones [50,82,98,110,116], age did not seem to hamper their willingness to use mHealth services [16,50,58,73,89]. In addition, some studies have indicated that patients who are more inclined to use digital health solutions at large [62,73] or receive guidance [60] are more prone to use mHealth interventions. Patients' attitudes toward digital technologies were also mentioned as an important factor in the acceptance of mHealth intervention [74,85,100].

The perception that individuals have about their ability to use a given intervention and how it changes over time falls under the *self-efficacy* and *individual stage of change* constructs [133]. Higher degrees of self-efficacy are associated with a greater willingness to embrace novel technologies [134]. Increasing self-efficacy is often among the primary goals of the selected studies [46,64,114,121,128,131]. Instruments such as the Stanford Inventory of Cancer Patient Adjustment scale were used to assess the self-efficacy of general health strategies during the cancer disease trajectory [114,131]. mHealth apps could support the patients better understand their symptoms and adverse events, thereby increasing their perceived safety and engagement with cancer therapy [16,49,73,80,94,95]. Severe side effects are a major concern for patients with cancer [47]. The willingness to cope better with cancer-related complications could increase the patient's propensity to rely on mHealth interventions. Patients' acceptability and usability were frequently assessed in the selected studies using study-specific or validated questionnaires (eg, Mobile Application Rating Scale questionnaire) [46,73,95,109], including scales that gauge the ease of use and perceived usefulness of a technology, such as the Technology Acceptance Model [8,72,84].

I*dentification with the organization* cannot be easily inferred from the selected papers. Pappot et al [88] reported that app users may not feel an added sense of belonging when using an app, thus potentially explaining the different benefits experienced by the treatment arm.

Finally, among *other personal attributes*, cultural views on smartphone use at work, such as the fear that colleagues might see it as a waste of time, were highlighted as potential barriers to mHealth use in the workplace by Jacob et al [74].

Process

Built on 4 dimensions (planning, engaging, executing, reflecting, and evaluating), *process* refers to the reliance on a well-defined implementation approach. This is the most difficult domain to define, measure, or evaluate in implementation research [135]. Appraisal of the implementation process was limited to a subset of study designs, excluding protocols or development studies. The study durations in RCTs and observational studies were limited (average 238 days; median 180 days; minimum 21 days; maximum 720 days). Although the design and development were extensively illustrated, rarely could the same level of detail be observed with respect to the implementation pathway. In the selected papers, no *opinion leaders*, *formally appointed implementation roles*, or *champions* are mentioned. Nurses seemed to be the stakeholders with the greatest potential to push mHealth uptake [66,73,100] and could be appointed as official reference persons for patients on any issues related to app use [12,52,55,59,61,66,67,77,87,94,106,111,129]. As for *external change agents*, recommendations from peer clinicians, medical societies, or social media channels could have an impact on the perception of mHealth [74], yet the appraisal of the long-term sustainability of the implementation process remains difficult, as these are general forces external to the organization [135]. Therefore, training was most frequently used to involve intended users, and participants were instructed on mHealth use by either the research team or dedicated clinical staff [9,12,16,46-48,50,51,53-55,57,59,67,69,73,80,91,95,111,119]. Dedicated meetings could allow for information exchange on implementation strategies, and easy access to technical support in case questions were deemed important in the process [100]. Technical information on the installation of the apps was sometimes provided as part of the studies [55,61,129], and integration in the hospital's informative systems and workflows was also cited as an enabler to implementation [9,52,58,124].

Key barriers and enablers of mHealth uptake are illustrated in Table 3.

Table 3. Summary of key identified enablers and barriers to mobile health implementation.

CFIR[a] construct and enablers	Barriers
Intervention characteristics	
- User-friendly interfaces - Pretesting through small-scale pilot trials - Patient's and HCP's[b] involvement in the app development	- Release of many subsequent app versions - Data privacy
Outer setting	
- New patient needs (eg, need for constant monitoring, or real-time communication with HCPs) - External policies and incentives fostering digital health - Scarcity of resources and need to search more cos-effective ways to deliver health services	- Unharmonized regulatory provisions across EU[c] countries - Tendency not to leverage on networks (ie, unrealized synergies of economies of scales
Inner setting	
- Interoperability with IT systems - Workforce shortages - New care pathways for cancer (eg, outpatient settings) - Social endorsement (eg, peer referral)	- HCPs' perception of extra workload (eg, more data input) - Clinician concern from following-up more patients - Linkage between app uptake and incentives only possible at organizational level
Characteristics of individuals	
- Routine use of smartphones, regardless of age - Positive attitude toward digital health	- Cultural norms (eg, smartphone use in the workplace - Perceived poorer communication with HCPs - Weakened sense of identification with health service providers
Process	
- Training on app benefits and functioning - Nurses' active support	- Unclear contribution of different stakeholders to implementation - Implementation plans missing or poorly defined

[a] CFIR: Consolidated Framework for Implementation Research.

[b] HCP: health care professional.

[c] EU: European Union.

Discussion

Summary of Key Results

The overarching aim of this study was to investigate the determinants of mHealth uptake to inform the translation efforts of mHealth interventions in routine care. Studies illustrating the development, evaluation, and implementation of mHealth apps for cancer patients were considered, and information on barriers and enablers of app uptake was extracted following the CFIR scheme.

Many facilitators of app implementation in clinical settings have been identified. The involvement of patients and HCPs in app development has frequently been observed. Codevelopment was presented as a way to include desired mHealth features in early design efforts, to prevent unnecessary shortcomings, and activate a sense of ownership. These findings corroborated the idea that users should be intimately involved in the identification, design, and conduct phases of research, and not just be targets for the dissemination of study results [136]. An iterative development approach was often mentioned, as it ensured extensive usability testing during the development process.

As for implementation barriers, gradual rollouts and subsequent app version releases could be perceived as burdensome. From the provider's perspective, mHealth could be referred to as a source of extra workload for the clinical staff. Conversely, factors characterizing providers, such as organizational leaders and management, staff, and culture, which can influence their ability to adapt and successfully use an intervention, were not systematically observed. From the user's perspective, the fear of poorer patient-clinician interactions (eg, through remote monitoring) can diminish the sense of trust in the organization, in line with what was observed in prior works [137]. Although references to the outer setting (eg, laws and guidelines) were reported, mHealth was presented more as a way to address new or existing patient needs than as a way to respond to a given external pressure.

Broader Implications

Although some of the findings discussed above are supported in previous research [138], and more broadly in the implementation science literature applied to DHTs, mHealth-specific dimensions resonated in this analysis. The peculiarities of mHealth, including the iterative nature of the corresponding interventions, frequent user interactions, a nonlinear relationship between technology use, engagement, and outcomes, implications at the organizational level, and challenges associated with genericization, distinguish apps from other DHTs [139]. For instance, compared with medical devices, typically evaluated through comparative evidence, studies on mHealth are often single-arm, noncomparative. Implementation hurdles related to system interoperability, data management, and patient privacy could appear to be more intricate for mHealth. Although these factors are reflective of the implementation challenges of DHTs, the distinctive features of mHealth seem to exacerbate their complexity.

mHealth will become increasingly important. On one hand smartphones are becoming increasingly prevalent and provide augmented functionalities (eg, cameras to capture high definition images of body parts). In contrast, demographic and epidemiological trends report a boom in chronic conditions, whose needs can be addressed by mHealth. Digitalization of the health care sector is a key priority in the political agenda, as confirmed by the expected massive capital injection in response to the COVID-19 pandemic. With more than €750 billion (US $798.38 billion), the next-generation European Union fund will invest a relevant share in promoting digital health, further boosting the development of mHealth apps. Although a stronger financial commitment is advocated [131], even in contexts where governments are directing huge health care spending to mHealth (eg, German DiGA), reimbursement policies do not always translate into actual clinicians' prescriptions and are not a guarantee for users' uptake [140]. Therefore, there is a need to adopt assessment frameworks for DHTs, including mHealth apps. Guidance on how to operationalize later implementation efforts is strongly advocated to avoid investing in technologies that are likely to be abandoned.

Comparison With Prior Work

To our knowledge, this is the first review of the literature that uses a theory-guided framework to explore the determinants of mHealth implementation using a comprehensive approach in the area of cancer care. Other syntheses of primary studies mostly investigate the distinguishing features of mHealth [141,142] or their effectiveness in improving patient outcomes [143,144]. Studies illustrating the implementation initiatives in the area of mHealth are still limited and mainly document individual case studies. Although the field of implementation science has been growing, there is still a need to expand the use of implementation research to contribute to more effective public health and clinical practices [136]. Evidence suggests that theory-informed approaches to implementation science can enhance the translation and use of digital technologies in daily practice [145,146]. Under the lens of implementation science, Bardosh et al [138] conducted a qualitative evaluation of a single mHealth intervention addressing medication adherence and patient engagement. Heinsch et al [147] conducted a review of the theories that inform the implementation of eHealth interventions, and concluded that these are focused predominantly on predicting or explaining end user acceptance, and suggested that future research should test models that reflect the multidimensional, dynamic, and relational nature of the implementation process. Our work adds to the available literature by conducting a multidomain, multiple-stakeholder assessment of the determinants of mHealth implementation using the CFIR model. Rather than focusing more on a limited set of studies describing prevailing implementation research, our findings provide an integrated perspective on the factors that could influence the uptake and implementation of mHealth in clinical settings.

Limitations

This study has several limitations. First, the papers selected for analysis were heterogeneous in terms of study characteristics (eg, purposes, study setting, design, duration, number, and types of participants). The decision to include a diverse range of studies was justified by the exploratory nature of scoping reviews [148] and stemmed from the observation that evidence from implementation research on mHealth solutions remains scarce. This was reflected in the search string, where implementation-related terms had to be. In addition, elaborating on implementation strategies, such as those described by the ERIC taxonomy Powell et al [149], seemed premature and was not performed. Although 29% (26/91) of the studies were RCTs, a proxy for evidence strength or quality, 24% (22/91) of the selected records had a sample size smaller than 20 patients, and 57% (52/91) were single-arm studies. Given this heterogeneity, a risk of bias assessment was not performed, although this is not unusual in scoping reviews [39,150]. Study heterogeneity also limits the possibility of performing meta-analyses on comparable outcomes. Finally, limiting the search to studies in English published since 2017 excluded a priori other potentially relevant earlier studies written in different languages.

Conclusions

This review sheds light on the determinants of mHealth uptake in clinical practice, exploring the barriers and enablers of the implementation of cancer care apps using an established implementation science framework. It contributes to filling the knowledge gap by systematizing the dimensions that should be factored into when designing an implementation strategy for mHealth apps.

Future studies should investigate whether and how specific dimensions such as app development and deployment platforms could affect implementation-related elements. In addition, a core set of outcomes associated with successful implementation, measured in studies that discuss implementation initiatives including hybrid designs, should be developed [151]. Finally, future studies should complement the organizational perspective from the current work with a patient-oriented (user) view and investigate the relationship between patient-reported measures and implementation outcomes. In this regard, technology adoption models such as the Technology Acceptance Model [152] or the Unified Theory of Acceptance and Use of Technology [153] could be relevant theoretical starting points.

Acknowledgments

This study is part of a larger research conducted by CERGAS SDA Bocconi School of Management, which received unconditioned funding from Roche Italy. VA, OC, and RT designed this study. VA and GG developed the search strategy for this study. GG conducted the original literature searches and VA and GG were involved in data screening and study selection. GG extracted the data, while VA checked the extracted data for consistency, and RT mediated where there was disagreement or uncertainty regarding inclusion. VA and GG synthesized the findings. All authors have contributed to and approved the final manuscript. The data sets analyzed during this study are available from the corresponding author upon reasonable request. Requests for materials should be sent to VA.

Conflicts of Interest

None declared.

Multimedia Appendix 1
The 22-item Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist for scoping reviews.
[DOCX File , 23 KB - cancer_v9i1e42092_app1.docx]

Multimedia Appendix 2
Consolidated Framework for Implementation Research domains and constructs.
[DOCX File , 27 KB - cancer_v9i1e42092_app2.docx]

Multimedia Appendix 3
Overview of the descriptive statistics.
[DOCX File , 24 KB - cancer_v9i1e42092_app3.docx]

Multimedia Appendix 4
Characteristics of the selected studies.
[DOCX File , 46 KB - cancer_v9i1e42092_app4.docx]

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Abbreviations

CFIR: Consolidated Framework for Implementation Research

DHT: digital health technology
DiGA: Digital Health Applications
HCP: health care professional
mHealth: mobile health
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews
RCT: randomized controlled trial

Edited by T Leung; submitted 22.08.22; peer-reviewed by J Satterfield, Y Chu; comments to author 17.11.22; revised version received 31.01.23; accepted 26.02.23; published 30.03.23.

Please cite as:
Ardito V, Golubev G, Ciani O, Tarricone R
Evaluating Barriers and Facilitators to the Uptake of mHealth Apps in Cancer Care Using the Consolidated Framework for Implementation Research: Scoping Literature Review
JMIR Cancer 2023;9:e42092
URL: https://cancer.jmir.org/2023/1/e42092
doi:10.2196/42092
PMID:36995750

Original Paper

A Mobile App to Support Self-Management in Patients with Multiple Myeloma or Chronic Lymphocytic Leukemia: Pilot Randomized Controlled Trial

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Abstract

Background: Patients with blood cancer experience serious physical and emotional symptoms throughout their cancer journey.

Objective: Building on previous work, we aimed to develop an app designed to help patients with multiple myeloma and chronic lymphocytic leukemia self-manage symptoms and test it for acceptability and preliminary efficacy.

Methods: We developed our Blood Cancer Coach app with input from clinicians and patients. Our 2-armed randomized controlled pilot trial recruited participants from Duke Health and nationally in partnerships with the Association of Oncology Social Work, Leukemia and Lymphoma Society, and other patient groups. Participants were randomized to the attention control (Springboard Beyond Cancer website) arm or the Blood Cancer Coach app intervention arm. The fully automated Blood Cancer Coach app included symptom and distress tracking with tailored feedback, medication reminders and adherence tracking, multiple myeloma and chronic lymphocytic leukemia education resources, and mindfulness activities. Patient-reported data were collected at baseline, 4 weeks, and 8 weeks for both arms through the Blood Cancer Coach app. Outcomes of interest were global health (Patient Reported Outcomes Measurement Information System Global Health), posttraumatic stress (Posttraumatic Stress Disorder Checklist for DSM-5), and cancer symptoms (Edmonton Symptom Assessment System Revised). Among participants in the intervention arm, satisfaction surveys and usage data were used to evaluate acceptability.

Results: Among 180 patients who downloaded the app, 49% (89) of them consented to participate and 40% (72) of them completed baseline surveys. Of those who completed baseline surveys, 53% (38) of them completed week 4 surveys (16 intervention and 22 control) and 39% (28) of them completed week 8 surveys (13 intervention and 15 control). Most participants found the app at least moderately effective at helping manage symptoms (87%), feeling more comfortable seeking help (87%), increasing awareness of resources (73%), and reported being satisfied with the app overall (73%). Participants completed an average of 248.5 app tasks over the 8-week study period. The most used functions within the app were medication log, distress tracking, guided meditations, and symptom tracking. There were no significant differences between the control and intervention arms at week 4 or 8 on any outcomes. We also saw no significant improvement over time within the intervention arm.

Conclusions: The results of our feasibility pilot were promising in which most participants found the app to be helpful in managing their symptoms, reported satisfaction with the app, and that it was helpful in several important areas. We did not, however, find significantly reduced symptoms or improved global mental and physical health over 2 months. Recruitment and retention were challenging for this app-based study, an experience echoed by others. Limitations included a predominantly White and college educated sample. Future studies would do well to include self-efficacy outcomes, target those with more symptoms, and emphasize diversity in recruitment and retention.

Trial Registration: ClinicalTrials.gov NCT05928156; https://clinicaltrials.gov/study/NCT05928156

(JMIR Cancer 2023;9:e44533) doi:10.2196/44533

KEYWORDS

chronic lymphocytic leukemia; distress; intervention; leukemia; mHealth; mobile application; multiple myeloma; post-traumatic stress; self-management; symptoms; treatment

Introduction

Physical and emotional symptoms are common among cancer survivors due to their disease and its treatment and are particularly debilitating for those with blood cancers [1,2]. Blood cancer survivors experience serious physical (eg, insomnia and fatigue) and emotional (eg, worry and distress) symptoms throughout their cancer journey [3-5]. Among blood cancers, multiple myeloma (MM) and chronic lymphocytic leukemia (CLL) are the 2nd and 3rd most common types, respectively, and are considered incurable. MM and CLL have a chronic relapsing remitting course that often requires multiple lines of treatment [6,7]. This increases the potential for disease and treatment-related physical symptoms and emotional distress [6-9].

Interventions that target physical and emotional symptoms are lacking for blood cancer survivors. Due to the increasing use of technology, digital health solutions are becoming more commonplace and are helping to bridge the gap in services for underserved populations. For example, in 2021 it was estimated that 85% of adults in the United States own a smartphone, including most adults (61%, 65 years of age or older) and 80% of adults who are living in rural settings [10]. mHealth apps present exciting opportunities to augment patients' disease self-management and meet needs wherever and whenever they arise in a way that is cost-effective, efficient, and convenient. Self-management apps have been developed and tested for those with diabetes, chronic lung disease, cardiovascular disease, and cancer, including Cancer Distress Coach which informed this study's Blood Cancer Coach app [11-13].

Despite the growing use of mHealth apps, evidence of their effectiveness in cancer survivors remains sparse [14]. Therefore, the purpose of this study was to develop and test a blood cancer app aimed at augmenting self-management for adults living with MM and CLL for acceptability and preliminary efficacy.

Methods

App Development

Our Blood Cancer Coach app development was largely informed by the Cancer Distress Coach app developed previously by our research team [11]. Cancer Distress Coach is focused on education and self-management of cancer-related posttraumatic stress (PTS) symptoms and includes education, support resources, mindfulness exercises, and self-assessments [11]. With Cancer Distress Coach as our starting point, we interviewed patients with blood cancer and clinicians to determine how best to deliver a more targeted app to specifically meet their needs and challenges.

Pilot Trial

Once developed, we aimed to test the app's acceptability and preliminary efficacy through a 2-armed randomized pilot clinical trial. Trial participants were recruited from the Duke University Health System using the web-based patient portal (MyChart) to send email invitations. National recruitment was facilitated through partnerships with the Association of Oncology Social Work, Leukemia and Lymphoma Society, and private patient groups that were contacted through Facebook. Our eligibility criteria included having either a MM or CLL diagnosis, being at least 18 years of age, being able to read English, owning a smartphone (iPhone or Android), and basic computer and internet literacy. Recruitment and enrollment occurred between December 2020, and October 2021. Participants were followed for 8 weeks following enrollment.

Potential participants were provided access codes to download Blood Cancer Coach through Pattern Health's iOS and Android platform app. The Blood Cancer Coach app was used to administer informed consent, randomize participants 1:1 to attention control (Springboard Beyond Cancer website) or the Blood Cancer Coach intervention arm, and collect self-reported data through surveys. Data were collected on intervention and control arm participants at baseline, and 4 and 8 weeks after study enrollment. Because our control arm was not a placebo, participants were aware of their group assignment.

Measures

Demographic and clinical characteristics were self-reported at baseline. Outcomes were self-reported at baseline, week 4, and week 8 through the Blood Cancer Coach app. App usage was assessed at the end of the study period using Pattern Health app usage analytics. For those in the intervention arm, acceptability was measured using a perceived helpfulness and satisfaction survey administered at week 8. All data collection were done through the Blood Cancer Coach app.

Efficacy outcomes of interest were global health, posttraumatic stress, and cancer symptoms [15-17]. Global health was measured using the 10-item PROMIS (Patient Reported Outcomes Measurement Information System) Scale version 1.2-Global Health [18]. This scale results in summary global mental health (GMH) and global physical health (GPH) scores [18]. The Global Health scale is made up of 5-point Likert-type items. Scoring was done using HealthMeasures scoring service [19]. Like all PROMIS measures scores are transformed onto a T-score metric, in which 50 corresponds to the general population mean with SD of 10 [20]. Higher scores indicate better global physical and mental health [20].

Cancer symptoms were assessed using the 10-item Edmonton Symptom Assessment System Revised (ESAS-r), which measures 9 common cancer symptoms on a 0-10 rating scale [21,22]. A total symptom score was calculated for analysis by summing severity scores across symptoms. Higher scores correspond to higher symptom burden.

PTS symptoms were measured using the Posttraumatic Stress Disorder Checklist for DSM-5 (PCL-5) [17]. This 20 item instrument measures the severity of 20 symptoms of PTS on a 5-point Likert scale (0=not at all to 4=extremely). Item scores are summed to result in a continuous measure of PTS symptoms where higher scores indicate a higher burden of PTS symptoms. Previous psychometric evaluation revealed an internal consistency (α) of .94 and test-retest reliability (r) of 0.82 [17].

Acceptability was assessed using a study based on perceived helpfulness and satisfaction survey. Participants were asked to rate their overall satisfaction using the app and their perceptions of the helpfulness of different features of the app on a 5-point Likert scale. Participants were also invited to provide free-text feedback through two prompts: (1) what did you like best about the Blood Cancer Coach App? (2) How can we change Blood Cancer Coach to make it better? App usage was tracked by Pattern Health mobile app platform. A date and time stamped log was created when a user began a task (eg, logging a medication) that further indicated whether the task was completed.

Analysis

Descriptive statistics were used to summarize participant characteristics across study arms. Results of the perceived helpfulness and satisfaction survey results were summarized with mean (SD). Further, the percentage of those endorsing Likert scale ratings of 3 (moderately satisfied or moderately helpful) was reported. Acceptability will be determined if more than 70% participants report overall satisfaction of moderate or better. Free text answers to the perceived helpfulness and satisfaction survey were narratively summarized to gain further insight into acceptability. We will also describe usage rates of the app overall and by task type.

Independent *t* tests were used to compare change from baseline to week 4 between intervention and control arms. Paired *t* tests were used to compare score changes from baseline to week 4, and from baseline to week 8 in participants of the intervention arm. Effect sizes were estimated using Cohen *d* [23].

Ethics Approval

This study was approved by the Duke University IRB (Pro00105025). Patients reviewed study details and indicated their consent within the Blood Cancer Coach App. Patients were encouraged to contact our study team if they had any questions or concerns before consenting and at any time during the study. Our app development partner Pattern Health is approved by Duke University to participate in research activities including hosting sensitive patient health information. Patient health information collected through the app include, name, age in years, email address, and date of MM or CLL diagnosis. All data were encrypted in transit and at rest on Pattern Health servers. Data stored locally on participants' mobile devices were encrypted by the Pattern Health App. Study team access to user data was password protected and limited to MRL, SKS, and JM. All data analyses were conducted on deidentified data. Patients did not receive compensation for this study.

Results

App Development

We interviewed 17 patients with blood cancer and 13 blood cancer clinicians to refine the Blood Cancer Coach mobile app. Our interviews used a previous app (Cancer Distress Coach) developed by the team as a starting point and explored what functionality would be helpful for the specific self-management needs of patients with blood cancer. These interviews resulted in several additions to the app which included feedback tailored to symptom severity, and the inclusion of a medication tracking feature with medication reminder notifications. Our Blood Cancer Coach app was developed in partnership with Pattern Health, a digital health platform provider, and was refined iteratively based on feedback from our clinician and cancer survivor partners [24].

The fully automated (no external human involvement) Blood Cancer Coach mobile app provides educational content on MM and CLL (treatments, symptom management, and available resources). Participants are prompted to record their emotional distress daily and their symptoms weekly through mobile phone notifications. Participants also have the ability to record distress and symptoms more often. A library of guided meditations is available to help participants manage distress. Tailored feedback is provided to encourage self-management and coach participants to reach out for support when appropriate. Symptom and distress graphs are generated to help participants understand and communicate patterns. The app also features custom medication reminders and a medication log to track adherence to cancer treatment and use of as needed medications.

Pilot Trial

Among the 180 patients who downloaded the app, 49% (89/180) consented to participate, and 40% (72/180) completed baseline surveys. Of those who completed baseline surveys, 53% (38/180) completed week 4 surveys (16 intervention and 22 control) and 39% (28/180) completed week 8 surveys (13 intervention and 15 control; Figure 1). Demographics are reported for those who completed week 4 surveys (Table 1). Our sample was 50% (19/38) female, 92% (35/38) non-Hispanic

White, 79% (30/38) college educated, and 8% (3/38) reported income less than US $30,000. Demographic and outcome measurements did not differ significantly at baseline between those who completed week 4 surveys and those who did not, except that those who completed baseline surveys but not week 4 surveys were on average 4.2 years older (t_{70}=2.41, P=.02).

Figure 1. CONSORT (Consolidated Standards of Reporting Trials) subject flow diagram.

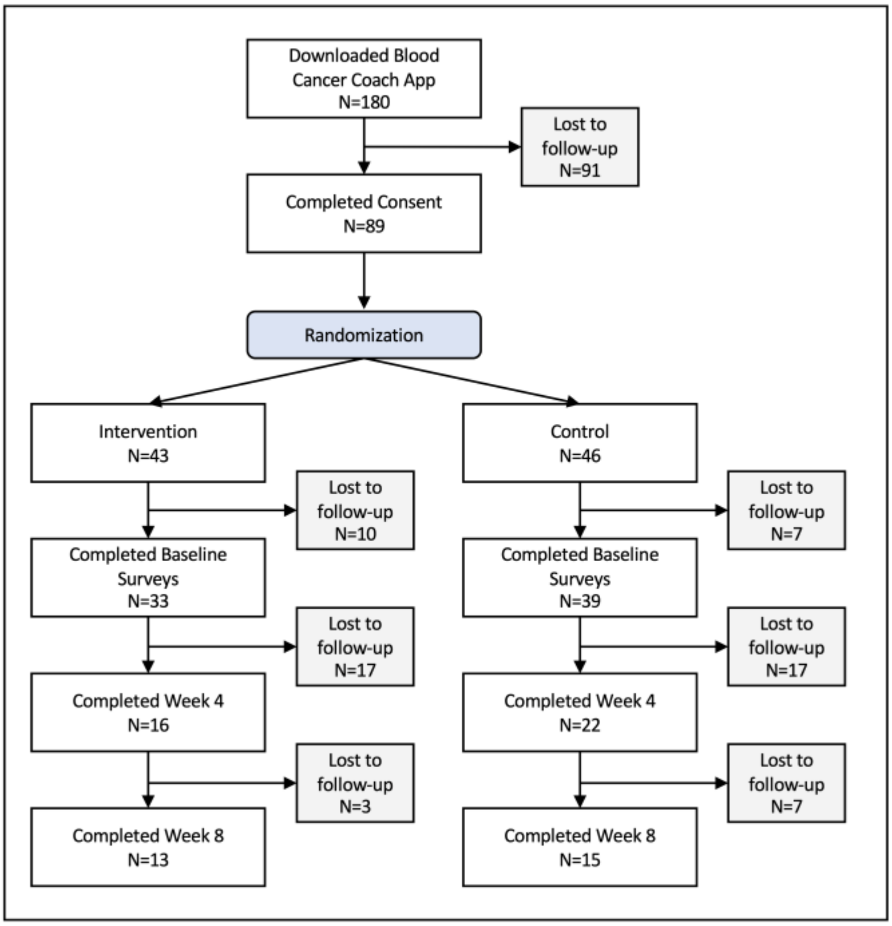

Table 1. Participant characteristics.

Characteristics	Total (N=38)	Control (N=22)	Intervention N=16
Age (years), mean (SD)	62.9 (7)	64.8 (6)	60.3 (7)
Sex, n (%)			
Female	19 (50)	11 (50)	8 (50)
Male	19 (50)	11 (50)	8 (50)
Race, n (%)			
White	35 (92)	22 (100)	13 (81)
Black	3 (7)	0 (0)	3 (18)
Other	0 (0)	0 (0)	0 (0)
Ethnicity, n (%)			
Hispanic	1 (2)	1 (4)	0 (0)
Partnered, n (%)	33 (87)	19 (86)	14 (87)
College graduate, n (%)	30 (79)	18 (81)	12 (75)
Employment, n (%)			
Employed	18 (47)	6 (27)	12 (75)
Retired	16 (42)	12 (54)	4 (25)
Disabled	1 (2)	1 (4)	0 (0)
Homemaker	1 (2)	1 (4)	0 (0)
Income (US $), n (%)			
<30,000	3 (8)	3 (13)	0 (0)
30,000-59,999	5 (13)	3 (13)	2 (13)
60,000-89,999	9 (23)	4 (18)	5 (31)
>90,000	21 (55)	12 (55)	9 (56)
Multiple myeloma, n (%)	14 (37)	8 (36)	6 (38)
Chronic lymphocytic leukemia, n (%)	24 (63)	14 (64)	10 (63)
Remission, n (%)	16 (42)	11 (50)	5 (31)
Current treatment, n (%)	17 (45)	10 (45)	7 (44)
Past treatment, n (%)			
None	13 (34)	6 (27)	7 (44)
Surgery	2 (5)	2 (9)	0 (0)
Radiation therapy	2 (5)	1 (5)	1 (6)
Intravenous therapy	19 (50)	13 (59)	6 (38)
Oral therapy	18 (47)	11 (50)	7 (44)
Stem cell transplant	9 (23)	6 (27)	3 (19)
Other cancer, n (%)	12 (32)	7 (32)	5 (31)

Acceptability Results

Of the 16 intervention arm participants, 15 participants completed our perceived helpfulness survey. Almost three quarters (n=11, 73%) reported at least moderate satisfaction with the app (Table 2). Additionally, most participants found the app at least moderately effective at helping manage symptoms (n=13, 87%), feeling more comfortable when seeking help (n=13, 87%), and increasing awareness of resources (n=11, 73%). Participants in the intervention arm completed an average of 148.5 (SD 118.6) app tasks during the 8-week study period and app usage ranged from 11 to 518 tasks completed. The most used functions within the app as measured by mean usage across participants were the medication log (mean 66.1, SD 76.3), distress tracking (mean 47.1, SD 25.5), and daily tips (mean 12.9, SD 21.5). Regarding the open-ended questions soliciting user satisfaction and perceived helpfulness, 27% (4/15) of participants cited the guided meditations and daily inspirational quotes as the best parts of the app, 20% (n=3) of them cited the ability to see how things change day by day, and 20% (3) of them said they appreciated the medication tracking and reminders. Three of 15 (20%) participants suggested changes in the way the app functioned, such as adding the ability to edit the previous day's entries. Further, 2 of 15 (13%) participants mentioned that they themselves were not experiencing many symptoms and thought the app might be more helpful for those with higher burdens of physical symptoms and emotional distress.

Table 2. Perceived helpfulness and satisfaction[a] (N=15).

Item	Mean (SD)	Endorsed moderately or greater, n (%)
Overall, how satisfied are you with Blood Cancer Coach?	3.27 (1.28)	11 (73)
How helpful was Blood Cancer Coach in the following areas?		
Helping me find effective ways of managing my symptoms	3.33 (1.11)	13 (87)
Helping me feel more comfortable in seeking support	3.07 (1.10)	13 (87)
Helping me feel that there is something I can do about my symptoms	3.60 (1.18)	13 (87)
Helping me track my symptoms	3.73 (1.39)	12 (80)
Helping me to know when I am doing better or when I am doing worse	3.47 (1.40)	12 (80)
Enhancing my knowledge of multiple myeloma or CLL[b]	3.33 (1.23)	12 (80)
Helping me overcome the stigma of seeking mental health services	3.07 (1.28)	11 (73)
Helping me better understand what I have been experiencing	3.27 (1.33)	11 (73)
Increasing my access to additional resources	3.33 (1.29)	11 (73)
Providing practical solutions to problems experience	3.13 (1.30)	10 (67)
Providing a way for me to talk about what I have been experiencing	3.20 (1.37)	10 (67)
Helping me learn about symptoms related to my multiple myeloma or CLL	2.93 (1.33)	9 (60)
Helping me learn about treatments for my multiple myeloma or CLL	2.80 (1.47)	9 (60)

[a] Likert-scale values: 1=not at all; 2=slightly; 3=moderately; 4=very; 5=extremely.

[b] CLL: chronic lymphocytic leukemia.

Preliminary Efficacy Results

At week 4, there were no significant differences in change from baseline between control and intervention arms for any of our patient-reported outcomes (Table 3). Among those in the intervention arm, mean improvements in GPH from baseline to week 4 (mean 0.49, SD 3.5) and from baseline to week 8 (mean 0.23, SD 5.9) were nonsignificant (*P*=.59 and *P*=.17; Table 4). Similarly, improvements in GMH from baseline to week 4 (mean 0.16, SD 5.7) and baseline to week 8 (mean 2.2, SD 5.7) were nonsignificant (*P*=.91 and *P*=.19). Mean reductions in ESAS-r symptom scores from baseline to week 4 (mean –1.5, SD 6.8) and baseline to week 8 (mean –0.76, SD 5.6) were also nonsignificant (*P*=.39 and *P*=.63). Mean reductions in PCL-5 scores from baseline to week 4 (mean –0.69, SD 5.2) and baseline to week 8 (mean –1.5, SD 6.5) were nonsignificant as well (*P*=.61 and *P*=.41). Effect sizes, measured using Cohen *d*, ranged from 0.03 to 0.40 (Table 4).

Table 3. Differences in change from baseline to week 4, independent *t* test.

Reports	Score change intervention (n=16), mean (SD)	Score change control (n=22), mean (SD)	*t* test (*df*)	*P* value
Global physical health	0.49 (3.51)	0.76 (4.61)	0.20 (36)	.84
Global mental health	0.17 (5.70)	0.28 (3.98)	0.08 (36)	.94
Cancer symptoms	–1.50 (6.80)	–5.22 (10.18)	–1.27 (36)	.21
Posttraumatic stress	–0.69 (5.21)	–1.59 (3.02)	–0.67 (36)	.50

Table 4. Change over time within the intervention arm, paired *t* test.

Reports	Baseline to 4 weeks (n=16)			Baseline to 8 weeks (n=13)		
	Mean (SD)	Effect size[a]	*P* value	Mean (SD)	Effect size[a]	*P* value
Global physical health	0.49 (3.51)	0.14	.59	2.37(5.92)	0.40	.17
Global mental health	0.17 (5.70)	0.03	.91	2.18 (5.70)	0.38	.19
Cancer symptoms	1.50 (6.80)	0.22	.39	0.77 (5.64)	0.13	.63
Posttraumatic stress	0.69 (5.21)	0.13	.61	1.54 (6.50)	0.24	.41

[a] Effect size: Cohen *d*.

Discussion

Overview

In this study, we aimed to develop and pilot test a mobile health app to help patients with blood cancer self-manage their physical and emotional symptoms. Through an iterative process in partnership with clinicians and patients with blood cancer, we developed the Blood Cancer Coach mobile app for testing acceptability and preliminarily efficacy.

Participants in the intervention arm reported high levels of overall satisfaction (11/15, 73.3%) and reported that they found the app helpful in important domains we were hoping to impact, such as understanding, tracking, and managing symptoms (Table 2). We also noted a high level of engagement with the app as measured by tasks completed. These high levels of user satisfaction and engagement are evidence for our app's acceptability and suggest that the Blood Cancer Coach app has the potential to help patients self-manage their MM- and CLL-related symptoms. On the other hand, high levels of study attrition are reason for concern and may suggest that the appeal of the app is limited to subpopulations of MM and CLL patients. In response to open-ended questions on our satisfaction survey, 2 participants indicated that they did not find the app useful and attributed this to the fact that they were experiencing low levels of symptoms and other issues. Perhaps, the app may not be useful or appealing to patients with low levels of physical and mental health concerns.

We found no significant effects on our outcomes of interest, either overtime in the intervention group, or between the intervention and control arms of the study. Negative efficacy results are not uncommon in mobile app studies. A recent systematic review of health behavior change mobile apps found that approximately 45% studies found no significant difference between mobile app users and comparator arms; furthermore, 31% of mobile app studies demonstrated some effectiveness in changing target health outcomes significantly more than comparator arms [25]. We believe there are several reasons for the nonsignificant findings among the outcomes of interest. For example, our sample size was quite small, and this pilot study was not powered to detect differences.

Unlike this study, a single arm pilot study of the Cancer Distress Coach app that served as our prototype found significant reductions in posttraumatic stress symptoms over 8 weeks [11]. Differences in app and study design may be instructive. The Cancer Distress Coach app was singularly focused on identifying and addressing emotional distress as measured by the posttraumatic stress disorder checklist, and it is possible that this more focused approach is more effective. Importantly, eligibility criteria required that participants have active symptoms of posttraumatic stress disorder. Responses to our free text survey question suggest that the app was not very helpful to those experiencing low levels of symptoms or distress. Further these responses also suggest the app may have had a positive effect on perceived self-management efficacy. Future studies should target participants with moderate to high levels of symptom burden and distress and include self-efficacy as an outcome.

We encountered several challenges and limitations while performing this study that are worth mentioning. Randomization resulted in suboptimal distribution of patient characteristics across trial arms. Of note, cancer symptoms as measured by the ESAS-r were substantially higher in the control arm across all study time points. Future studies with larger sample size and recruitment targeted toward patients with moderate to high levels of cancer symptoms would potentially address this limitation (Table 5). We also experienced significant attrition as only 39% of participants completed the week 8 surveys (ie, all planned data collection). These low response rates introduce potential bias if those who respond are systematically different from those who do not respond. Like other mHealth studies, our study sample was overwhelmingly White and highly educated (Table 1) [11,14]. This is problematic for several reasons, among them that racial minorities and those with lower socioeconomic status consistently report worse health outcomes than their White peers and those with higher socioeconomic status [26,27]. Our trials are not reaching the patient populations who might have the greatest need for emotional and physical symptom management, robbing us of evidence in these populations with high needs. A more targeted recruitment strategy focusing on underserved cancer patient populations is warranted.

Table 5. Patient-reported outcome scores across time[a].

Reports	Baseline	Week 4	Week 8
Global physical health, mean (SD)			
Intervention	46.02 (6.95)	46.51 (6.20)	48.92 (8.21)
Control	46.32 (6.09)	47.08 (7.06)	46.47 (7.28)
Global mental health, mean (SD)			
Intervention	49.49 (6.35)	49.66 (7.90)	52.52 (7.38)
Control	46.59 (5.31)	46.87 (6.83)	46.68 (6.04)
Cancer symptoms, mean (SD)			
Intervention	10.94 (7.63)	9.44 (7.47)	9.69 (8.27)
Control	22.59 (15.24)	17.36 (11.90)	20.40 (13.74)
Posttraumatic stress, mean (SD)			
Intervention	7.56 (6.21)	7.56 (6.21)	6.54 (6.60)
Control	8.91 (9.26)	8.91 (9.26)	6.64 (6.10)

[a] Reported as mean (SD). Sample sizes for baseline and week 4 are as follows: intervention=16, control=22. Sample size for week 8 is as follows: intervention=13, control=15.

Conclusions

Most treatment arm participants reported satisfaction with the app and that it was helpful in several important areas, though we did not find significantly improved GMH or GPH, cancer symptoms, or PTS over 2 months. Satisfaction survey results suggest the app may work best for those with higher symptom burden and that self-efficacy would be an important outcome to measure in future studies. Recruitment and retention were challenging for this app-based study, an experience echoed by others [28]. Of particular concern is the lack of racially diverse and lower income participants, populations known to experience high levels of physical and emotional symptoms [26,27]. Future studies would do well to include self-efficacy outcomes, target those with moderate to high burdens of symptoms and distress, and emphasize diversity in recruitment and retention.

Acknowledgments

This study was supported by the Association of Oncology Social Work.

Data Availability

The data sets generated and analyzed during this study are not publicly available but are available from the corresponding author on reasonable request.

Conflicts of Interest

TWL is currently or has recently been a consultant for or has received honoraria from AbbVie, Agilix, Agios/Servier, Astellas, AstraZeneca, Beigene, BlueNote, BMS/Celgene, CareVive, Flatiron, Genentech, GSK, Lilly, Meter Health, Novartis, and Pfizer. TWL has served on recent advisory boards for AbbVie, Agios, and BMS. TWL has received honoraria from AbbVie, Agios, Astellas, BMS/Celgene, and Incyte for recent speaking engagements has equity interest in Dosentrx. TWL has received recent research funding from the AbbVie, American Cancer Society, AstraZeneca, BMS, Deverra Therapeutics, Duke University, Jazz Pharmaceuticals, the Leukemia and Lymphoma Society, the National Institute of Nursing Research/ National Institutes of Health, and Seattle Genetics.

Editorial Notice

This randomized study was only retrospectively registered. The authors explained that their institutional review board (IRB) did not require prospective registration for this small pilot trial in which recruitment was limited to their institution. The editor granted an exception from ICMJE rules mandating prospective registration of randomized trials because the risk of bias appears low and the study was considered formative. However, readers are advised to carefully assess the validity of any potential explicit or implicit claims related to primary outcomes or effectiveness, as retrospective registration does not prevent authors from changing their outcome measures retrospectively.

Multimedia Appendix 1
CONSORT-eHEALTH checklist (V 1.6.1).
[PDF File (Adobe PDF File), 324 KB - cancer_v9i1e44533_app1.pdf]

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Abbreviations

CLL: chronic lymphocytic leukemia
ESAS-r: Edmonton Symptom Assessment System Revised
GMH: global mental health
GPH: global physical health
MM: multiple myeloma
PCL-5: Posttraumatic Stress Disorder Checklist for DSM-5
PROMIS: Patient Reported Outcomes Measurement Information System
PTS: posttraumatic stress

Edited by A Mavragani; submitted 28.11.22; peer-reviewed by E Børøsund, Horner; comments to author 06.02.23; revised version received 20.04.23; accepted 18.05.23; published 06.07.23.

Please cite as:
LeBlanc MR, LeBlanc TW, Yang Q, McLaughlin J, Irish K, Smith SK
A Mobile App to Support Self-Management in Patients with Multiple Myeloma or Chronic Lymphocytic Leukemia: Pilot Randomized Controlled Trial
JMIR Cancer 2023;9:e44533
URL: https://cancer.jmir.org/2023/1/e44533
doi:10.2196/44533
PMID:37410541

Original Paper

Identification of the Needs and Preferences of Patients With Cancer for the Development of a Clinic App: Qualitative Study

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Abstract

Background: Mobile health (mHealth) tools were developed during the past decades and are increasingly used by patients in cancer care too. Scientific research in the development of mHealth services is required in order to meet the various needs of patients and test usability.

Objective: The aim of this study is to assess patients' needs, preferences, and usability of an app (My University Clinic [MUC] app) developed by the Comprehensive Cancer Center Freiburg (CCCF) Germany.

Methods: Based on a qualitative cross-sectional approach, we conducted semistructured interviews with patients with cancer, addressing their needs, preferences, and usability of the designed MUC app. Patients treated by the CCCF were recruited based on a purposive sampling technique focusing on age, sex, cancer diagnoses, and treatment setting (inpatient, outpatient). Data analysis followed the qualitative content analysis according to Kuckartz and was performed using computer-assisted software (MAXQDA).

Results: For the interviews, 17 patients with cancer were selected, covering a broad range of sampling parameters. The results showed that patients expect benefits in terms of improved information about the disease and communication with the clinic staff. Demands for additional features were identified (eg, a list of contact persons and medication management). The most important concerns referred to data security and the potential restriction of personal contacts with health care professionals of the clinical departments of the CCCF. In addition, some features for improving the design of the MUC app with respect to usability or for inclusion of interacting tools were suggested by the patients.

Conclusions: The results of this qualitative study were discussed within the multidisciplinary team and the MUC app providers. Patients' perspectives and needs will be included in further development of the MUC app. There will be a second study phase in which patients will receive a test version of the MUC app and will be asked about their experiences with it.

Trial Registration: Deutsches Register Klinischer Studien DRKS00022162; https://drks.de/search/de/trial/DRKS00022162

(JMIR Cancer 2023;9:e40891) doi:10.2196/40891

KEYWORDS

cancer; mobile app; mHealth; mobile health; needs assessment; patient-centered care; PROM; patient-reported outcome measures; qualitative methods

Introduction

There is a need for more patient empowerment, self-management, and patient participation in health care. Mobile health (mHealth) has proven effective as a technology addressing this need [1]. mHealth is defined by the Global Observatory for eHealth as a medical and public health practice supported by mobile devices, such as mobile phones, patient-monitoring devices, personal digital assistants, and other wireless devices [2]. There is a growing number of mHealth interventions, such as smartphone apps for patients with cancer [3-6]. The range of apps used in oncology is extensive and includes various features, such as symptom assessment through online questionnaires applying patient-reported outcome measures (PROMs), appointment coordination, recommendations for self-care (eg, nutrition, exercise, wound care), and psychological-related self-care (eg, coping). In addition, there are app features, such as diagnosis-specific medical information, medication reminders, access to personal medical data, and social support through interactive communication with peers [4,7-9]. The willingness of patients to use these apps ranges from 52% to 87% [10-12]. However, there are also typical concerns that discourage patients from using such apps: the desire for personal contact with the treating physician, concerns about the security of personal data, and the insecurity about one’s own technical abilities [13-15]. In studies, a young age, the male gender, solid technical know-how, a higher socioeconomic status, and higher educational and income levels were associated factors influencing the willingness of patients to use apps in cancer care [10,13,16,17].

As only a small part of mHealth interventions is scientifically evaluated [18], there is a need for including scientific evaluation into the development of mHealth tools already in early phases. Therefore, it is necessary to involve patients in the development process of mHealth apps [19,20] to meet patients' needs for more empowerment and self-management and to develop best-practice features and services for clinical application. However, this recommendation to involve patients at the beginning of the app development process has been rarely followed. This can lead to a lower usage rate due to a lack of a needs-based approach.

Against the background of this study, the Medical Center – University of Freiburg (Germany) developed an app (My University Clinic [MUC]) as a communication tool for patients to support comprehensive cancer care at a large Comprehensive Cancer Center Freiburg (CCCF). The MUC app is not designed as a digital health app but as an information and communication tool for patients at the university clinic. The MUC app includes the following basic functions: (1) appointment management and navigation, (2) access to medical reports, (3) online forms and PROM questionnaires, (4) a health diary to track the development of cancer symptoms and treatment side effects, (5) and general information about the clinic and the disease.

Methods

Study Design

The overall aim of our study is to actively involve patients in the development process of the MUC app in order to assess their needs and preferences and investigate their acceptance and usability of the basic structure of the MUC app. The detailed objectives of this qualitative study are (1) to assess the needs, wishes, and preferences of patients with cancer related to the MUC app and (2) to identify patients’ barriers and fears that may limit the use of mHealth and the usability of this patient group. The findings will be incorporated into the app development process, which should help achieve higher acceptance and a higher rate of use. For this purpose, we chose a qualitative study approach and conducted semistructured interviews with patients with cancer using the qualitative content analysis model [21,22] as an explorative approach.

Recruitment

The inclusion criteria for participation were any cancer diagnosis, current or past cancer treatment at the Medical Center – University of Freiburg, a minimum age of 18 years, and command of the German language. The recruitment period lasted from October 2020 to March 2021. Based on purposive sampling, we distributed information material on our interview study within the Medical Center – University of Freiburg. In addition, we contacted physicians from different departments to address patients. During the recruitment period, we monitored the sampling parameters, focusing on age, sex, cancer diagnoses, and treatment setting (inpatient, outpatient). We consecutively included 17 patients from various oncological departments of the Medical Center – University of Freiburg.

Data Collection

After conducting a literature search, identifying important issues for patients concerning the needs, barriers, and feasibility related to health apps, a team of multidisciplinary experts (n=4), including physicians, psychologists, biologists, and computer scientists, developed a semistructured interview guide in a multistage consensus process. The final interview guide (see Multimedia Appendix 1) was structured into 13 thematic domains with detailed subqueries. Before the semistructured interviews were conducted and digitally recorded, the patients were introduced to the concept of the MUC app to support cancer care via standardized instructions, including a presentation of the 5 intended main functions of the app, and they completed a questionnaire on demographics and cancer status. All the main functions were presented in an illustrative way. We started the interview asking for general attitudes in terms of app use in daily life and in the health area, followed by an assessment of needs, concerns, and perceived advantages of an app to support cancer care. At the beginning of each domain, the interviewers started with key story–generating questions and optional subqueries [23]. In the second part, the interviewers explained the planned MUC app with its 5 basic features. Patients commented on the basic features and answered questions on how acceptance and usability could be improved. The interviewees got an opportunity to make further suggestions for the MUC app's functions. All interviews were conducted by

LRW, author of this paper. The interviews were consecutively transcribed and analyzed to obtain a first overview about the main content categories. Referring to the concept of saturation, we stopped recruitment after verifying that no new aspects emerged from the interview data.

Patients were interviewed in person (n=7, 41.2%) or over the phone due to the COVID-19 pandemic (n=10, 58.8%). The interviews lasted on average 71 minutes (range 60-98 minutes).

Analysis

The recorded interviews were transcribed verbatim and anonymized. Two scientists with an MSc (authors LRW and CD) coded and analyzed the transcripts independently with the software tool MAXQDA 2020 using content-structuring qualitative content analysis according to Kuckartz [21] and thereby following the model of qualitative content analysis [21,22] to identify themes and subthemes. We combined a deductive and an inductive approach. We formed 13 main categories based on the structure of the interview guide (deductive). Following the inductive approach, we identified subcategories from the interview material. The inductive process was already developed in parallel with the data collection phase, so it was possible to get an idea of whether theoretical saturation (no significantly new topic areas are identified) had been achieved. During this process, the 2 coders discussed the resulting category system until they finally agreed on the final category system. Anchor citations were assigned to the codes, as well as the respective number of people endorsing the code. Using the final hierarchical category system, 12 of 17 (70.6%) interviews were then recoded in a second run to determine the interrater reliability. The kappa (κ_n) coefficient according to Brennan and Prediger [24] was calculated. The resulting κ_n=0.93 corresponded to good agreement between coders [25,26].

Ethical Considerations

Before the start of the study, an ethics vote was obtained from the Ethics Committee of the University in Freiburg (no. 435/20) and the study was registered in the Deutsches Register Klinischer Studien (DRKS; reg. no. DRKS00022162). Before the interviews started, all participants were informed about the study. Participants were included after they provided informed consent. A signed informed consent form was available for all participants. In the transcription of the interviews, we confirm that all patient identifiers were removed or disguised, so the patients described are not identifiable (they cannot be identified through the details of the paper), and the interviews were analyzed anonymously. There was no financial compensation for participation.

Results

Description of the Sample

A total of 17 patients (n=8, 47.1%, female and n=9, 52.9%, male) with cancer participated in the needs assessment interviews. As can be seen in Table 1, the patients ranged in age from 26 to 76 years, with a mean age of 54 (SD 13) years. The educational level of the sample was heterogeneous, with most of the patients (n=12, 70.8%) indicating secondary school as their highest school diploma. The sample was heterogeneous in terms of diagnosis, treatment, and tumor status (see Table 2). The patients were in different phases of their cancer treatment. The time since the first diagnosis ranged from 4 months to 16 years (mean 3.6 years, SD 52 months). The most common diagnoses were breast cancer (n=5, 29.4%) and lymphoma (n=3, 17.6%). At the time of the interviews, the majority of patients (n=14, 82.4%) were under ongoing treatment.

Table 1. Sociodemographic data of the sample (N=17).

Sociodemographics	Value
Age (years)	
Mean (SD)	54 (13)
Range	26-76
Gender, n (%)	
Female	8 (47.1)
Male	9 (52.9)
Highest education level, n (%)	
University	2 (11.8)
A level	3 (17.7)
Secondary school	12 (70.8)
Profession, n (%)	
Employee	5 (29.4)
Pensioner	7 (41.2)
Self-employed	3 (17.6)
Unemployed	1 (5.9)
Civil servant	1 (5.9)

Table 2. Medical data of the sample (N=17).

Cancer status	Value
Diagnosis, n (%)	
Breast cancer	5 (29.4)
Lymphoma	3 (17.6)
Lung cancer	2 (11.8)
Brain tumor	2 (11.8)
Laryngeal cancer	1 (5.9)
Pancreatic cancer	1 (5.9)
Skin cancer	1 (5.9)
Myeloma	1 (5.9)
Ovarian cancer	1 (5.9)
Metastasis, n (%)	
Yes	3 (17.6)
No	14 (82.4)
Disease status, n (%)	
Complete remission (tumor-free)	9 (52.9)
Partial remission	4 (23.5)
Recurrence	1 (5.9)
Other	2 (11.8)
Missing	1 (5.9)
Treatment status, n (%)	
Ongoing	14 (82.4)
Completed	2 (11.8)
Missing	1 (5.9)
Previous treatment[a], n (%)	
Surgery	12 (70.6)
Radiotherapy	7 (41.2)
Chemotherapy	11 (64.7)
Immunotherapy	2 (11.8)
Antihormone therapy	1 (5.9)
Antibody therapy	1 (5.9)
Treatment location[a], n (%)	
University clinic	17 (100)
Outpatient practice	3 (17.6)
Time since diagnosis (months)	
Mean (SD)	40.3 (52.0)
Range	4-199

[a] Multiple answers possible.

Interview Results

In total, we coded 1162 text passages and assigned them to the deductively formed main categories. Inductively, subcategories (n=44) were formed and specifications were made up to the fourth sublevel. Since the aim of the study was to derive implications for app development from the interviews, we focused on the results with respect to further development of the MUC app. Table 3 shows a summary of the category system.

Table 3. Summary of the category system.

Main category	Subcategory
Benefits of the MUC[a] app	• Time savings for patients and medical staff • Paper savings • COVID-19–conditioned contact reduction
Concerns about the MUC app	• Data security and confidentiality • Replacement of personal contact with the practitioner • Concerned by negative information • Loss of control • Too much information • Hidden costs
Requested app features	• Support for a healthy lifestyle • List of contact persons • Networking with other institutions • Organizational matters • Social service themes • Medication management • Support for coping with the disease • Exchange with others • Feature for relatives • Audio recording of the doctor’s appointment
Comments on basic feature 1 (appointment display and navigation)	From *remarks on app structure*: • Possibility to book and manage appointments • Arrival tips • Preparation for treatment appointments • Indication of waiting times and examination duration • Location plan • Link to Google Maps
Comments on basic feature 2 (access to medical reports)	From *remarks on app structure*: • Central overview of medical reports • Data transmission between general practitioner and hospital • Processing status of cancer finding
Comments on basic feature 3 (forms and questionnaires)	From *remarks on app structure*: • Control by doctors • Fill-in help
Comments on basic feature 4 (health diary)	From *remarks on app structure*: • Resulting consequences • Limitation to specific aspects • Feedback on health status • Image transmission in the case of suspicion (skin cancer)
Comments on basic feature 5 (information about the clinic and the disease)	From *remarks on app structure*: • General information (eg, digitization of flyers, individualization of information) • Information about treatment (eg, description of treatment options and consequences, treatment process) • Information about the disease (eg, disease stages, genetic testing of children)
Aspects for optimizing acceptance and usability	• Technical aspects (eg, reminder function, selection and deselection of features) • Design aspects (eg, clear structure, absence of advertisements) • Communication about the MUC app (eg, recommendation by doctors, active thematization of data protection) • Patient characteristics to facilitate app usage (eg, young age, chronic disease)

[a] MUC: My University Clinic.

Perceived Benefits of the MUC App

Patients mentioned some general *benefits of the MUC app*. These benefits included time savings for patients and medical staff (n=11, 64.7%), as well as paper saving (n=8, 47.1%) with respect to the goal that digitalization could replace printouts. Concerning *access to medical reports*, some patients had a positive view regarding always having medical records digitally available in order to check certain details (n=12, 70.6%). This aspect was assessed as being particularly important when patients change from primary care to outpatient care with private practice physicians (n=9, 52.9%). Faster transmission of medical reports via the MUC app was another perceived benefit (n=4, 23.5%). The possibility to fill in *forms and questionnaires* in the MUC app appealed to patients as it might be a facilitation for the clinic staff, where patients have more time to fill in forms (n=5, 29.4%) and are able to look up necessary medical details (n=4, 23.5%). Patients rated that a *health diary* could help them feel more confident (n=5, 29.4%) and better prepared for their medical consultations (n=2, 11.8%). Entries in a health diary might be more reliable than what patients remember from memory (n=4, 23.5%). Many patients favored the function *information about the disease* (eg, the statement that more information might reduce their anxiety; n=5, 29.4%).

> *So I imagine that you simply take away fears through educational information. Because fears are also caused by ignorance.* [Interview 11, item 78]

In addition, most patients perceived the MUC app as a trustworthy source of information (n=11, 64.7%).

> *I mean, I can be sure that when the University Medical Center provides information about my illness, that it is correct.* [Interview 15, item 196]

Perceived Concerns About the MUC App

Data security and confidentiality were the most frequently mentioned *concern*s. Therefore, patients suggested that the MUC app should be password-protected (n=3, 17.6%), data transmission should be encrypted (n=2, 11.8%), and data should be deleted after a certain time (n=1, 5.9%). Other patients were not concerned about data security and confidentiality and expressed their trust in the MUC app (n=8, 47.1%). A further major concern was that personal contact with the physician could be reduced or replaced by the MUC app (n=9, 52.9%).

> *Well, it [the MUC app] should definitely not replace the doctor's consultation. I wouldn't like that.* [Interview 12, item 121]

The concern of losing control over the MUC app was important as well (n=7, 41.2%). To prevent this, patients wanted to be able to activate and deactivate individual functions (n=3, 17.6%). Patients also wanted the use of the MUC app to be voluntary at any time, with explicit consent being required for use (n=5, 29.4%). This aspect was particularly important for the function that allows the transfer of personal medical data to other medical staff or institutions (n=3, 17.6%). Patients pointed out that personal medical data should not be transferred to any other third parties, such as health insurance companies or banks (n=8, 47.1%). Concerning *access to medical reports*, patients expressed the concern that they might not be able to understand technical terms or may misinterpret or misunderstand the medical reports (n=5, 29.4%). Regarding a *health diary*, some patients were worried that the questions might contain intimate details of their lifestyle (n=3, 17.6%). Regarding the function *information about the disease*, some patients were concerned that they might be confronted with upsetting information about their diagnosis (n=8, 47.1%).

Prerequisites for the Use of MUC App Features

All the patients in this study expressed the will to try and use the MUC app, even though some patients expressed the condition that all information should still be available in analogue format (n=5, 29.4%). Some patients expressed prerequisites for the use of the designed MUC app features (eg, some patients only wanted *access to their medical reports* via the MUC app, in combination with a face-to-face conversation with their doctor; n=2, 11.8%). In addition, 16 (94.1%) patients consented that their data may be transmitted via the MUC app to their general practitioner, but some patients wished a mandatory patient consent for this function (n=4, 23.5%).

Suggestions for Improving the MUC App Features

Patients generated various ideas on how the individual basic features should be designed. They requested that the *appointment management and navigation* feature have a location map or route description to the appointment (n=2, 11.8%) and a link to Google Maps (n=1, 5.9%). In addition, some patients wished a checklist of required documents for a medical consultation (n=4, 23.5%) and an opportunity to take notes about medical examinations, a list of relevant questions to the doctor for the next appointment, and a general note function (n=3, 17.6%). Some patients wanted that *access to medical reports* be designed, including the possibility to send medical reports from the general practitioner to the Medical Center – University of Freiburg (n=6, 35.3%). This could minimize the frequent loss of information due to transmission via fax machines.

> *Then I had to go back to the general practitioner to find out where it [the blood count] was, why it wasn't faxed [to the clinic]. So, if you could maybe somehow solve this a bit differently or via the app.* [Interview 10, item 42]

For a better overview, some patients wished for an archive of all their medical reports concerning their cancer diagnosis (n=12, 70.6%). They also wanted automatic access to all medical records of the clinic and of their general practitioner, for example, diagnostic imaging (n=7, 41.2%).

Concerning the feature *forms and questionnaires*, patients requested fill-in help for forms in the MUC app (n=1, 5.9%) and that doctors should control the patients' input for omissions and false data (n=4, 23.5%). Regarding the *health diary*, some patients requested feedback concerning their health status (n=4, 23.5%) and expected a response on what to do if the health state deteriorates (eg, being called in earlier for a check-up; n=2, 11.8%).

Concerning *information about the clinic and thedisease*, the interviews revealed that the need for information about cancer was broad and contained general information, information about the disease, and information about treatment. Many patients wished for individualized information about their diagnosis (n=9, 52.9%) and also requested digitalization of flyers (n=9, 52.9%), links to serious websites (n=3, 17.6%), and a glossary of medical terms (n=5, 29.4%). Moreover, some patients requested information about new treatment methods or the possibility to participate in studies and new research findings (n=5, 29.4%). Many patients wished to get an overview on the clinics’ cancer-related supplementary health care programs (n=8, 47.1%), testimonials of other patients (n=3, 17.6%), and a description of treatment options and their consequences (n=6, 35.3%).

Demand for Additional App Features

In addition to the 5 designed features of the MUC app, patients suggested a large number of additional *app features*. Some of the features listed next could be integrated into existing features. Patients asked for a list of health care professionals (n=5, 29.4%) with a direct function to contact them and ask medical questions (n=11, 64.7%). They also wanted it to be possible to communicate asynchronously (n=7, 41.2%).

> *But I think that now that we have come back to the contact persons and somehow the team to which I am now assigned, or to which I may turn. That is, I think, quite – quite nice to still have that somehow.* [Interview 8, item 157]

Most patients suggested app features to support healthy lifestyles (eg, advice on cancer-specific nutrition, suggestions for exercise and relaxation; n=16, 94.1%), as well as features to connect with other internal (eg, psychosocial counseling, sport oncology) and external (eg, cancer support groups, gene laboratory) services (n=9, 52.9%). Many patients named organizational matters (eg, daily schedule for inpatients and an overview of clinic departments to be easily depicted in the MUC app; n=12, 37.3%). They proposed to include topics of social security (eg, how to apply for the severely disabled status; n=9, 52.9%). Some patients wanted an app function with practical recommendations on how to cope with their disease (eg, by positive reports of how other patients with cancer successfully adapted to or overcame their disease; n=7, 41.2%). Patients also wished to have medication management in the MUC app (n=8, 47.1%). This function could include a reminder of when to take which medication and an explanation of the purpose of the medication.

Improving Acceptance and Usability

Regarding aspects that increase the acceptance and usability of the MUC app, 4 themes emerged: a clear structure (n=10, 58.8%), easy handling (n=4, 23.5%), no advertising (n=2, 11.8%), and an appealing design (n=1, 5.9%). In addition, patients named technical aspects, such as a reminder feature that helps remember medical appointments, medication intake, or health diary entries (n=11, 64.7%). A few patients stated that they should be able to choose which features they want to use (n=10, 58.8%).

> *Yes, of course I have to be able to adapt it [the MUC app] to my needs without being a programmer. And that should to be different modules that I can then compose myself.* [Interview 3, item 170]

Some patients expressed their wish for the MUC app to be barrier free in terms of varying font sizes, voice control, or provision in other languages (n=9, 52.9%).

Discussion

Principal Findings

As far as we know, this study is one of the first to explore patients’ preferences and evaluate an app to support cancer treatment with a qualitative approach during its development in Germany. Our objective was to assess the needs and preferences of patients with cancer related to the MUC app and to identify possible barriers and concerns that might limit the acceptance of the app. Based on purposive sampling, we included 17 patients with cancer, reaching a satisfying variety of sampling characteristics. With 17 semistructured interviews, a saturation of the thematic content was reached. A key finding of our study is that all patients interviewed would test and use the MUC app. This indicates a high level of acceptance of the MUC app by patients, even if the benefits of the 5 app functions designed are judged differently.

Patients mentioned a variety of general benefits of the MUC app; the most common were time saving, less paperwork, and more rapid access to information [27]. The most important concerns were the fear that the MUC app might reduce personal contact with medical staff, and data security and confidentiality. On the one hand, there was the patients' desire for individualized information; on the other hand was their wish for privacy protection. We identified the patients' wish to restrict access to their individual health information and the worry that individual information could be compromised by third parties (eg, health insurance). In our study, we found 2 additional aspects: First, there was a clear statement that the use of the MUC app should be voluntary and not replace other analogue sources of information. Second, when using the MUC app, the user should be able to select features and deactivate those they do not want to use. We found that the MUC app might improve the flow of information between general practitioner and clinic and vice versa. It turned out that the health diary is a well-accepted and helpful tool, especially for patients during cancer treatment. Thereby, symptom monitoring can contribute to better health care [28,29] and to a feeling of safety for outpatients [19,30,31]. We detected a great variety of information needs in our study sample, which may reflect the heterogeneous sample characteristics (eg, the broad range of time since diagnosis, various treatment settings, ongoing and completed treatment).

As known from the literature, the need for information in patients with cancer is high [32-34] and changes over the course of cancer care [14,32,33,35,36]. It is important to meet these information needs, as access to health information has a significant effect on reducing anxiety and depression [37,38]. In our study, patients reported the wish for individualized information about diagnosis and treatment to reduce anxiety. In practice, it is important that an app provide individualized information, depending on the stage of treatment, as this is seen as an essential requirement for the successful use of app-based assistance. Most patients in our study stated that they would estimate the MUC app as a trustworthy source of information. Nevertheless, with respect to information, we found both advantages, such as a reduction in anxiety, and disadvantages, such as being concerned by too detailed information [11]. As a possible explanation, the perception of information may be influenced by different coping strategies: patients predominantly using an avoidant coping strategy [39-41] may be more afraid of detailed information. In addition, according to the common-sense model (CSM) [42], cognitive factors, such as information from the external social environment (eg, caregivers or authoritative sources, such as physicians), influence illness representations, illness coping behaviors, and illness and emotional outcomes.

Beyond the designed app features, patients suggested some new app features, such as an interactive contact list and support for a healthy lifestyle. These aspects have also been identified as patients' needs in other studies [14,43]. In line with previous studies are concerns that the MUC app may reduce face-to-face contact with health care professionals [13,19], as well as concerns about data security and confidentiality [14,44-46]. Consistent with existing studies, patients want control over who has access to their personal health information [47,48]. Concerns that personal information will be interpreted to the patient's disadvantage (eg, by a health insurance company) are also consistent with existing evidence [47]. As found in the literature [49], patients requested an interactive communication feature in mHealth tools instead of a unidirectional delivery of information. This emphasizes the potential benefit of bidirectional communication between patients and physicians in the MUC app. Asynchronous communication with medical staff was another important desire identified in our study. The transmission of data (eg, between the outpatient and inpatient health care sector) via the MUC app was partly seen as useful. These aspects could help improve trans-sectoral communication and optimize patient-centered care.

Young age [11,13,50] and open-mindedness toward mHealth [47] was found both in the literature and in our study to be a common patient characteristic to facilitate app usage. A new finding from our study is that patients explicitly wish for medication management via the MUC app. Our study provides evidence that medication management is seen as an important part of an app by patients with cancer. In addition, as far as we know, it has not yet been documented in the literature whether the voluntary use of the MUC app and the possibility to decide individually which functions should be used are relevant aspects from the patient's point of view. Both aspects could be linked to the desire for more patient autonomy and should definitely be considered in app development.

Limitations

There are a number of limitations to our research. Although we used purposive sampling, it is possible that patients with low technical skills were either not approached by physicians to participate in the study or did not feel interested by the study call. It is also possible that mostly patients with open-mindedness toward mHealth took part in our study. This may have led to participants being more positive about mHealth than the overall population of patients with cancer. There might have been a response bias in the direction of social desirability, as the interviewer was probably seen by the patients as a clinical representative. As a monocenter study, the generalization of our results in terms of mHealth apps in general is not possible, as some topics named by the patients may be specific to their oncological care situation at the Medical Center – University of Freiburg. Furthermore, patients were asked to imagine a hypothetical app they might use during their illness. Even though the functions of the app were explained in detail and clearly by using visual material, the data are not based on concrete experiences with the MUC app itself. Consequently, expressing a desire for a particular app function does not automatically imply that that person will use the app function as soon as it is available.

Conclusion

The patients’ wishes and concerns revealed early in the development process show the relevance of involving patients in the development of mHealth apps. During app development, it should be kept in mind that patients with cancer are more often older patients, which means that the app should be clear and simple in structure. In addition to technical aspects, communication about the app is important, which is why possible concerns about data privacy should be actively thematized. The COVID-19 pandemic may increase the acceptance and need for mHealth apps to support contact-free health care [51].

The findings provide insights into how to improve the MUC app based on the patients’ perspective. The study reported in this paper comprises a second phase, in which patients will receive a test version of the app. At the end of the test phase, interviews will be conducted to gather feedback and suggestions for improvement. It seems important that the MUC app should not reduce but optimize personal contact with health care professionals. The MUC app may contribute to the improvement of the relationship between practitioner and patient by simplifying organizational processes. Implementation of the MUC app requires education by clinic staff for those patients with low technical experience [44,52]. Patients and patients’ representatives should be involved in all subsequent phases of app development.

Acknowledgments

This work was funded by the Zentrum für Innovative Versorgung grant of the Ministry of Science, Research and the Arts Baden-Württemberg, Germany (grant no. digital@bw I and II).

We would like to thank all the patients who agreed to participate in this study. We would also like to acknowledge the doctors and medical personnel who recruited patients for this study, namely Dr Julia Waldschmidt, Prof Dr Marcia Machein, Dr Christine Greil, Petra Fofana, Dr Esther Anna Biesel, and Elisabeth Hecht. Thanks to Fiona Burton for transcribing the interviews and assisting during the study. We thank David Leuschner for discussion and app development. M Boerries is supported by the German

Federal Ministry of Education and Research by Medical Informatics in Research and Care in University Medicine (MIRACUM) within the Medical Informatics Funding Scheme (FKZ 01ZZ1801B).

Data Availability

The qualitative data are available from the corresponding author upon reasonable request.

Authors' Contributions

The individual contributions of the authors are as follows: JW was responsible for conceptualization, methodology, supervision, resources, and writing—review and editing; LRW for investigation, formal analysis, writing—original draft preparation, and project administration; M Boerries for conceptualization, funding acquisition, and writing—review and editing; M Boeker for conceptualization and writing—review and editing; DK for project administration and writing—review and editing; and CD for formal analysis and writing—original draft preparation.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Interview guide.
[PDF File (Adobe PDF File), 870 KB - cancer_v9i1e40891_app1.pdf]

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Abbreviations

CCCF: Comprehensive Cancer Center Freiburg
mHealth: mobile health
MUC: My University Clinic
PROM: patient-reported outcome measure

Edited by A Mavragani; submitted 11.07.22; peer-reviewed by A Dinkel, J Galinsky, C Berterö; comments to author 29.11.22; revised version received 29.04.23; accepted 09.05.23; published 27.07.23.

Please cite as:
Weis J, Wolf LR, Boerries M, Kassahn D, Boeker M, Dresch C
Identification of the Needs and Preferences of Patients With Cancer for the Development of a Clinic App: Qualitative Study
JMIR Cancer 2023;9:e40891
URL: https://cancer.jmir.org/2023/1/e40891
doi:10.2196/40891
PMID:37498653

Original Paper

User-Centered Development of a Mobile App to Assess the Quality of Life of Patients With Cancer: Iterative Investigation and Usability Testing

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Abstract

Background: The treatment for cancer can have a negative impact not only on physical well-being but also on mental health and the quality of life (QoL). Health apps enable the monitoring of different parameters, but to date, there are only few that support patients with cancer and none that focuses on the assessment of QoL. Furthermore, patients as stakeholders are often only integrated at the late stage of the development process, if at all.

Objective: The aim of this research was to develop and evaluate a smartphone app (Lion-App) to enable patients with cancer to autonomously measure the QoL with an iterative, user-centered approach.

Methods: Patients with cancer were involved in a 3-stage process from conceptualization to the point when the app was available on the tester’s private device. First, focus groups with members (N=21) of cancer support groups were conducted to understand their expectations and needs. Thereafter, individual tests were performed. After developing a prototype that incorporated findings from the focus groups, a second test cycle was conducted, followed by a beta test lasting 2 months. In our app, the QoL can be assessed via a patient diary and an integrated questionnaire. Through all stages, usability was evaluated using the modular extended version of the User Experience Questionnaire (UEQ+), including the calculation of a key performance indicator (KPI). If possible, the impact of sex on the results was evaluated. As part of the beta test, usage rates as well as age-dependent differences were also assessed.

Results: A total of 21 participants took part in the initial 3 focus groups. In the subsequent usability testing (N=18), 17 (94%) participants rated their impression through the UEQ+, with a mean KPI of 2.12 (SD 0.64, range: –3 to 3). In the second usability test (N=14), the mean KPI increased to 2.28 (SD=0.49). In the beta test, the usage rate of 19 participants was evaluated, of whom 14 (74%) also answered the UEQ+ (mean KPI 1.78, SD 0.84). An influence of age on the number of questionnaire responses in Lion-App was observed, with a decrease in responses with increasing age (P=.02). Sex-dependent analyses were only possible for the first usability test and the beta test. The main adjustments based on user feedback were a restructuring of the diary as well as integration of a shorter questionnaire to assess the QoL.

Conclusions: The iterative, user-centered approach for development and usability testing resulted in positive evaluations of Lion-App. Our app was rated as suitable for everyday use to monitor the QoL of patients with cancer. Initial results indicated that the sex and age of participants seem to play only a minor role.

(JMIR Cancer 2023;9:e44985) doi:10.2196/44985

KEYWORDS

quality of life; cancer; mHealth; mobile health; patient empowerment; user-centered design; user; user centered; design; physical well-being; well-being; mental health; monitoring; development; usability

Introduction

Quality of Life and Cancer

Cancer is a noncommunicable disease with high prevalence and is considered the most common cause of death in an aging and growing society [1,2]. In 2020, 19.3 million new cases, with approximately 10 million deaths, were estimated to occur worldwide [3]. Even though the survival rate after diagnosis, depending on the type of cancer, can be high, cancer treatment often has severe side effects [4,5]. Symptoms, such as fatigue and nausea, can decrease patients' quality of life (QoL). According to the World Health Organization (WHO), the QoL is defined as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" [6]. In the context of diseases, the health-related QoL is used. This describes a multidimensional concept that focuses on the patient's subjective perceptions about the effects of illness and the impact of treatment on their daily life, including the physical, psychological, and social burden on the patient [7]. Although the QoL has become increasingly important, there is no gold standard available to assess it [8-10]. The QoL is mainly measured via questionnaires, indices, or patient diaries. One of the most widely used questionnaires for assessing the QoL in oncology is the Core Quality-of-Life Questionnaire (QLQ-C30) of the European Organization for Research and Treatment of Cancer (EORTC) [11].

Improving the QoL has a major impact on the patient's therapy: An increase in the QoL not only improves satisfaction with the treatment but also significantly influences compliance and outcomes in a positive way and may increase the survival rate accordingly [8,9,12]. Even though the positive impact of an increase in the QoL has already been shown, none of the identified projects as well as none of the papers analyzed in a review [13] published in 2018 about health promotion and disease management have focused on the patient's QoL itself. These previous results were confirmed by Stark et al [14], in a review of publications between 2010 and 2020 on health promotion and prevention, who found few papers focusing on mental health and well-being in general. In most cases, the QoL is considered a secondary outcome but not the focus of the survey [15-19]. Even when the QoL is considered a key component, research mainly focuses on the current QoL of patients at a given point of time. In longitudinal studies, for example, patients' QoL is only assessed every few months instead of daily or weekly [20-23]. Thus, there is a need for tools to continuously monitor patients' QoL, which may be enabled using health apps.

Health Apps

Since patients with cancer are often treated as outpatients, monitoring and symptom support are necessary. In this context, the keywords in patient-reported outcomes and patient-generated health data are becoming increasingly important. Data from patients may be used to measure the effectiveness of treatment, improve the physician-patient relationship, and concomitantly increase patient satisfaction and improve the QoL [24,25].

Still, these data can only be collected with close involvement of the patient. There are many new approaches to include patients in therapy: one of them is the use of health apps. Many studies have shown a positive impact of mobile health interventions on the well-being or outcome of patients with cancer (eg, by supporting the monitoring of symptoms or providing relevant information in the personal context of the disease and therapy) [16,18,24,26,27]. One of the key challenges in the use of smartphones is the influence of different factors, such as the previous experience of the users, the comprehensibility of the survey, and the preparation of the information for the users [28]. This is especially important when patients need to interact directly with the developed system. Despite this, users are often not involved in development until fundamental decisions about the architecture or basic processes have already been made. Maramba et al [29] revealed that only about a third of all publications that conducted usability testing have incorporated user feedback into further development [29].

To consider patients' needs, expectations, and experiences, they should be integrated into the development stages before the start of the implementation in order to discuss and form processes in cooperation with them. Even though applying a user-centered design is a common method for doing so, there are still different approaches to how a user-centered development may be realized [30-32]. The aim of this research was to develop and evaluate a smartphone app (Lion-App) to enable patients with cancer to autonomously measure their QoL with an iterative, user-centered approach. The impact of sex and age on the development process and product was also assessed.

Methods

Study Design

App Development

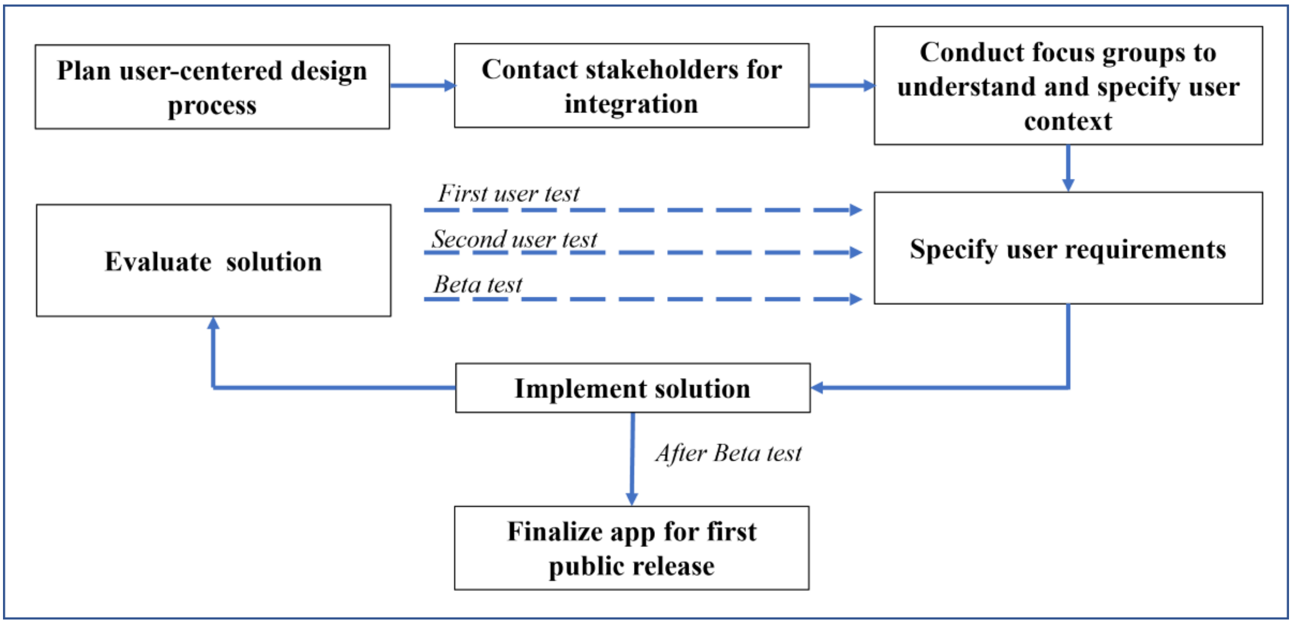
The app developed in this research is called Lion-App, which enables a longitudinal survey of the QoL in oncology using a smartphone. As questionnaires have high objectivity, reliability, and validity [33], as well as high sensitivity to monitor changes over time, the app provided an assessment of the QoL through the EORTC QLQ-C30 in our research. Responses to the questionnaires could either be viewed as individual answer sheets or displayed in an evaluation over time. The evaluation of the app included a calculated total score of the questionnaire responses as well as the individual progressions of the subscales. Additionally, it is possible for users to document their well-being via an integrated patient diary.

The aim of the app is to help patients gain a better awareness of their personal QoL. The goal is to support them in self-management through different stages of their disease as this knowledge can be used to specifically promote the QoL in therapy or to identify and address limitations in long-term survivorship. Therefore, the application of the app is detached from clinical treatment but describes a solution for patients to assess their QoL independently at home. As the app is intended to be installed on the patient's private device, it was developed in a user-centered way to reduce usability issues for better applicability.

User-Centered Design

In general, the design of the app's interfaces was based on the International Organization for Standardization (ISO) standard 9241, and a graphic designer managed the aspects of usability and user experience (UX). The goal was to develop an easy-to-use app for users to document their QoL through various functions. In doing so, the steps in the ISO 9241-210 process were performed iteratively, as seen in Figure 1. The first step in planning the human-centered design process was performed at the end of 2020. As a next step, several cancer support groups were contacted, and focus groups were conducted at the beginning of 2021 to understand and specify the user context. Consequently, user requirements were specified, which led to a first prototype for the first usability test (usability test 1) from April to June 2021. Based on the evaluation of this implementation, further design solutions were developed, which were again evaluated in October 2021 (usability test 2) and from December 2021 to February 2022 (beta test). In the process, the maturity of the implementation increased over 3 cycles (usability test 1, usability test 2, and beta test). Final adaptations in 2022 led to the release of the product afterward.

Figure 1. Process workflow of our user-centered design.



Implementation

After the initial planning phase of the human-centered design process, several cancer support groups were contacted, to whom the project was briefly introduced and whose interest in participation was requested. The following cancer support groups provided consent to participate:

- Regional association of the support group for women in Baden-Württemberg/Bayern
- Regional association of the prostate cancer support group in Baden-Württemberg
- State association of patients with lung cancer and their relatives in Baden-Württemberg

Three focus groups were conducted for each support group. The aim of the focus groups was to collect the end users' perceptions regarding eHealth apps and their needs to better understand user requirements. All focus groups were moderated, and a transcript writer was present.

The focus group for the support group for women in Baden-Württemberg was conducted on April 21, 2021 (n=8, 38%, all female), the focus group for the prostate cancer support group was conducted on June 8, 2021 (n=3, 14%, all male), and the focus group for the lung cancer support group was conducted on June 16, 2021 (n=10, 48%; n=6, 60%, female and n=4, 40%, male). At that time, legal restrictions due to the COVID-19 pandemic prohibited on-site meetings. Thus, all focus groups were performed online. Participants were free to participate in the meetings.

All focus groups were guide-oriented and structured in the same way: First, an introduction to Lion-App was provided. Second, questions about prior experiences with QoL surveys were elicited. Third, various options to map the QoL were presented and individual preferences evaluated, followed by discussions of their applicability and usefulness in a health app.

Finally, potential features of the app were presented and discussed. For an initial evaluation of the look of a possible color concept to be used in the app, an exemplary design of a dashboard was shown to the participants. This screen also included possible structural information about basic processes of the app (eg, how to access features from the start page). Participants were asked to rate this concept through a questionnaire. After they answered the questionnaire, the focus group concluded with an open discussion of additional suggestions. At the end of the meeting, participants were informed about individual usability tests, in which a more detailed insight into the app would be possible, and invited to participate in them. Patients included in the focus groups were re-invited to participate in all further test stages. In addition, new support group members participated, as well as nonmembers of any support group who learned about this project through word of mouth.

The basic user requirements and prioritization of functions derived from the focus groups were analyzed and used as a basis for the implementation of a first prototype. This prototype consisted of mockups that were visualized in Adobe XD. The first and second digital usability tests and the beta test (usability test 3) are described in more detail in Multimedia Appendix 1.

In short, through our development cycles, we moved step by step from a prototype in a controlled user environment to a real-world setting and release version of the app. In usability test 1, a prototype was presented based on mockups that were to be tested with predefined tasks. In usability test 2, the app was made available on a test device and users were asked to use the app to document their QoL without using predefined specific functions. In the final usability test (beta test), the app was installed on users' private devices and there were no specifications for usage. Therefore, testing could be carried out to any extent. Afterward, the app was processed for public release. Written and verbal feedback was collected per test stage, analyzed, and processed for the next development steps.

Since the literature states that user engagement should only be measured if usability is already evaluated at a high level [26,34,35], we decided to assess user engagement only in the beta test after the previous usability tests. A combination of the passively collected usage pattern, subjective evaluations of the UX, and expectations was gathered for better insight. We also investigated whether the integration of certain elements for extrinsic or instinctive motivation (eg, certain gamification elements) would impact user engagement over a longer period of use.

Evaluation

User evaluations of the usability of Lion-App were analyzed using verbal feedback by expressing the thoughts and expectations via the "thinking aloud" methodology during use of the app or at the end of usability tests or by observation of user behavior. These results were combined with the responses to the usability questionnaire that was included in all 3 usability tests.

To evaluate usability and the UX across our development stages, we decided to use different User Experience Questionnaires (UEQs) from the existing framework [36]. A short version of the general User Experience Questionnaire (UEQ-S) was used once in the focus groups. It enabled users to classify the answers provided into pragmatic quality (usability aspects), such as functionality or efficiency, and hedonic quality (satisfaction), such as innovativeness or novelty [37]. A modular extended version of the User Experience Questionnaire (UEQ+) was used for all further usability tests. This questionnaire can be modularly built from a list of different UX scales. We decided to use the scales assessing efficiency, clarity, intuitive use, usefulness, quality of content, and trustworthiness of content for our evaluation [38]. For each scale, the subjective importance can be rated. Both scale assessment and importance can be extracted with a 7-item Likert scale ranging from –3 to 3. The combination of these values can be used to calculate a key performance indicator (KPI) as well as the overall UX impression across evaluations [39]. Even though the assessment of the UX using the UEQ+ is not as common as when using other tools, such as the System Usability Scale (SUS), we decided on this approach because the UEQ+ scales provide information about potential gaps in performance. Other well-known survey methods, such as the SUS, often only provide information about whether usability problems exist and may need further work to identify the problems rather than relying on existing limitations.

To better classify the responses of participants, the UEQ+ was augmented by including additional questions about sex, age (assessed in 5-year increments), and previous experience with mobile devices. In usability test 2 as well as the beta test, participants were also asked to indicate whether they had previously participated in a usability test of Lion-App.

As the beta test was the first test conducted over a longer period and on participants' private devices, we could additionally explore the impact of different displays and gamification elements on user engagement. For this, participants were randomly assigned to 3 versions of the app after registration. All versions had the same basic functionalities as version A but differed in add-ons, as shown in Table 1. We compared usage rates as well as the use of certain functions in detail, such as the number of responses provided to the integrated questionnaire, depending on the version and gender or age.

Table 1. Overview of the functionalities of the 3 versions of Lion-App used for the beta test.

Version	Functionalities	Add-ons
A	QLQ-C30[a] Patient diary Information page for relevant topics related to cancer Push notifications as a reminder for usage	N/A[b]
B	QLQ-C30 Patient diary Information page for relevant topics related to cancer Push notifications as a reminder for usage	Count of active weeks[c] Medals
C	QLQ-C30 Patient diary Information page for relevant topics related to cancer Push notifications as a reminder for usage	Extended evaluation: (1) comparison of scores and (2) display of IQR[d]

[a] QLQ-C30: Core Quality-of-Life Questionnaire. Users were able to fill out the questionnaire at any time. Questionnaire responses were visible as an answer sheet or in an evaluation (with a calculation of the scores).

[b] N/A: not applicable.

[c] Number of interactions≥1.

[d] Reference values from Scott et al [40].

Participants could only register for the beta test until 4 weeks before the end of the test cycle, as we determined that a minimum period of use of 4 weeks is required to evaluate usability and to be able to draw a conclusion about user engagement. Again, usability assessment was conducted using the UEQ+, and an additional questionnaire for the general impression and user engagement was administered. In this questionnaire, participants were able to provide an overall rating and state whether they would recommend the app and to what extent they could imagine themselves using it in the future. The results were also used to decide about the long-term integration of an extended evaluation or gamification elements.

Since participants had to answer 2 questionnaires during the beta test, the UEQ+ was assigned 2 weeks before the end of the test cycle, whereas the other questionnaire was administered after completion. After the beta test came closest to a real-world application of Lion-App, we decided not to conduct another test if the KPI was in the upper quarter (>1.5). In this case, feedback was still incorporated before the app was published.

Participants

According to Nielsen and Landauer [41], 85% of usability problems can be identified with only 5 users and almost 100% can be identified with 15 users. Thus, we aimed to exceed the critical number of 5 users per usability test conducted and to reach ≥15 users, if possible.

Patients with cancer, during or after treatment of their cancer, and older than 18 years were included in the usability tests. The beta test contained 1 more exclusion criterion: as the app needed to be installed on a private mobile device, participants without a mobile device could not take part, as no one in the study could be provided with a smartphone. In addition, participants did not receive any compensation for participation. Throughout all test stages, interested parties were informed about further usability tests via support groups or email.

Data Analysis

To assess user requirements, the transcripts of the respective focus groups were subsequently analyzed. This involved evaluating what interest and experience existed across participants and what prioritization of functions was preferred. Accordingly, the order of the functions to be implemented was determined. In addition to the KPI of the questionnaires of the UEQ framework, descriptive analyses of the mean score (SD), variance (var), confidence (C), and 95% CI were performed. For internal consistency of the scales, the Cronbach α coefficient was evaluated [42]. In addition, the median age of participants was calculated, and the Mann-Whitney U test was performed to detect differences between the UEQ+ ratings of the app based on sex. In the beta test, a *t* test for independent samples was additionally performed, including a test of equality of variance using the Levene test for the exploration of the effect of sex on the number and type of entries. For all age-dependent calculations, a 1-factor ANOVA was performed. ANOVA included all participants who indicated their age (12/19, 63%). Post hoc tests were only performed when the first analysis showed a significance of 5%. To determine the correlation with a 2-tailed significance of 5%, a Pearson correlation was performed. Before performing parametric tests, the normal distribution of data was assessed based on a significance value of >.05 in the Shapiro-Wilk test, which then was additionally confirmed with the corresponding Q-Q diagram as well as the histogram of the data.

SPSS version 28.0.1.1 (IBM Corp) was used for calculations. Detailed descriptive analyses of the UEQ-S and the overall UEQ+ are grouped in Multimedia Appendix 2, corresponding statistical calculations stratified by sex are summarized in Multimedia Appendix 3, and an overview of the interactions stratified by the app version of the beta test is provided in Multimedia Appendix 4.

Ethical Considerations

According to the exclusion criteria of our local Münster German Ethic Kommission guidelines for the ethical evaluation of research projects of the University of Münster [43], this research did not need ethical approval, as participants were not exposed to any personal risk at any time and no individual personal data were evaluated: participants were exclusively considered as collective. The research did not include any interventions, nor did it influence the patients' therapy. In addition, no health-related data were evaluated: participants only had to confirm to have received an oncological diagnosis in the past. Additionally, general conditions of the study, such as a review of the app development processes, were verified and approved by an external data protection officer. Data collection was exclusively performed in the context of evaluating usability and user engagement.

Results

Characteristics of Participants

Characteristics of the participants through the test stages are provided in Table 2. In general, no distinction was made between diagnoses, symptoms, or stages of disease, as the aim was to develop a generally applicable solution. Therefore, no additional clinical data were collected in addition to those shown in Table 2.

Table 2. Characteristics of participants through our stages of user-centered design. For the beta test, data could be drawn from the registration within the app as well as from the answers to the UEQ+[a].

Characteristics	Focus group (N=21)	Usability test 1 (N=18)[b]	Usability test 2 (N=14)	Beta test (N=19; UEQ+ n=14, Lion-App: n=19)
Time period (months)	April-June 2021[c]	April-June 2021[c]	October 2021	December 2021-February 2022
Sex, n (%)[d]				
Female	14 (67)	13 (72)	11 (79)	UEQ+: 8 (57); App: 10 (53)
Male	7 (33)	5 (28)	3 (21)	UEQ+: 6 (43); App: 9 (47)
Age (years), n (%)[d]				
30-34	N/C[e]	N/A[f]	1 (7)	UEQ+: N/A; App: N/A
40-44	N/C	N/A	N/A	UEQ+: N/A; App: 1 (5)
45-49	N/C	N/A	N/A	UEQ+: 1 (7); App: N/A
50-54	N/C	2 (12)	2 (14)	UEQ+: 3 (21); App: 2 (11)
55-59	N/C	4 (24)	4 (29)	UEQ+: 5 (36); App: 3 (16)
60-64	N/C	8 (47)	4 (29)	UEQ+: 1 (7); App: 2 (11)
65-69	N/C	1 (6)	1 (7)	UEQ+: 2 (14); App: 2 (11)
70-74	N/C	2 (12)	2 (14)	UEQ+: 2 (14); App: 1 (5)
75-79	N/C	N/A	N/A	UEQ+: N/A; App: 1 (5)
Not indicated	N/C	N/A	N/A	UEQ+: N/A; App: 7 (37)
Experience with mobile devices and apps, n (%)[d]				
Never worked with mobile devices	N/C	N/A	N/A	N/A
Rarely work with mobile devices	N/C	5 (30)	2 (14)	3 (21)
Often work with mobile devices	N/C	12 (70)	12 (86)	11 (79)
Participation in previous usability tests, n (%)[d]				
Yes	N/C	N/C	10 (71)	9 (64)
No	N/C	N/C	4 (29)	5 (36)
Version, n (%)				
A	N/C	N/C	N/C	9 (47)
B	N/C	N/C	N/C	6 (32)
C	N/C	N/C	N/C	4 (21)

[a] UEQ+: extended version of the User Experience Questionnaire.

[b] One person was unable to complete the interview due to illness, so information in the UEQ+ and additional questions asked were based on 17 participants.

[c] Group-specific procedures (date of focus group), period of usability test 1: (1) regional association of the support group for women in Baden-Württemberg/Bayern (April 21, 2021), April-May 2021; (2) regional association of the prostatic cancer support group in Baden-Württemberg (June 8, 2021), June 2021; and (3) state association of patients with lung cancer and their relatives in Baden-Württemberg (June 16, 2021), June 2021.

[d] Unless otherwise stated, information was taken from the UEQ+.

[e] N/C: not collected.

[f] N/A: not applicable.

Assessment of User Requirements

In general, most of the participants had no previous experience with the survey of the QoL but were interested in regular mapping of the QoL in their daily lives. In the discussion of the applicability of such an app, not only the app’s use in therapy but also the transition from treatment to posttreatment and survival was addressed. Within the discussion of the prioritization of features, documentation of the QoL through a patient diary and questionnaire was given the highest priority. Other aspects, such as automated recording of movement via sensors or the possibility of networking with others in the app, were perceived as positive but received lower prioritization.

Across all participants, the UEQ-S was completed 11 times. The evaluation indicated a higher pragmatic (mean 2.16, SD 0.76) than hedonic (mean 1.05, SD 1.43) quality. The confidence of the pragmatic quality was 0.45 (95% CI 1.71-2.61), whereas that of the hedonic quality was 0.85 (95% CI 0.21-1.90). Overall, without separating the qualities, a mean value of 1.64 (SD 0.73), with a confidence of 0.43 (95% CI 1.21-2.08) was achieved. Cronbach α was .91 across all participants.

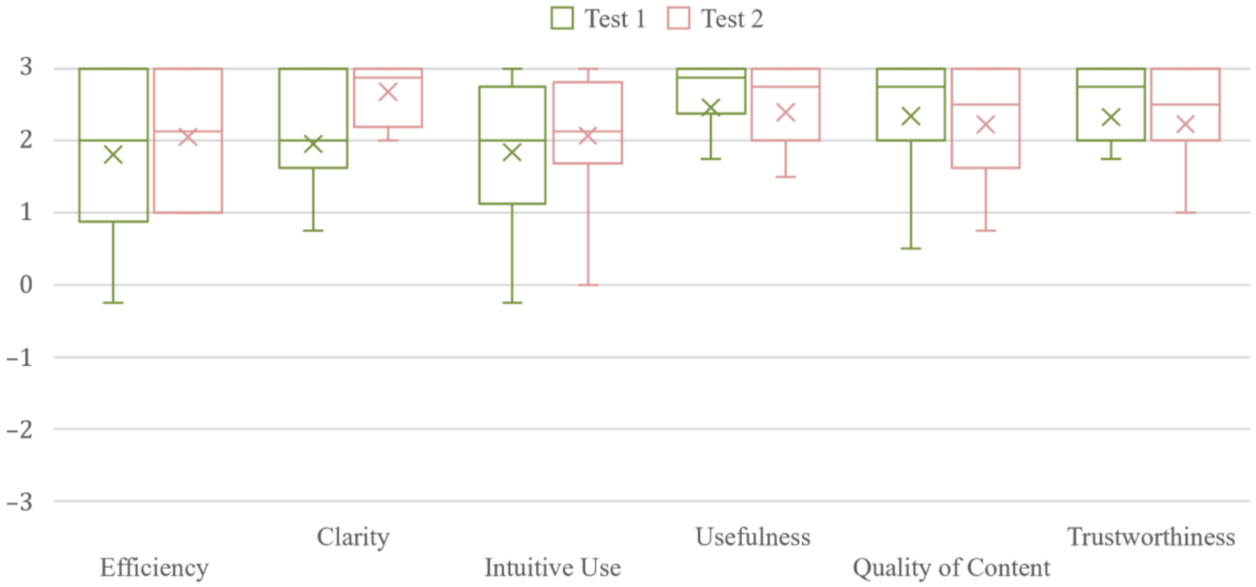
As the UEQ-S evaluation achieved sufficient results, neither the basic process of accessing the main functions from the dashboard nor the color concept was adjusted for the first prototype.

Usability Test 1

In total 18 participants underwent usability test 1. The test cycles for the support group for women were conducted from April 26 to May 7, 2021 (n=8, 44%, all female). In the same period, 2 (11%) additional people (nonmembers of any support group; n=1, 50%, male and n=1, 50%, female) were included after they asked to participate. Individual tests for the prostate cancer support group were conducted on June 6, 2021 (n=2, 11%, all male), and tests for the lung cancer support group were conducted from June 21 to July 1, 2021 (n=5, 28%; n=2, 40%, male and n=3, 60%, female). Each participant was given 30-45 minutes for the usability test. Within this period, participants were provided with a short introduction, tested the app, and evaluated their experience through the UEQ+. Since 1 (6%) participant from the support group for women canceled her participation before completing all tasks, the sum of UEQ+ responses was based on 17 (94%) of 18 participants.

All 18 (100%; median age 60 years) participants used a computer to open the dummy version of Lion-App in their preferred browser. A comparison of the assessment of the UEQ+ with the results of usability test 2 is displayed in Figure 2. Overall, a mean KPI of 2.12 (SD 0.64) was achieved, and Cronbach α was >.85 for all scales. Efficiency showed the lowest average (1.75) with the highest variance (1.75). Utility achieved the highest rating with a score of 2.43 and the lowest variance (0.89) in the survey.

Figure 2. Overall rating of the UEQ+ (range: –3 to 3) for the first and second usability tests per scale. UEQ+: extended version of the User Experience Questionnaire.



A separate sex-dependent analysis of the rating was also carried out. The mean KPI of the female participants was 2.05 (SD 0.67) and that of the male participants was 2.24 (SD 0.57). The Mann-Whitney U test did not result in significant differences between sexes (*P*=.59).

The basic concept of the app was understood by most of the participants. The most common problem was that scrolling was overlooked. However, when overcoming the problem, participants stated that they would scroll more intuitively on a smartphone and that they would not change the process. Such input was tested in usability test 2, when the app was available on a test device.

In addition, more user feedback within the app was requested, such as success messages when saving a diary entry or a questionnaire response. As a result, toasts were planned to be integrated for such messages. Additionally, a new subpage was planned with a tutorial for all functions within the app.

Usability Test 2

Since the app was provided on a test device for the second stage of usability testing, on-site meetings were necessary. As the lung cancer support group could not participate in meetings on-site, the number of participating groups reduced. Several local groups of the support group for women in Baden-Württemberg/Bayern, the prostate cancer support group, and the 2 nonmembers of usability test 1 participated from September 29 to October 18, 2021 (N=14; n=11, 79%, female and n=3, 21%, male). Again, the test period per person was set from 30 to 45 minutes.

Although the critical number of 5 persons was exceeded, the overall target of ≥15 users per usability test was not reached. The median age of participants was 60 years. An overview of the evaluation of the UEQ+ can be found in Figure 2. Across all participants, a mean KPI of 2.28 (SD 0.49) was achieved. No significant differences between ratings from usability tests

1 and 2 could be found through the Mann-Whitney U test (*P*=.65).

Since the number of male participants was below the critical sum of 5 users, no further analysis stratified by sex was performed.

Beta Test

The app could be downloaded and tested from December 8, 2021, to February 7, 2022, for a maximum usage of 60 days (7.5 weeks). The app was installed a maximum of 20 times on Android and 2 times on iOS smartphones. In total, 20 participants registered in Lion-App, and 19 (95%) had at least 1 interaction. For further analysis of the research questions, the age and sex of the participants were taken from the user registration in the app. Again, the median age of the participants was 60 years. Across all responses to the UEQ+, a mean KPI of 1.78 (SD 0.84) was calculated. For all subscales, Cronbach α was >.85, except for the efficiency subscale (Cronbach α=.61).

Overall, 73 (64%) of 115 interactions were made by women. Furthermore, 54 (74%) of 73 diary entries and 19 (45%) of 42 questionnaire responses were submitted by women. The mean KPI for women was 1.46 (SD 0.98) and that for men was 2.2 (SD 0.23). The Mann-Whitney U test showed no statistical significance between sexes (*P*=.18). In addition, no significant sex-dependent differences were found in the general usage rate (*P*=.30), the use of the diary function (*P*=.09), or the number of questionnaire responses (*P*=.47).

Regarding the analysis of the usage rate related to the participant's age, no impact of age was found on overall usage (*P*=.11) as well as on creating diary entries (*P*=.26). However, we did find an effect of age on the number of questionnaire responses (ANOVA *P*=.04). Of the 19 participants in the beta test, 7 (37%) did not indicate their age, which left 12 (63%) participants for further analysis. A 1-factor ANOVA with them resulted in *P*=.02 (F_5=7.3), indicating that there is a strong negative correlation between age and questionnaire responses with a 2-tailed significance of 5% (Pearson correlation coefficient=–0.67, *P*=.02). Thus, the higher the age of the participant, the fewer the questionnaire responses submitted. The estimation of the dedicated 95% CI according to the r/z transformation of Fisher resulted in a lower threshold of –0.9 and an upper threshold of 0.16.

Due to an error in the code, the randomized assignment of participants into the 3 versions (A, B, and C; Table 1) did not lead to the same group size. Due to the uneven distribution of participants in the 3 app versions, group comparisons could not be performed. Even though no statistical evaluations were possible, we were able to extract the direction for further development by considering the subjective experience submitted by participants in the final questionnaire (n=7, 37%) as well as the verbal and written feedback.

Even though 4 (57%) of 7 answers were related to the basic version A without any add-ons, 5 (71%) of 7 users stated that they could imagine using the app on a daily-to-weekly basis in the future, and all respondents stated that they would recommend the app to others. Additionally, we analyzed the KPI through all test stages as the comparability of data was given as a minimum of 64% (n=9; see Table 2) of participants already engaged in previous usability tests. Figure 3 provides an overview of the trend. The results of the UEQ+ analysis across all stages as well as the evaluation of the app as applicable and recommendable in the beta test indicated that additional features of gamification and extended evaluation are not necessary for an app for a regular survey of the QoL. Therefore, we decided to exclude these features from further development. In addition to the finding that these additional features did not seem to have any influence, another conclusion could be drawn from the beta test: participants reported that the length of the QLQ-C30 had a negative impact on the regular use of the app. A regular response to 30 questions was too burdensome to be integrated into daily life, which led to the identification of a new user requirement for a shorter questionnaire. Furthermore, the beta test demonstrated that despite the extended explanation of how the title and category of the diary differed, problems continued to occur when using the diary. For this reason, the distinction between category and title was discarded after the beta test. We decided that an indication of a category would be deprecated but the input for a title would remain. To assist users in selecting an appropriate title, previous categories can be used to prefill the title as an auxiliary.

Figure 3. KPIs (range: –3 to 3) reflecting all three stages of usability testing. The KPIs are comparable in all 3 stages of development. KPI: key performance indicator.

Since the measurement of the QoL worldwide does not seem to be influenced by sex or age [44], we decided to publish 1 general version in the Google Play Store and the Apple App Store after the KPI reached the specified minimum value of 1.5. Lion-App was released after incorporating the user requirements with regard to critical problems. Therefore, the input of a diary entry was adapted, and additionally, a shorter questionnaire, the EuroQol 5 Dimension 5 Level (EQ-5D-5L), for regular assessment of the QoL was integrated. As a requirement for further versions, personalized periods for push messages as a reminder for assessing the QoL were documented. In the beta test, the user requirement for reminders of usage from the second test cycle was also implemented through push messages. These were sent if users had been inactive for at least 7 days. In the evaluation of the beta version of the app, this feature was perceived as positive but a requirement to personalize this period could be identified.

Discussion

Principal Findings

An app for surveying the QoL of patients with cancer was developed, which was rated as acceptable and applicable by participants in the beta test following a user-centered development approach. The app has now been released in the Google Play Store and the Apple App Store. Even though there exist many health apps, few have been developed to support patients with cancer and none of them could be identified as focusing on assessment of the QoL. This is an important step toward increased patient empowerment of oncology patients in clinical settings by facilitating personalized treatment with closer inclusion of the patients' QoL.

Impact of Age and Sex

Even though no significant differences in the sex-dependent evaluation of the KPI were found, they cannot be ruled out completely, as for both analyses, from usability test 1 to the beta test, the average number of male testers was lower than that of female testers. In both evaluations, the SD was higher for women than for men. Interestingly, men rated the basic version of usability test 1 almost the same as the beta version (usability test 1=2.24, beta test=2.20), while the rating of the beta test by women was far below their rating of usability test 1 (usability test 1=2.05, beta test=1.46).

Due to the small number of men in usability test 1, there was most likely less variability in the evaluation data. Even though more men participated in the beta test, they used the app more seldom compared to women; 73 (64%) of 115 interactions were carried out by women. Therefore, we cannot rule out that the probability to detect a faulty function or a confusing process was driven by women, which might also be reflected in the KPI for the app's rating. Moreover, as the research was conducted with a small cohort of 19 participants and within the environment of a beta test, sex differences of smaller effect sizes may have been overlooked and should be further assessed in an independent study.

Age was the only factor that influenced the entry form of a questionnaire response. Of note, the 95% CI of the correlation coefficient was 0, with a slightly higher upper threshold (0.16). This may indicate that there is no influence of age on the number of questionnaire responses within the app. However, with an upper value only slightly above 0 but the lower threshold almost at –1 (–0.9) and *P*=.02, the probability that there is an actual effect cannot be completely ruled out.

Strengths and Limitations

One strength of our approach is that we not only focused on user-centered development but also included assessment of the QoL as a central component. Throughout our research, user-centered development led to good results on usability. A good acceptance of the concept over the development cycles was also demonstrated in the evaluation via the UEQ+: throughout all stages of development, the KPI of the UEQ+ responses was around 2. According to the literature, it is difficult to achieve a KPI above 2 with large cohorts, due to the different perceptions and experiences of the users [39].

Participants stated that they could imagine using the app for self-management in their daily lives. By including end users not only once at the beginning or end of a development but throughout the whole implementation, we were able to not only assess the expectations of users but also include their feedback directly in the concept and conduct testing of the revised implementation in the next iteration of usability tests. This enabled us to first identify expectations and problem areas and then focus on those functionalities step by step until a solution was found that is user friendly and matches user requirements.

Even though we achieved good evaluation results, our results might be biased as usability tests were conducted in cooperation with cancer support groups. The participants of such groups are already sensitive to questions related to the symptoms and treatment of their own disease. In addition, the “thinking aloud” methodology may cause participants to be more actively engaged with the app than they would normally be if they were using it in real life. This might also have influenced the outcomes of the tests. Furthermore, adding personal questions before the UEQ+ might have led to a bias in the evaluation.

Moreover, our study sample was not homogenous: patients with cancer during as well as after completion of therapy were included in our research. Neither the type of their cancer nor the year of diagnosis was controlled for. Moreover, as no medical records were collected or available, we had to rely on the participants’ self-reporting of having received a cancer diagnosis in the past. Another limitation may be the relatively low number of participants. When conducting usability tests with only small sample sizes, less deviations may occur within evaluations. Therefore, corroboration in a further study with a larger cohort to obtain robust results that could either confirm or reject identified trends is needed.

Still, regarding the evaluation of usability, the number of participants was sufficient according to the literature. On the one hand, the critical number of 5 participants by Nielsen and Landauer [41] was exceeded in all usability tests and the recommendation of the Common Industry Format (CIF) to include at least 8 people for usability research was met. In addition, Chomutare et al [45] recommended a number above 7 to be sufficient, and Spyridakis [46] reported that groups of 10-12 participants yield statistically significant results. In summary, our research exceeded these critical totals in all evaluations.

Clinical Impact

The development of an app for the longitudinal survey of the QoL of patients with cancer provides the possibility of including the QoL and its monitoring into regular patient care. As data collection can be performed by patients at home, monitoring of the QoL can be performed easily. This provides the possibility of symptom-based treatment during therapy and assessment of the QoL posttherapy. By monitoring the QoL, not only can the quality of treatment be improved and better tailored to the patients’ needs but also the long-term impact of treatment may be better understood [47].

Studies have already shown a positive impact of symptom-based treatment on the course and outcome of therapy, but in clinical practice, assessing patients’ QoL is still challenging, since retrospective reports are usually distorted by recall bias [48]. It is therefore important to provide patients with a self-management tool that enables them to record their daily stress, symptoms, and QoL on a regular basis. Thus, not only the impact of treatment but also how it affects patients can be assessed [49]. The clinical impact of Lion-App has yet to be investigated.

Conclusion

The results of our app development indicate that an iterative, user-centered approach leads to a solution that is both user friendly and can be used to document the patient’s QoL at home. This is an important step toward empowering and engaging patients to integrate them into therapy as part of the treatment team. Our results can serve as an example of how user-centered development may be executed. In this research, a standardized self-management tool for patients with cancer to assess their QoL was developed. As end users were integrated iteratively into all stages of the development process, this led to a continuous adaptation of user requirements, with improved usability to implement a solution tailored to the needs of end users. The results of this study may be used for scientific exchange on new approaches to the user-centered development of health apps and QoL research. In further research, the long-term applicability and acceptance of Lion-App should be assessed, as well as its clinical impact.

Acknowledgments

We want to thank all participants for their contribution to the usability tests. The research was funded by the MOLIT Institute as well as by the Dieter Schwarz Foundation.

Data Availability

The data sets generated and analyzed during this study are not publicly available but may be requested from the corresponding author. These data sets only include data needed for the evaluation of usability and user engagement. In the research, no health-related data, such as quality-of-life data, were acquired.

Authors' Contributions

The contributions of the authors are as follows: CB: conceptualization, data curation, formal analysis, investigation, methodology, project administration, and writing—original draft; KZ: conceptualization, software, and writing—review and editing, UM:

writing—review and editing; BP: supervision and writing—review and editing; and CF: funding acquisition, supervision, and writing—review and editing. The authors declare that no AI was used for writing the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
A detailed description of the procedure of user testing.
[DOCX File , 19 KB - cancer_v9i1e44985_app1.docx]

Multimedia Appendix 2
Detailed evaluations of the UEQ-S and UEQ+ of all usability tests. UEQ+: extended version of the User Experience Questionnaire; UEQ-S: short form of the User Experience Questionnaire.
[DOCX File , 37 KB - cancer_v9i1e44985_app2.docx]

Multimedia Appendix 3
Overview of sex-dependent evaluations.
[DOCX File , 32 KB - cancer_v9i1e44985_app3.docx]

Multimedia Appendix 4
Overview of interactions in the third usability test per version.
[DOCX File , 28 KB - cancer_v9i1e44985_app4.docx]

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Abbreviations

EORTC: European Organization for Research and Treatment of Cancer
KPI: key performance indicator
QLQ-C30: Core Quality-of-Life Questionnaire
QoL: quality of life
SUS: System Usability Scale
UEQ: User Experience Questionnaire
UEQ+: extended version of the User Experience Questionnaire
UEQ-S: short version of the User Experience Questionnaire
UX: user experience

Edited by T de Azevedo Cardoso; submitted 12.12.22; peer-reviewed by P Rasche, K Ferrini, YC Liu, V Mylonopoulou, A Dennett; comments to author 24.04.23; revised version received 15.06.23; accepted 24.08.23; published 26.09.23.

Please cite as:
Beutter CNL, Zeller K, Martens UM, Pfleiderer B, Fegeler C
User-Centered Development of a Mobile App to Assess the Quality of Life of Patients With Cancer: Iterative Investigation and Usability Testing
JMIR Cancer 2023;9:e44985
URL: https://cancer.jmir.org/2023/1/e44985
doi:10.2196/44985
PMID:37751285

Original Paper

Supporting Pain Self-Management in Patients With Cancer: App Development Based on a Theoretical and Evidence-Driven Approach

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Abstract

Background: To inform the development of an intervention, it is essential to have a well-developed theoretical understanding of how an intervention causes change, as stated in the UK Medical Research Council guidelines for developing complex interventions. Theoretical foundations are often ignored in the development of mobile health apps intended to support pain self-management for patients with cancer.

Objective: This study aims to systematically set a theory- and evidence-driven design for a pain self-management app and specify the app's active features.

Methods: The Behavior Change Wheel (BCW) framework, a step-by-step theoretical approach to the development of interventions, was adopted to achieve the aim of this study. This started by understanding and identifying sources of behavior that could be targeted to support better pain management. Ultimately, the application of the BCW framework guided the identification of the active contents of the app, which were characterized using the Behavior Change Technique Taxonomy version 1.

Results: The theoretical analysis revealed that patients may have deficits in their capability, opportunity, and motivation that prevent them from performing pain self-management. The app needs to use education, persuasion, training, and enablement intervention functions because, based on the analysis, they were found the most likely to address the specified factors. Eighteen behavior change techniques were selected to describe precisely how the intervention functions can be presented to induce the desired change regarding the intervention context. In other words, they were selected to form the active contents of the app, potentially reducing barriers and serving to support patients in the self-management of pain while using the app.

Conclusions: This study fully reports the design and development of a pain self-management app underpinned by theory and evidence and intended for patients with cancer. It provides a model example of the BCW framework application for health app development. The work presented in this study is the first systematic theory- and evidence-driven design for a pain app for patients with cancer. This systematic approach can support clarity in evaluating the intervention's underlying mechanisms and support future replication.

(JMIR Cancer 2023;9:e49471) doi:10.2196/49471

KEYWORDS

pain; cancer; behavior change; capability, opportunity, motivation, and behavior model; COM-B model; Behavior Change Wheel; BCW; mobile health; mHealth; app; pain self-management; evidence-based; intervention design; theory

Introduction

Background

In patients with cancer, pain is one of the most devastating symptoms throughout the cancer stages, during which it increases in prevalence throughout and beyond cancer treatment [1,2]. Approximately one-third (31.8%) of the patients with cancer who experience pain do not receive pain medication proportional to their pain intensity [3]. Uncontrolled pain has a significant disabling effect on the daily activities and emotions of a patient with cancer, reducing their quality of life [4,5]. Evidence suggests that empowering patients with cancer and endorsing pain self-management have significant benefits in optimizing pain management [6-8].

A systematic review revealed that mobile apps have been increasingly reported as delivering health behavior change interventions and showing promising results [9]. Significantly, evidence shows that self-management interventions for patients delivered via mobile apps are effective compared with self-management interventions delivered via traditional methods or along with usual care in chronic conditions such as diabetes and cardiovascular diseases [10]. However, there is a paucity of evidence exploring the use of mobile health (mHealth) apps for improving the care of patients with cancer and particularly for supporting pain management, as also observed by Boceta et al [11].

According to the UK Medical Research Council (MRC) guidelines for developing complex interventions, a solid theoretical understanding of how an intervention causes change is required to inform its development [12]. Indeed, the use, particularly extensive use, of theory and multiple behavior change techniques (BCTs) in internet- and mHealth-based interventions was associated with significant levels of effectiveness [13,14]. However, contrary to this guidance, evidence has shown that the use of theory was either not mentioned or not explicitly discussed regarding how it was applied to drive the design and development of mobile apps, particularly apps for people with cancer [14,15]. Many reviews on pain-related apps in general have confirmed that the reviewed apps lacked both theoretical rationale and evidence-based features and strategies [16-18]. The reviews concluded with highlighting the need to consider the theoretical and evidence-based foundation for designing and developing pain apps to better support patients' pain self-management.

In relation to interventions for pain self-management for patients with cancer in particular, systematic reviews and meta-analyses have shown that such interventions are effective in supporting better pain management [7,8,19-21]. However, the studies did not reveal which intervention component or combination of components was the most effective. Koller et al [8] and later Howell et al [7] reviewed the structure and content of interventions designed to improve patients' self-management of cancer pain, aiming to identify the efficacy of different components. Despite the detailed description of the interventions' components provided by the 2 reviews, the most efficacious component or group of components could not be determined. As discussed by the authors, this was related to the heterogeneity in the designs of the reviewed studies and the variability in the number of structure and content components of the interventions. Therefore, there is a need for interventions to be designed and developed considering a systematic approach that makes it possible to characterize interventions. Certainly, characterizing interventions by standardized and well-defined BCTs, which are active components, is required to achieve two important aspects: (1) enable tracking mechanisms subsidizing effectiveness across interventions and (2) enable the replication and development of effective interventions [22-25]. In addition, it seems that there is a variation in perceiving the term *pain self-management*. This has led to heterogeneity in the focus and content of pain self-management support interventions for patients with cancer. Indeed, Howell et al [7] emphasized the need for consensus when defining the essential components of cancer self-management to ensure the consistent and effective delivery of such interventions.

Insight Into Pain Self-Management Concept

A review of Cochrane reviews of the self-management of chronic condition interventions stated that, in practice, the term "self-management" has been used to describe both simple and complex interventions aimed to empower individuals to manage their own health. Such interventions focused on educating patients about their condition and providing them with basic skills to manage their disease symptoms daily [26]. The latter is required to build self-efficacy, which is deemed a key element attributed to behavior change and health outcomes [27]. It refers to the belief in one's own abilities to establish and execute the courses of action required to achieve specified goals [28].

Pain self-management interventions for patients with cancer have been described as complex interventions because they need to incorporate several interacting components, reflecting the complexity of cancer pain [7,12,29]. A recent review has addressed the need for defining these components and detailed the concept of self-management of cancer pain [30]. Consequently, the latter has been defined as "the process in which patients with cancer pain make the decision to manage their pain, enhance their self-efficacy by solving problems caused by the pain, and incorporate pain-relieving strategies into daily life, through interactions with health-care professionals" [30]. Thus, five attributes were identified for cancer pain self-management as follows: (1) interactions with health care professionals (HCPs), (2) decision-making for pain management, (3) pain-related problem-solving, (4) self-efficacy, and (5) incorporating strategies for pain relief into daily life. These attributes were suggested to be used as modules of nursing practice promoting patient self-management of cancer pain [30].

Behavior Change Theories and Models

There are many theories and models for behavior change, such as the theory of reasoned action [31] and the theory of planned behavior [32]; however, there has been a lack of guidance and rationale for selecting a specific model or theory for a particular context [33,34]. In addition, many of the models or theories share or have overlapping constructs, making it difficult to know how to select and apply theories [35]. Behavior change intervention development frameworks, such as intervention mapping [36] and the BCT taxonomy developed by Abraham et al [37], contribute to translating theory into practice [34]. Nineteen existing frameworks, including the aforementioned ones, were identified in a systematic review study, evaluated in terms of usefulness, and criticized in regard to ≥1 of 3 aspects: not being linked to an overarching behavior model, being conceptually incoherent, or being uncomprehensive in terms of offering designers the full range of options to change behavior [34]. The Behavior Change Wheel (BCW) framework was constructed to overcome these limitations by synthesizing the common features of the frameworks. It provides a step-by-step method for systematic and theory-based design and the development of behavior change interventions that can be characterized by BCTs [34,38].

The BCW is based on the capability, opportunity, motivation, and behavior (COM-B) model that suggests that interaction among 3 components, namely capability (C), opportunity (O), and motivation (M), produces behavior (B) that, in turn, influences them [34,38]. Thus, changing behavior requires changing ≥1 of these components. Each component is subdivided into 2 types as follows: physical and psychological capability, social and physical opportunity, and reflective and automatic motivation. The BCW is designed to drive intervention designers into building behavioral analysis to understand the targeted behavior using this model. The analysis helps identify what is missing and what needs to change for a desired behavior to occur and contribute to solving a problem. Next, the BCW allows designers to identify which of 9 possible intervention functions could best bring about change. Moreover, it supports the selection of the best policy category, if required, for delivering the intervention from 7 specified categories. It then suggests specifying the content of the intervention through selecting the appropriate BCTs that best serve the identified intervention functions. The BCTs, or the "active ingredients of an intervention" as described by the BCW, can be selected from the Behavior Change Technique Taxonomy version 1 (BCTTv1), which is the international consensus taxonomy of 93 evidence-based BCTs clustered within 16 categories [25]. The BCW framework also provides guidance in specifying the appropriate mode of delivery to implement an intervention, if needed [38].

The BCW is an increasingly applied framework for designing and developing behavior change interventions in various health-related problems and contexts [39-42] (some interventions were delivered through apps [43-46]). However, to the best of our knowledge, the BCW has never been used in the context of supporting pain self-management for patients with cancer. Indeed, Koller et al [29] used only the BCTTv1 to code and describe their "ANtiPain" intervention for patients with cancer in their pilot randomized controlled trial study. Therefore, this study aims to design a pain self-management app for patients with cancer and specify its active features by following a detailed application of the BCW. This is the first systematic theory- and evidence-driven design for an app in this context.

Methods

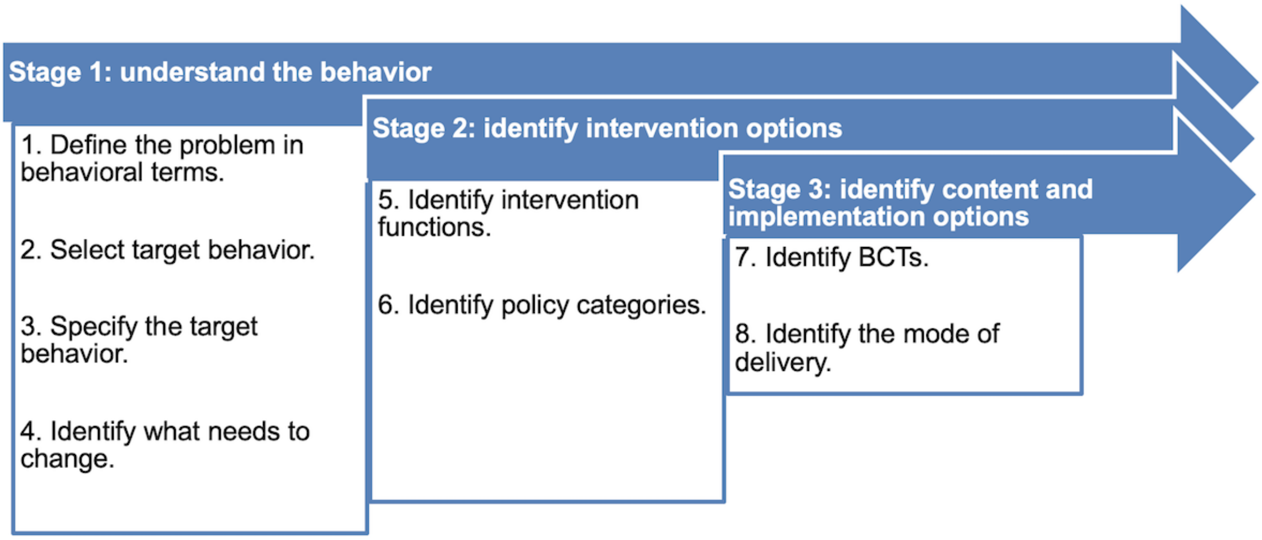
Ethical Considerations

No ethical approval was required for this study, according to the Research Ethics Committee at King Saud University. The study was based on reviewing the literature and applying a theoretical framework, and no human or animal subjects were involved.

Overview

According to the BCW framework, there are 8 steps grouped into 3 stages for designing behavior change interventions (Figure 1). The steps can be conducted with flexibility according to the need and context for each individual study [38]. For this study, they were adapted and conducted as detailed in the following subsections.

Figure 1. Behavior change intervention design process. BCT: behavior change technique.



Stage 1: Understanding the Behavior and What Needs to Change

Step 1: Defining the Problem in Behavioral Terms

This step aims to define the problem of inadequate pain management for patients with cancer in behavioral terms. This involved considering all behaviors from individuals, groups, or populations that potentially contribute to the problem. To accomplish this step, we relied on reviewing the literature to understand the barriers and facilitators of adequate cancer pain management. The MEDLINE electronic database was searched using a combination of terms, including *barriers*, *facilitators*, *pain management*, and *cancer*, and synonyms of these terms.

Step 2: Selecting Target Behavior

The aim of this step was to select 1 target behavior to be addressed by the intervention because it is recommended limiting the intervention to just 1 or a few behaviors to increase the intensity and effectiveness of the intervention [38]. The target behavior was selected based on evidence discussed in the literature regarding factors that hinder effective pain management [6-8]. As the app is oriented to the patient's use in the home setting, we focused on pain management behaviors attributed to patients. The behavior that showed the strongest supporting evidence for better pain management was selected as the target behavior.

Step 3: Specifying the Target Behavior or Behaviors

In this step, the target behavior was specified in terms of the context in which it occurs, including who performs it, what needs to be performed to achieve the desired change, and when and where it is performed.

Step 4: Identifying What Needs to Change

This step aims to identify the determinants for the target behavior specified from the previous steps, which involved pain self-management. A behavioral diagnosis was conducted to identify what needs to be changed in relation to the COM-B components for the selected target behavior to be performed. This means exploring the barriers to, and facilitators of, patients' capability, opportunity, and motivation to perform pain self-management, as defined earlier (refer to the Introduction section). The MEDLINE database was searched using a combination of keywords and relevant Medical Subject Headings (MeSH) terms, such as *pain management*, *self-management*, *cancer*, *pain*, *barriers*, *facilitators*, and *patient-related barriers* (refer to Multimedia Appendix 1 for the search strategy). The search was restricted to any type of review article to identify the evidence-based barriers to, and facilitators of, the target behaviors. The identified relevant articles were analyzed to extract all barriers and facilitators relevant to pain self-management. The barriers and facilitators were coded and mapped to the COM-B components. This was represented in a table that served as the foundation for mapping theoretical components to app features.

Stage 2: Identifying Intervention Options

Step 5: Identifying Intervention Functions

There are 9 BCW intervention functions (each function can serve multiple COM-B components, and each component can be served by different functions). They are education, persuasion, incentivization, coercion, training, restriction, environmental restructuring, modeling, and enablement [34,38]. The COM-B components identified in the previous stage were mapped to intervention functions that are likely to serve them and bring about change according to the BCW's guidelines [38].

Step 6: Identifying Policy Categories

The BCW identified 7 policy categories that could effectively support the delivery of the intervention functions and provided a matrix for this process. The possible policy categories are communication and marketing, guidelines, fiscal measures, regulation, legislation, environmental and social planning, and service provision [34,38]. In this study, the intended app was conceptualized as falling in the service provision policy category according to the BCW [34,38]. Therefore, this step was used to refine the candidate intervention functions identified in the previous step to only the functions that could be delivered using this policy category.

Furthermore, the BCW framework emphasizes the importance of considering the context of the intervention as all steps are implemented and selecting what is most appropriate for the intervention to ensure effectiveness [34,38]. In line with this, the affordability, practicability, effectiveness and cost-effectiveness, acceptability, side effects and safety, and equity (APEASE) criteria, suggested by the BCW [38], were applied to the candidate intervention functions. This was to guide the judgment in selecting the most suitable functions that the intervention can serve within its context. The judgment was first made by AAA based on the criteria application; subsequently, it was reviewed by the other authors. The selected functions were then mapped to the original intervention table produced in the first stage.

Stage 3: Identifying Content and Implementation Options

Step 7: Identifying BCTs

The contents of the intervention were identified in this step using the BCTTv1 [25]. This was achieved, in accordance with the BCW guidelines [38], through mapping the selected intervention functions from the previous steps to possible BCTs that are relevant to serve the functions and induce the desired change. The BCW identified a list of candidate BCTs for each intervention function and classified them into most and least frequently used BCTs. Both groups were considered for this intervention. Some BCTs are deemed appropriate for different intervention functions. Web-based training provided by the BCTTv1 developers [47] was taken to help in understanding BCT labels and definitions and in applying the taxonomy accurately and reliably. All candidate BCTs for the intervention were considered with regard to their appropriateness to the context using the APEASE criteria. Next, evidence from the literature on BCTs used in effective interventions was considered to support the final selection of potentially effective and evidence-based BCTs to be incorporated into the app design. The database of BCTTv1-coded interventions [48] was searched for interventions that focused on self-management as the target behavior. There was found to be a lack of interventions and reviews in supporting pain self-management for patients with cancer using the BCTTv1. Therefore, BCTs serving effective interventions supporting self-management in any health condition were included. The selected BCTs were then mapped to the original intervention table with examples given on how these BCTs could be applied in the intervention context. Translating BCTs into app features was not guided by the BCW framework. Digital behavior change interventions [41,43,44,46,49] that used some of the BCTs identified for the app were reviewed to learn how the BCTs could be represented.

Step 8: Identifying the Mode of Delivery

The selected mode of delivery, as discussed earlier, is a mobile phone app. Therefore, this step of the framework was not considered.

Results

Stage 1: Understanding the Behavior and What Needs to Change

Steps 1, 2, and 3: Defining, Selecting, and Specifying the Target Behaviors

Step 1

From a behavioral perspective, it was clear from the literature that the problem of unsatisfactory pain management is related to a combination of behaviors on the HCP, health care system, and patient levels [50-52].

Step 2

Pain self-management was selected as the target behavior for the app because it shows strong supporting evidence for better pain management [53-58].

Step 3

Patients need to self-manage their pain at home and during the period of experiencing pain by incorporating pain control strategies into daily life and communicating with HCPs.

Step 4: Identifying What Needs to Change

Five relevant review articles [51,55-58] were generated from the search and used for the behavioral diagnosis. The behavioral diagnosis shown in Multimedia Appendix 2 indicated that physical and psychological capability, physical and social opportunity, and automatic and reflective motivation needed to change for the pain self-management to be performed. Multimedia Appendix 2 serves as the intervention mapping table for the rest of the analysis results.

Stage 2: Identifying Intervention Options (Steps 5 and 6: Identifying and Refining Intervention Functions)

Mapping the intervention functions to the corresponding COM-B components indicated that all 9 intervention functions were appropriate for addressing the identified determinants for pain self-management behavior (Table 1). However, refining the functions to be delivered through the app (ie, service provision policy category) resulted in the following 7 (78%) of 9 functions being considered for inclusion: education, persuasion, incentivization, coercion, training, modeling, and enablement (Table 1). Moreover, after considering each candidate of the intervention functions using the APEASE criteria, 4 (57%) of the 7 functions were selected: education, persuasion, training, and enablement; the reasons for selecting these are detailed in Table 2. Multimedia Appendix 2 illustrates mapping the selected functions to the previous results.

Table 1. Mapping intervention functions to capability, opportunity, motivation, and behavior (COM-B) components with consideration to the selected policy category.

COM-B components	Candidate intervention functions								
	Education	Persuasion	Incentivization	Coercion	Training	Restriction	Environmental restructuring	Modeling	Enablement
Physical capability					✓				✓
Psychological capability	✓				✓				✓
Physical opportunity					✓	✓[a]	✓[a]		✓
Social opportunity						✓[a]	✓[a]	✓	✓
Automatic motivation		✓	✓	✓	✓		✓[a]	✓	✓
Reflective motivation	✓	✓	✓	✓					

[a] Inappropriate intervention function to deliver through service provision policy category.

Table 2. Applying the affordability, practicability, effectiveness and cost-effectiveness, acceptability, side effects and safety, and equity (APEASE) criteria to guide the selection of intervention functions.

Candidate intervention functions	Definition [34,38]	Does the intervention function meet the APEASE criteria in the context of using an app to support pain self-management?
Education	"Increasing knowledge or understanding"	Yes
Persuasion	"Using communication to induce positive or negative feelings or stimulate action"	Yes
Incentivization	"Creating an expectation of reward"	Not practicable and unlikely to be effective in this context
Coercion	"Creating an expectation of punishment or cost"	Not acceptable to patients and not practicable to deliver in this context
Training	"Imparting skills"	Yes
Modeling	"Providing an example for people to aspire to or imitate"	Not practicable or relevant to deliver in this context
Enablement	"Increasing means or reducing barriers to increase capability or opportunity"	Yes

Stage 3: Identifying Content and Implementation Options (Step 7: Identifying BCTs)

A total of 65 candidate BCTs were derived from linking the selected intervention functions to BCTs. This set was refined based on considering the context and applying the APEASE criteria to the 18 BCTs listed in Table 3 (refer to Multimedia Appendix 3 [25] for the full analysis), 15 (83%) of which were found to have been used in effective self-management interventions, as specified in Table 3. Multimedia Appendix 2 outlines how these 18 BCTs were mapped to the previous analysis, along with examples of how they could be represented to bring about change and encourage patients to perform pain self-management.

Table 3. Mapping intervention functions to behavior change techniques (BCTs).

Intervention function and BCT label[a]	BCT definition [25]	Evidence for effectiveness
Education		
2.2. Feedback on behavior	"Monitor and provide informative or evaluative feedback on performance of the behavior (eg, form, frequency, duration, and intensity)"	Yes [29,59]
2.3. Self-monitoring of behavior	"Establish a method for the person to monitor and record their behavior of behaviors as part of a behavior change strategy"	Yes [29,60]
2.7. Feedback on outcome of behavior	"Monitor and provide feedback on the outcome of performance of the behavior"	Yes [60]
5.1. Information about health consequences	"Provide information (eg, written, verbal, and visual) about health consequences of performing the behavior"	Yes [29,59,60]
5.3. Information about social and environmental consequences	"Provide information (eg, written, verbal, and visual) about social and environmental consequences of performing the behavior"	No
7.1. Prompts or cues	"Introduce or define environmental or social stimulus with the purpose of prompting or cueing the behavior"	Yes [60]
2.4. Self-monitoring of outcome(s) of behavior[b]	"Establish a method for the person to monitor and record the outcome(s) of their behavior as part of a behavior change strategy"	Yes [29]
5.6. Information about emotional consequences[b]	"Provide information (eg, written, verbal, and visual) about emotional consequences of performing the behavior"	No
6.3. Information about others' approval[b]	"Provide information about what other people think about the behavior. The information clarifies whether others will like, approve or disapprove of what the person is doing or will do"	No
Persuasion		
2.2. Feedback on behavior	"Monitor and provide informative or evaluative feedback on performance of the behavior (eg, form, frequency, duration, and intensity)"	Yes [29,59]
2.7. Feedback on outcome(s) of behavior	"Monitor and provide feedback on the outcome of performance of the behavior"	Yes [60]
5.1. Information about health consequences	"Provide information (eg, written, verbal, and visual) about health consequences of performing the behavior"	Yes [29,59,60]
5.3. Information about social and environmental consequences	"Provide information (eg, written, verbal, and visual) about social and environmental consequences of performing the behavior"	No
5.6. Information about emotional consequences[b]	"Provide information (eg, written, verbal, and visual) about emotional consequences of performing the behavior"	No
6.3. Information about others' approval[b]	"Provide information about what other people think about the behavior. The information clarifies whether others will like, approve or disapprove of what the person is doing or will do"	No
Training		
2.2. Feedback on behavior	"Monitor and provide informative or evaluative feedback on performance of the behavior (eg, form, frequency, duration, and intensity)"	Yes [29,59]
2.3. Self-monitoring of behavior	"Establish a method for the person to monitor and record their behavior(s) as part of a behavior change strategy"	Yes [29,60]
2.7. Feedback on outcome(s) of behavior	"Monitor and provide feedback on the outcome of performance of the behavior"	Yes [60]
4.1. Instruction on how to perform a behavior	"Advise or agree on how to perform the behavior"	Yes [60,61]
2.4. Self-monitoring of outcome(s) of behavior[b]	"Establish a method for the person to monitor and record the outcome(s) of their behavior as part of a behavior change strategy"	Yes [29]
Enablement		
1.2. Problem-solving	"Analyze, or prompt the person to analyze, factors influencing the behavior and generate or select strategies that include overcoming barriers and/or increasing facilitators"	Yes [29,59,61,62]

Intervention function and BCT label[a]	BCT definition [25]	Evidence for effectiveness
2.3. Self-monitoring of behavior	“Establish a method for the person to monitor and record their behavior(s) as part of a behavior change strategy”	Yes [29,60]
3.1. Social support (unspecified)	“Advise on, arrange or provide social support (eg, from friends, relatives, colleagues, ‘buddies,’ or staff) or non-contingent praise or reward for performance of the behavior”	Yes [29]
3.2. Social support (practical)	“Advise on, arrange, or provide practical help (eg, from friends, relatives, colleagues, ‘buddies’ or staff) for performance of the behavior”	Yes [60]
2.4. Self-monitoring of outcome(s) of behavior[b]	“Establish a method for the person to monitor and record the outcome(s) of their behavior as part of a behavior change strategy”	Yes [29]
3.3. Social support (emotional)[b]	“Advise on, arrange, or provide emotional social support (eg, from friends, relatives, colleagues, ‘buddies’ or staff) for performance of the behavior”	Yes [29]
11.1. Pharmacological support[b]	“Provide, or encourage the use of or adherence to, drugs to facilitate behavior change”	Yes [29,61,62]
11.2. Reduce negative emotions[b]	“Advise on ways of reducing negative emotions to facilitate performance of the behavior”	Yes [29,62]
12.2. Restructuring the social environment[b]	“Change, or advise to change, the social environment in order to facilitate performance of the wanted behavior, or create barriers to the unwanted behavior”	Yes [29]
12.6. Body changes[b]	“Alter body structure, functioning or support directly to facilitate behavior change”	Yes [61]

[a] The number beside each BCT label refers to the classification label in the Behavior Change Technique Taxonomy version 1.

[b] Less frequently used BCTs identified for the intervention function.

Discussion

Principal Findings

Much of the recent literature on evaluating pain apps has revealed the absence of any theoretical foundation and evidence-based features [16-18]. This study reports the theory- and evidence-driven design of an app, which is intended to support pain self-management, through the application of the BCW framework. This theoretical framework helps explain the mechanisms through which the intervention is likely to influence behavior change [46]. This is in line with the UK MRC recommendation for developing and evaluating complex interventions [12].

In this study, the results of the fundamental phase of the BCW, the behavioral diagnosis based on the COM-B model, revealed that patients may have deficits in their capability, opportunity, and motivation that prevent them from performing pain self-management (Multimedia Appendix 2). Consequently, the determinants derived from the literature in relation to the diagnosis were identified to be targeted by the app. They were in accordance with indicators that have been identified for nurses to assess whether patients with cancer pain can perform pain self-management [30]. These were labeled as physical functions, cognitive abilities, motivation, undergoing treatment for pain, receiving individual education, receiving family and HCPs’ support, and health literacy [30].

The app needs to use education, persuasion, training, and enablement intervention functions because, based on the analysis, they were found the most likely to address the specified factors. Incentivization, coercion, and modeling intervention functions were also suggested by the BCW, but they were excluded (Table 2). This was because the nature and complexity of the disease and the pain do not allow these types of intervention functions to be practicable or acceptable; for example, it would be inappropriate to show any form of reward or punishment simply because pain was controlled or not, respectively. In some cases, a patient’s effort to cope with pain might not be very successful.

Eighteen BCTs were selected to describe specifically how the intervention functions can be presented to induce the desired change regarding the intervention context (Table 3). In other words, they were selected to form the active contents of the app, potentially reducing barriers and serving to support patients in the self-management of pain while using the app, as the context examples illustrate in Multimedia Appendix 2; for example, to increase patients’ motivation, which could be affected by the belief that pain increases as the disease progresses and so cannot be managed, the app can serve to educate patients by explaining the health consequences of cancer, including pain, to correct the misconception. In addition, the app can use a persuasion function, which could be presented through asking patients to monitor and record pain levels. This has the potential to improve self-efficacy through observing positive experiences and trigger problem-solving through noting unsuccessful ones.

The results showed that, of the 18 identified BCTs, 15 (83%) had previously been applied in effective self-management interventions, whereas 3 (17%), namely *information about others’approval*, *information about emotional consequences*, and *information about social and environmental consequences*, had no evidence of earlier use. Despite the lack of evidence of the effectiveness to support the exceptions, it was decided to include them in the design of the app to provide evidence about their effectiveness in a future work. Some of the BCTs (38/65, 58%) proposed by the BCW were found inappropriate to the context, such as *biofeedback*, *identification of self as role model*, and *social comparison*. Other promising BCTs (9/65, 14%) cannot be delivered through the app, such as *goal setting*, *review behavior goal*, and *action planning*; these are likely to require nurse coaching to be better implemented, which was beyond the scope of this study (Multimedia Appendix 3); for example, the aforementioned BCTs were successfully implemented by Koller et al [29] in their intervention, which involved coaching nurses to support patients' pain self-management. In addition, not every face-to-face intervention can be translated to mobile technology, but questioning whether it is possible is important [63].

The BCTs specified for the app need to be carefully translated and implemented as meaningful app features because no guidance is provided by the BCW in relation to this matter. It is crucial that the BCTs are delivered in optimal ways that ensure patients' engagement; therefore, the user-centered design approach is recommended to be adopted for building the app in line with patients' preferences. BCTs such as *self-monitoring* and *feedback* will not be effective if patients lose interest in using the app.

It is important to acknowledge that the application of behavior change theory in digital health is still an emerging area of research, with creation of an agenda to guide the development of research only started in recent years [64]. The behavioral intervention technology (BIT) model is another conceptual framework that aims to integrate behavioral science and technology and to support the translation of the behavior change strategies into features of BIT, such as apps [65]. Unlike the BCW framework, the BIT model does not consider understanding the target behavior from the early stages, and it does not provide intervention designers with all possible options for solving the problem; therefore, they can systematically select the most appropriate one for the context. In addition, it does not support the integration of the user-centered design method [43]. Indeed, these aspects were believed to be essential factors for increasing the likelihood of success of mHealth apps [43].

On the basis of the aforementioned particulars, this study provided a step-by-step theory- and evidence-based design for the intended app. Such clarity was considered minimal or even nonexistent in the practice of interventions claiming that they are guided by theory [66]. Characterizing the app by well-defined and evidence-based BCTs might allow replication and easier evidence synthesis regarding the effectiveness of intervention contents, which was difficult to achieve as the evidence suggested [7,8,19-21].

Limitations

The behavioral analysis was based on literature from only 1 database because the topic of patients' barriers to cancer pain management seemed well investigated. Nevertheless, searching more databases and additional data from multiple sources, such as focus groups or interviews, could have revealed further insights and strengthened the understanding of cancer pain self-management behaviors. Consequently, this could have resulted in a more precise selection of BCTs and effective interventions. Another limitation was related to implementing the stepwise approach recommended by the BCW team (Figure 1). Although it seems straightforward, it was hard to follow in practice because it involved shifting back and forth among steps as issues were discovered. It required using a great amount of judgment regarding what is most appropriate for the context, which involved consultations with the framework developers as well as with some experts in pain management. This may make it necessary to revisit the earlier stages at times, and this might not be clearly documented.

Conclusions

There has been increasing emphasis on the need for underpinning theory and evidence for mHealth interventions to ensure their success and facilitate their appraisal. The work in this study demonstrated the application of the BCW framework in designing and developing an app for supporting pain self-management for patients with cancer. The app design will be based on education, persuasion, training, and enablement intervention functions that will be presented by 18 BCTs. To the best of our knowledge, this is the first systematic theory- and evidence-driven design for a pain app for patients with cancer. This systematic approach can support clarity in the evaluation of the underlying mechanisms of the intervention and support future replication.

Acknowledgments

This study is funded by King Saud University, Riyadh, Saudi Arabia (Research Supporting Project number RSPD2023R615). The funder is gratefully acknowledged.

Data Availability

Data collected in this work are presented within the manuscript and the supplementary documents.

Authors' Contributions

AAA designed the study and collected the data. All authors contributed to analyzing and interpreting the data. AAA drafted the manuscript, and all authors revised it and approved the final version.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Search strategy for the behavioral diagnosis.

[DOCX File , 34 KB - cancer_v9i1e49471_app1.docx]

Multimedia Appendix 2

Behavioral diagnosis for pain self-management using the capability, opportunity, motivation, and behavior (COM-B) model.

[DOCX File , 28 KB - cancer_v9i1e49471_app2.docx]

Multimedia Appendix 3

Mapping intervention functions to behavior change techniques and applying affordability, practicability, effectiveness and cost-effectiveness, acceptability, side effects and safety, and equity (APEASE) criteria.

[DOCX File , 45 KB - cancer_v9i1e49471_app3.docx]

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Abbreviations

APEASE: affordability, practicability, effectiveness and cost-effectiveness, acceptability, side effects and safety, and equity
BCT: behavior change technique
BCTTv1: Behavior Change Technique Taxonomy version 1
BCW: Behavior Change Wheel
BIT: behavioral intervention technology
COM-B: capability, opportunity, motivation, and behavior
HCP: health care professional
MeSH: Medical Subject Headings
mHealth: mobile health
MRC: Medical Research Council

Edited by T de Azevedo Cardoso; submitted 30.05.23; peer-reviewed by SA Steindal, E Ross; comments to author 09.08.23; revised version received 21.08.23; accepted 22.08.23; published 09.10.23.

Please cite as:
Abahussin AA, West RM, Wong DC, Ziegler LE, Allsop MJ
Supporting Pain Self-Management in Patients With Cancer: App Development Based on a Theoretical and Evidence-Driven Approach
JMIR Cancer 2023;9:e49471
URL: https://cancer.jmir.org/2023/1/e49471
doi:10.2196/49471
PMID:37812491

Original Paper

Development and Promotion of an mHealth App for Adolescents Based on the European Code Against Cancer: Retrospective Cohort Study

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Abstract

Background: Mobile health technologies, underpinned by scientific evidence and ethical standards, exhibit considerable promise and potential in actively engaging consumers and patients while also assisting health care providers in delivering cancer prevention and care services. The WASABY mobile app was conceived as an innovative, evidence-based mobile health tool aimed at disseminating age-appropriate messages from the European Code Against Cancer (ECAC) to adolescents across Europe.

Objective: This study aims to assess the outcomes of the design, development, and promotion of the WASABY app through a 3-pronged evaluation framework that encompasses data on social media promotion, app store traffic, and user engagement.

Methods: The WASABY app's content, cocreated with cancer-focused civil society organizations across 6 European countries, drew upon scientific evidence from the ECAC. The app's 10 modules were designed using the health belief model and a gamification conceptual framework characterized by spaced repetition learning techniques, refined through 2 rounds of testing. To evaluate the effectiveness of the app, we conducted a retrospective cohort study using the WASABY app's user database registered from February 4 to June 30, 2021, using a 3-pronged assessment framework: social media promotion, app store traffic, and user engagement. Descriptive statistics and association analyses explored the relationship between sociodemographic variables and user performance analytics.

Results: After extensive promotion on various social media platforms and subsequent traffic to the Apple App and Google Play stores, a sample of 748 users aged between 14 and 19 years was included in the study cohort. The selected sample exhibited a mean age of 16.08 (SD 1.28) years and was characterized by a predominant representation of female users (499/748, 66.7%). Most app users identified themselves as nonsmokers (689/748, 92.1%), reported either no or infrequent alcohol consumption (432/748, 57.8% and 250/748, 33.4%, respectively), and indicated being physically active for 1 to 5 hours per week (505/748, 67.5%). In aggregate, the app's content garnered substantial interest, as evidenced by 40.8% (305/748) of users visiting each of the 10 individual modules. Notably, sex and smoking habits emerged as predictors of app completion rates; specifically, male and smoking users demonstrated a decreased likelihood of successfully completing the app's content (odds ratio 0.878, 95% CI 0.809-0.954 and odds ratio 0.835, 95% CI 0.735-0.949, respectively).

Conclusions: The development and promotion of the WASABY app presents a valuable case study, illustrating the effective dissemination of evidence-based recommendations on cancer prevention within the ECAC through an innovative mobile app aimed at European adolescents. The data derived from this study provide insightful findings for the implementation of Europe's Beating Cancer Plan, particularly the creation of the EU Mobile App for Cancer Prevention.

(JMIR Cancer 2023;9:e48040) doi:10.2196/48040

KEYWORDS

adolescent health; cancer prevention; digital health; ECAC; European Code Against Cancer; health promotion; mHealth; mobile app; mobile health; NCD; noncommunicable disease; primary prevention

Introduction

Background

Cancer cases are on the rise due to changes in demographics and exposure to risk factors, adding to the significant financial costs already linked to the disease [1]. Europe has a tenth of the world's population but accounts for a quarter of the world's cancer cases. In 2020, a total of 2.7 million people in the European Union (EU) were diagnosed with the disease, and another 1.3 million people lost their lives to it [2]. Moreover, in 2018, the financial burden of cancer in Europe due to health expenditure, loss of productivity, and informal care costs was €199 billion (US $213 billion) [3]. Unless we take decisive action, the number of lives lost to cancer in the EU is set to increase by more than 24% by 2035, making it the leading cause of death in the EU [4]. The significant expected increase in the number of cancers demands measures to encourage the prevention of the disease.

The European Code Against Cancer (ECAC) [5] has been a key health literacy measure used by the public and third sectors since the 1980s to promote and mainstream cancer prevention [6]. The ECAC, which is a trusted preventive tool free of commercial influence providing a reliable synthesis of the latest scientific evidence on cancer prevention, suggests that around 40% of cancers in Europe could be prevented through a mix of individual- and population-level actions known to be effective [5]. The current fourth edition of the ECAC aims to inform people about how to avoid or reduce their exposure to carcinogens, adopt behaviors that can lower their risk of developing cancer, and participate in organized screening programs through 12 easy-to-follow recommendations that do not require any special skills or advice [5]. The available evidence that cancer can be greatly prevented in Europe, coupled with support from the World Health Organization (WHO) for an inclusive, life-course approach to cancer prevention in its worldwide action plan for the prevention and control of noncommunicable diseases (NCDs) [7], sets a strong case for targeting adolescents and young people to multiply the benefits [8].

The Importance of Adolescent Health for Cancer Prevention

Adolescence, as defined by the WHO, spans from the 10th to the 19th year of life and represents a period characterized by rapid and pivotal growth and transformation, second only to infancy [9]. During this life stage, individuals undergo substantial changes in their physical, cognitive, and psychosocial development. This is a crucial phase for the establishment of positive habits and the development of behaviors that can exert a lasting influence on both their current and future health, as well as the health of their potential children [10].

The welfare of adolescents varies considerably across European countries [11]. Some of the health issues they face are associated with their lifestyles and risky behaviors, including alcohol and tobacco consumption, as well as sedentary and poor dietary habits [12,13]. Consequently, enhancing adolescents' awareness of the prevention messages within the ECAC and how modifiable lifestyle factors can influence cancer risk is imperative for shaping their lifelong patterns of healthy behavior.

To grow and develop in good health, adolescents require access to information, including age-appropriate comprehensive cancer prevention education. It is widely recognized that adolescents heavily rely on web-based information; however, they frequently fall victim to misinformation concerning modifiable risk factors and healthy lifestyles [14]. Moreover, their strategies for evaluating information tend to be unsophisticated and inadequate [15]. This underscores the importance of offering them easily accessible, robust, and evidence-based information.

Mobile Health Technologies for Cancer Prevention

Mobile health (mHealth) technologies, underpinned by scientific evidence and ethical standards, exhibit considerable promise and potential in actively engaging consumers and patients while also assisting healthcare providers in delivering evidence-based care across the cancer control continuum [16]. This is substantiated by the WHO, which acknowledges that digital tools are an asset in supporting healthy lifestyles and addressing NCDs [17].

Numerous mobile apps with a focus on cancer often emphasize patient empowerment and self-care [18,19] or concentrate on addressing specific risk factors and types of cancer [20,21]. Hence, these apps may not inherently suit the context of healthy adolescents. Regarding concerns on the effectiveness of app-based interventions in promoting healthier lifestyles, the results are mixed and heavily reliant on the primary recommendations being conveyed. For young adults, these interventions have proven to be successful in promoting smoking cessation [22], improving dietary habits [23], managing weight [24], and reducing alcohol consumption [25]. Adolescents have also benefited from digital tools, particularly in terms of improving their diet [26-28] and promoting sun protection habits [29,30]. Additionally, positive results have been observed when using apps that target multiple health risks simultaneously, both in review studies [31,32] and primary research [33,34]. However, these apps lack comprehensiveness in addressing the entirety of modifiable risk factors recognized by the ECAC.

Considering the widespread adoption of mobile technology among adolescents and the findings from the literature mentioned above, leveraging smartphone technology to promote behaviors that enhance adolescents' health literacy regarding cancer risk factors appears promising. Therefore, we developed a novel mobile app (WASABY) to encourage the adoption of a healthy lifestyle for the purpose of cancer prevention within the adolescent subpopulation.

App Rationale

The WASABY app (hereafter “app”) was developed by the Association of European Cancer Leagues (ECL) as an evidence-based, educational mHealth tool to facilitate the dissemination and comprehension of age-appropriate messages outlined in the ECAC to a demographic of healthy adolescents within Europe, spanning the age range of 14-19 years. In particular, the app was designed to impart knowledge on modifiable cancer risk factors and guidance on mitigating individual risk in a fun and interactive way. Importantly, it does not dispense medical advice for patients with cancer or any other vulnerable or ill populations.

The app was primarily devised with the intention of being seamlessly integrated into preexisting or new health promotion and cancer education programs and interventions carried out by cancer-focused civil society organizations (hereafter “cancer leagues”) across Europe. Indeed, despite being publicly available for download in the Google Play and Apple App stores, the ECL did not intend solely to develop a new app; rather, we wished to enhance the effectiveness and reach of cancer leagues’ initiatives and provide them with a valuable tool for assessing knowledge acquisition regarding the ECAC at no cost.

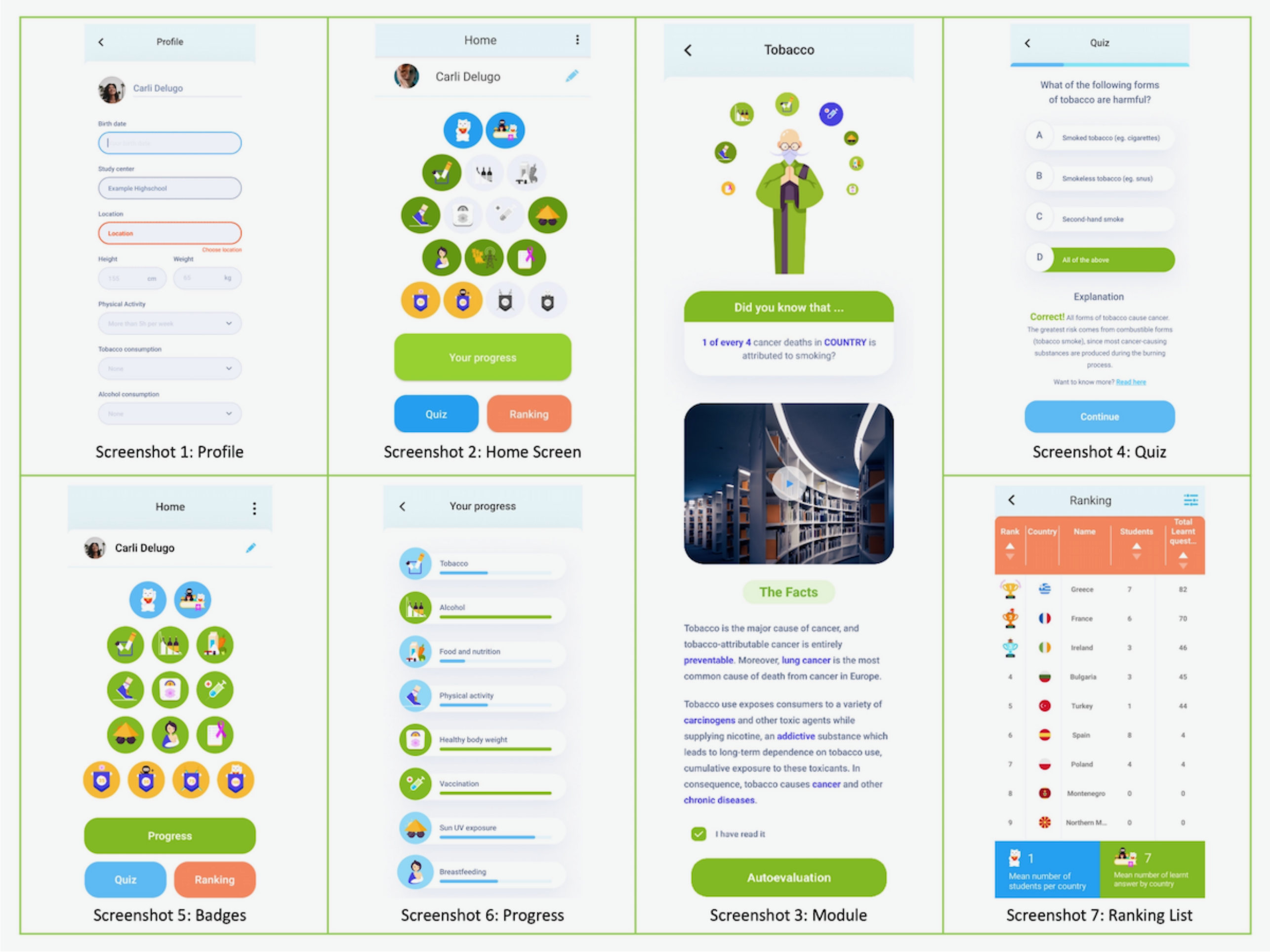
In a subsequent phase, the ultimate goal would be to determine whether the integration of the WASABY app into cancer leagues’ multidimensional interventions can effectively foster the adoption of evidence-based cancer prevention recommendations among the adolescent demographic.

App Description

Within the WASABY app, users are guided through the completion of 10 interactive modules designed to dispel common cancer prevention myths. Each module is structured around one of the prevention recommendations from the ECAC and features a combination of videos, practical tips, and interactive quizzes.

In compliance with EU privacy regulations, users are required to create a personal account and insert their personal details and lifestyle factors in order to access the app (Figure 1, screenshot 1). Once logged in, users can navigate the app from the home screen, as shown in screenshot 2 in Figure 1. From the home screen, users can access any of the 10 interactive modules, where they can read practical recommendations, view engaging videos, and participate in interactive quizzes (Figure 1, screenshot 3). Each module consists of 4 sections: a teaser question, a short introductory video, easily digestible facts, and a self-assessment quiz. The self-assessment quizzes are made up of 3 questions (Figure 1, screenshot 4). Users receive detailed explanations upon selecting their responses.

Figure 1. Structure overview of the WASABY app.



Screenshot 1: Profile

Screenshot 2: Home Screen

Did you know that ...

1 of every 4 cancer deaths in COUNTRY is attributed to smoking?

The Facts

Tobacco is the major cause of cancer, and tobacco-attributable cancer is entirely preventable. Moreover, lung cancer is the most common cause of death from cancer in Europe.

Tobacco use exposes consumers to a variety of carcinogens and other toxic agents while supplying nicotine, an addictive substance which leads to long-term dependence on tobacco use, cumulative exposure to these toxicants. In consequence, tobacco causes cancer and other chronic diseases.

☑ I have read it

Screenshot 3: Module

What of the following forms of tobacco are harmful?

A Smoked tobacco (eg. cigarettes)
B Smokeless tobacco (eg. snus)
C Second-hand smoke
D All of the above

Explanation

Correct! All forms of tobacco cause cancer. The greatest risk comes from combustible forms (tobacco smoke), since most cancer-causing substances are produced during the burning process.

Want to know more? Read here

Screenshot 4: Quiz

Screenshot 5: Badges

Screenshot 6: Progress

Rank	Country	Name	Students	Total Learnt quest...
		Greece	7	82
		France	6	70
		Ireland	3	46
4		Bulgaria	3	45
5		Turkey	1	44
6		Spain	8	4
7		Poland	4	4
8		Montenegro	0	0
9		Northern M...	0	0

1 Mean number of students per country

7 Mean number of learnt answer by country

Screenshot 7: Ranking List

Returning to the home screen, users can review their profiles, earn reward badges, and track their progress. Additionally, they can access the final quiz and the ranking of the top learners. Regarding the badges, the app uses an incentive-based mechanism wherein achievement badges are unlocked upon completing each module, with icons becoming colorful as users advance in their learning (Figure 1, screenshot 5). By clicking on the progress button, users can monitor which modules they have completed, have not started, or are currently ongoing (Figure 1, screenshot 6). Upon the completion of all modules, users have the opportunity to take a final quiz to test their knowledge.

Importantly, real-time progress data are recorded, enabling users to share their progress and quiz results with friends and other players. This contributes to the creation of an international ranking list of "top learners" across Europe (Figure 1, screenshot 7). These features foster a competitive spirit, instill a sense of accomplishment, and encourage the repeated use of the app.

Aim of the Study

In this paper, we present the preliminary findings of the design, iterative development, and promotion of the WASABY app, made available to European adolescents in real-life settings. The objectives of this study were threefold: (1) to analyze data pertaining to the app's promotion on social media, (2) to assess the traffic generated on Google Play and Apple App stores, and (3) to evaluate the level of user participation and engagement with the app.

Methods

WASABY App Development

The WASABY app's content was developed by drawing upon the ECAC's scientific evidence [5]. Specifically, a total of 6 cancer leagues located in Spain (Asociación Española Contra el Cáncer), the United Kingdom (Cancer Focus Northern Ireland), Slovenia (Zveza slovenskih društev za boj proti raku; Association of Slovenian Cancer Societies), France (La Ligue contre le Cancer), Switzerland (Krebsliga), and Romania (Societatea Română de Cancer) were engaged in this process. Additionally, a total of 111 adolescents aged between 14 and 19 years from 25 EU Member States actively participated in 2 testing rounds.

First, a selection of relevant ECAC messages (specifically, ECAC messages 1-7 and 10-11) was made, taking into consideration the age group of the target audience. Second, materials sourced from the ECAC's scientific website [35], which served as the foundation for the content of the app, were operationalized by applying the health belief model (HBM) [36]. The operationalization of the HBM within the WASABY app involved the strategic design and presentation of content that aligned with the core constructs of the model. The process involved integrating educational modules and interactive elements to raise awareness of the risks of unhealthy behaviors, emphasizing the benefits of adopting healthy habits, providing practical strategies to overcome barriers, and incorporating cues to action to boost users' confidence in making positive lifestyle changes. Thus, the app's content was crafted to influence users' perceptions, attitudes, and intentions related to health behaviors. Consistent with similar apps assessed in the existing literature and using a methodology evocative of the well-known Duolingo Language app [37], the app was also grounded in a conceptual framework of gamification, characterized by spaced repetition learning techniques aimed at promoting efficient and effective learning, especially in achieving long-term information retention compared to concentrated massed practice [38].

Third, the 10 content modules and associated quizzes that resulted from the selection of specific ECAC messages and their operationalization through the HBM underwent a series of revisions, which were conducted by cancer leagues to assess their adequacy, comprehensibility, and accuracy. We used a structured approach to ensure the adequacy and accuracy of the content. Initially, we used the nominal group technique to collaboratively define the scope of each module. Subsequently, an iterative expert review process engaged specialists from both medical and educational domains within the ECL's network of cancer leagues. These experts critically assessed and refined the content to enhance its clarity and alignment with user needs. Subsequent refinements were made to ensure that the messaging would be suitable for a reading level appropriate for 12-year-old children. This was achieved following beta and alpha tests with the app's target population.

WASABY App Testing

The beta version of the app was developed for Android devices and made available in the 27 EU member states (plus the United Kingdom). It underwent a first round of testing through a web-supported 19-item questionnaire to assess comprehension and suitability of the app's content. From May 27 to June 10, 2020, a social media campaign was used to recruit 83 testers within the app's target group (ie, healthy 14- to 19-year-olds residing in Europe) from 25 EU countries to participate in the beta test (Multimedia Appendix 1).

Originally developed in English, the app was later translated into 6 additional languages (French, German, Italian, Romanian, Slovenian, and Spanish) and adapted to be used on iOS devices. It underwent a second round of testing (alpha test) to check for functionality and technical aspects through a dedicated 18-item questionnaire, enrolling a total of 28 testers: 4 individuals per language and 2 per platform (Android and iOS). The final version of the app included feedback implemented from the 2 subsequent rounds of testing and was made available in all countries of the WHO Europe region in both the Google Play and Apple App stores.

Study Design and Population

We conducted a retrospective cohort study using data from the app's database of registered users, covering the period from February 4 to June 30, 2021. The sample size was determined based on the available retrospective cohort of 976 registered users. Exclusion criteria were applied to users outside of the age target group (14- to 19-year-olds) and those with invalid or partially missing registration data. Anonymized data were used for all analyses. This study adhered to the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) reporting guideline [39].

WASABY App Evaluation Framework

A 3-pronged evaluation framework was developed with indicators reflecting the promotion of the app on social media, the traffic generated on Google Play and Apple App stores, and the level of engagement exhibited by app users. Instagram-powered analytics were monitored and analyzed monthly during the study period. Variables collected included: accounts reached, content interactions, profile visits, website taps, top posts, and follower-specific analysis. The app's traffic in app stores was analyzed through Google- and Apple-powered key performance indicators (KPIs), including product page views, product installations, conversion rate, deletions, crashes, and average rating [40,41]. Such KPIs were stratified by country, date, and download source.

Variables from the user registry database were collected, including anonymized user identification, demographics (birth date, sex, country, region, and language), anthropometrics (height and weight, through which BMI was calculated), and self-reported cancer risk factors (physical activity, tobacco use, and alcohol consumption). The database also contained information on the completion of the app's modules according to 3 variables (visits, readings, and completed auto-evaluation). Variables were operationalized to serve as proxies for the following constructs: content interest, content completion, and quiz completion (Table 1 presents details on variable definition and assessment). Overall, the app as a tool was considered completed upon 100% module reading registry.

Table 1. Variables capturing WASABY mobile app individual user performance. Each variable was assessed separately for each of the app's 10 content modules.

Variable	Construct	Definition and interpretation
Module visits	Content interest	Variable registering the amount of page visits into a specific module. Interest was operationalized as a continuous variable, by which greater values capture greater interest.
Module readings	Content completion	Variable registering the click on "I have read it" button present at the end of each module. Content completion was operationalized as a dichotomous variable, considered complete if 1 or more readings were recorded.
Completed autoevaluations	Quiz completion	Variable registering the number of completed quiz questions per module (7 available per module, with unlimited response opportunities). Quiz completion was operationalized as a dichotomous variable, by which a given module's autoevaluation was considered complete if 3 or more questions were registered.

Statistical Analysis

We performed descriptive statistics based on frequencies (for categorical variables) and mean and median values (including SD for continuous ones). Statistical differences among users' app completion (outcome variables) according to demographic (age and sex) and self-reported risk factors (tobacco, alcohol, and physical activity; independent variables) characteristics were tested using the Mann-Whitney Wilcoxon test at .05 significance level. Outcome variables were treated as continuous (details on their operationalization are in Table 1). Odds ratio (OR) and 95% CI were used to assess the interrelation of the independent variables mentioned above with a proxy for the app's completion. The WASABY app was considered completed upon 100% of the module reading, and thus the outcome variable was dichotomized. All statistical analyses were performed using the R software (version 4.2.1; R Foundation for Statistical Computing).

Ethical Considerations

This project received ethical approval through the WASABY project consortium (EC PP-2-5-2016). Data collection and storage were managed by Adhere Health Inc (formerly Salumedia Tecnologías S.L.U). The storage of the database adhered to the General Data Protection Regulation (GDPR) and the corresponding Spanish regulation. Correspondingly, a privacy policy, legal notice, and terms of use were formulated (Multimedia Appendix 2). All participants agreed to the terms of use upon app registration independently, that is, without parental approval being required. All data from the WASABY app registration database were obtained in anonymized form for the purposes of the analysis hereby presented.

Results

The results we present below have been organized according to the 3 components of the app's evaluation framework.

Social Media Promotion

A 10-day social media campaign, beginning on World Cancer Day (February 4, 2021), was run on Instagram to launch and promote the app. The boosted social media posts reached 851,149 people and received 2,470,418 impressions. Subsequently, the app was promoted again during European Week Against Cancer (May 25-31, 2021) through an organic social media campaign, which received 3799 impressions, as well as GDPR-compliant targeted emails sent to over 100 contacts within the ECL's network of cancer leagues and youths. As of June 30, 2021, the app's dedicated web page on the ECL's website [42] had been visited 10,315 times.

WASABY App Store Traffic

Between January and June 2021, the app received a total of 3426 impressions on both the iOS and Android stores, resulting in 1109 downloads. This translates to a 32.37% (1109/3426) conversion rate, which was largely influenced by the World

Cancer Day and European Week Against Cancer promotional web-based campaigns. Over the same period, 645 app deletions were reported, which are to be contextualized given the 2-week completion time frame under which the app was designed. Additionally, on the iOS platform, an average of 3.32 sessions per active user were recorded. A summary of the app stores' KPIs is found in Multimedia Appendix 3.

WASABY App User Engagement

During the study period, a total of 976 users were fully registered in the app's database. After applying all inclusion and exclusion criteria, 748 users aged between 14 and 19 years were included in the study cohort. Table 2 includes a summary of the sample demographics. As more than half (n=392, 52.4%) of the sample was composed of users from Slovenia, this subgroup is reported separately.

Overall, the mean age was 16.08 (SD 1.28) years with a median of 16 years, similar to Slovenia's cohort (mean 16.31, SD 3.83; median 16 years). Female users were overrepresented, accounting for 66.7% (499/748) of all users (Slovenia: 281/392, 71.7%). The app's interface was predominantly accessed in English (351/748, 46.9%) or Slovenian (350/748, 46.7%). Self-reported anthropometric data were used to estimate BMI, and the cohort had a mean of 21.86 (SD 4.18) kg/m^2. Approximately 72.1% (539/748) of users fell within the 18-25 kg/m^2 range, which is considered normal according to international standards.

Self-reported behavioral risk factors related to tobacco smoking, alcohol consumption, and physical activity were collected upon registration (Table 3). Most users identified themselves as nonsmokers (689/748, 92.1%) and reported either no or infrequent alcohol consumption (432/748, 57.8% and 250/748, 33.4%, respectively). Moreover, 67.5% (505/748) of users indicated being physically active for 1-5 hours per week.

Table 2. Demographics of users registered in the WASABY app database.

Demographics	Overall (N=748), n (%)	Slovenia (n=392), n (%)
Age (years)		
14	76 (10.2)	8 (2)
15	200 (26.7)	103 (26.3)
16	186 (24.9)	104 (26.5)
17	187 (25)	123 (31.4)
18	71 (9.5)	43 (11)
19	28 (3.7)	11 (2.8)
Sex		
Female	499 (66.7)	281 (71.7)
Male	179 (23.9)	63 (16.1)
Unreported	70 (9.4)	48 (12.2)
Country[a]		
Belgium	7 (0.9)	N/A[b]
Bulgaria	16 (2.1)	N/A
Czechia	13 (1.7)	N/A
Denmark	1 (0.1)	N/A
Germany	13 (1.7)	N/A
Estonia	12 (1.6)	N/A
Ireland	12 (1.6)	N/A
Greece	14 (1.9)	N/A
Spain	14 (1.9)	N/A
France	5 (0.7)	N/A
Croatia	23 (3.1)	N/A
Italy	25 (3.3)	N/A
Latvia	21 (2.8)	N/A
Lithuania	17 (2.3)	N/A
Luxembourg	3 (0.4)	N/A
Hungary	12 (1.6)	N/A
Malta	5 (0.7)	N/A
The Netherlands	9 (1.2)	N/A
Austria	2 (0.3)	N/A
Poland	34 (4.6)	N/A
Portugal	13 (1.7)	N/A
Romania	49 (6.6)	N/A
Slovenia	392 (52.4)	N/A
Slovakia	13 (1.7)	N/A
Finland	5 (0.7)	N/A
Sweden	6 (0.8)	N/A
United Kingdom	10 (1.3)	N/A
Switzerland	1 (0.1)	N/A
Northern Macedonia	1 (0.1)	N/A

Demographics	Overall (N=748), n (%)	Slovenia (n=392), n (%)
Language interface		
English	351 (46.9)	46 (11.7)
Spanish	11 (1.5)	0 (0)
Italian	18 (2.4)	0 (0)
German	16 (2.1)	0 (0)
Slovenian	350 (46.8)	346 (88.3)
Romanian	2 (0.3)	0 (0)
French	6 (0.8)	0 (0)
Height (cm)		
130-140	1 (0.1)	1 (0.3)
140-150	2 (0.3)	1 (0.3)
150-160	61 (8.2)	28 (7.1)
160-170	330 (44.1)	182 (46.4)
170-180	257 (34.4)	134 (34.2)
180-190	82 (11)	40 (10.2)
190-200	11 (1.5)	5 (1.3)
Unreported	4 (0.5)	1 (0.3)
Weight (kg)		
30-40	2 (0.3)	0 (0)
40-50	65 (8.7)	30 (7.7)
50-60	266 (35.6)	148 (37.8)
60-70	231 (30.9)	115 (29.3)
70-80	102 (13.6)	56 (14.3)
80-90	48 (6.4)	26 (6.6)
90-100	18 (2.4)	9 (2.3)
100-110	8 (1.1)	4 (1)
110-120	2 (0.3)	2 (0.5)
120-130	6 (0.8)	2 (0.5)
BMI (kg/m^2)		
10-18	89 (11.9)	35 (8.9)
18-20	180 (24.1)	94 (24)
20-25	359 (48)	203 (51.8)
25-30	84 (11.2)	43 (11)
30-35	18 (2.4)	9 (2.3)
35-40	7 (0.9)	4 (1)
>40	7 (0.9)	3 (0.8)
Unknown	4 (0.5)	1 (0.3)

[a] 8 countries within the World Health Organization Europe region were excluded, given there were no registered users in the WASABY app database (Cyprus, Iceland, Liechtenstein, Norway, Montenegro, Albania, Serbia, and Turkey).

[b] N/A: not applicable.

Table 3. Self-reported risk factors upon use registration in the WASABY app.

Self-reported risk factors	Overall (N=748), n (%)	Slovenia (n=392), n (%)
Tobacco use (cigarettes per day)		
None	689 (92.1)	361 (92.1)
1-5	38 (5.1)	22 (5.6)
5-10	14 (1.9)	8 (2)
10-20	4 (0.5)	0 (0)
≥20	3 (0.4)	1 (0.3)
Alcohol consumption (frequency)		
None	432 (57.8)	221 (56.4)
Rarely	250 (33.4)	131 (33.4)
Only on weekends	50 (6.7)	27 (6.9)
Often	12 (1.6)	10 (2.6)
Everyday	4 (0.5)	3 (0.8)
Physical activity (approximate hours per week)		
Sedentary	70 (9.4)	28 (7.1)
1	125 (16.7)	61 (15.6)
3	238 (31.8)	121 (30.9)
5	142 (19)	84 (21.4)
>5	173 (23.1)	98 (25)

The individual and overall app's performance was investigated through 3 variables (defined in Table 1 and results presented in Table 4). In aggregate, the app's content garnered substantial interest, as evidenced by 40.8% (305/748) of users accessing each of the 10 individual modules. Similarly, a comparable proportion of users completed the modules, with 36.9% (276/748) reading all of them and 34.5% (258/748) finishing all self-assessment quizzes. Notably, Slovenian users demonstrated the highest level of engagement: they were most likely to access all modules (190/392, 48.5%), read the modules' contents (167/392, 42.6%), and complete the quizzes (145/392, 37%).

Table 4. WASABY app performance metrics in terms of app interest, content completion, and quiz completion (operationalized variable description available in Table 1).

App use constructs	Overall (N=748), n (%)	Slovenia (n=392), n (%)
App interest (number of modules visited)		
0	36 (4.8)	31 (7.9)
1	101 (13.5)	43 (11)
2	75 (10)	30 (7.7)
3	72 (9.6)	22 (5.6)
4	47 (6.3)	18 (4.6)
5	48 (6.4)	23 (5.9)
6	33 (4.4)	18 (4.6)
7	14 (1.9)	6 (1.5)
8	7 (0.9)	2 (0.5)
9	10 (1.3)	9 (2.3)
10 (all)	305 (40.8)	190 (48.5)
Content completion (number of modules read)		
0	139 (18.6)	75 (19.1)
1	86 (11.5)	30 (7.7)
2	62 (8.3)	27 (6.9)
3	53 (7.1)	19 (4.9)
4	41 (5.5)	17 (4.3)
5	35 (4.7)	18 (4.6)
6	27 (3.6)	18 (4.6)
7	11 (1.5)	7 (1.8)
8	6 (0.8)	2 (0.5)
9	12 (1.6)	12 (3.1)
10 (all)	276 (36.9)	167 (42.6)
Quiz completion (number of modules with quiz completed)		
0	171 (22.9)	88 (22.5)
1	83 (11.1)	29 (7.4)
2	61 (8.2)	31 (7.9)
3	62 (8.3)	31 (7.9)
4	37 (5)	16 (4.1)
5	29 (3.9)	17 (4.3)
6	18 (2.4)	10 (2.6)
7	9 (1.2)	5 (1.3)
8	6 (0.8)	6 (1.5)
9	14 (1.9)	14 (3.6)
10 (all)	258 (34.5)	145 (37)

Significant differences were observed by sex in terms of the number of modules visited, read, and quizzes completed (*P*=.02, *P*=.047, and *P*=.03, respectively), with male users being less likely to complete the overall app (OR 0.878, 95% CI 0.809-0.954). Conversely, there were no differences found by age group (dichotomized as 14-16 years vs 17-19 years) in the abovementioned tested associations.

Additionally, significant variations were noted in the abovementioned associations concerning self-reported user risk factors based on dichotomized tobacco consumption (*P*=.04, *P*=.07, and *P*=.03). Self-reported tobacco users demonstrated a reduced likelihood of completing the app (OR 0.835, 95% CI 0.735-0.949). No notable distinctions were detected concerning alcohol consumption or physical activity. Finally, while evaluating the app's performance based on individual modules, a decreasing linear relationship was observed while progressing through module 1 (on tobacco) to module 10 (on cancer prevention; Figure 2).

Discussion

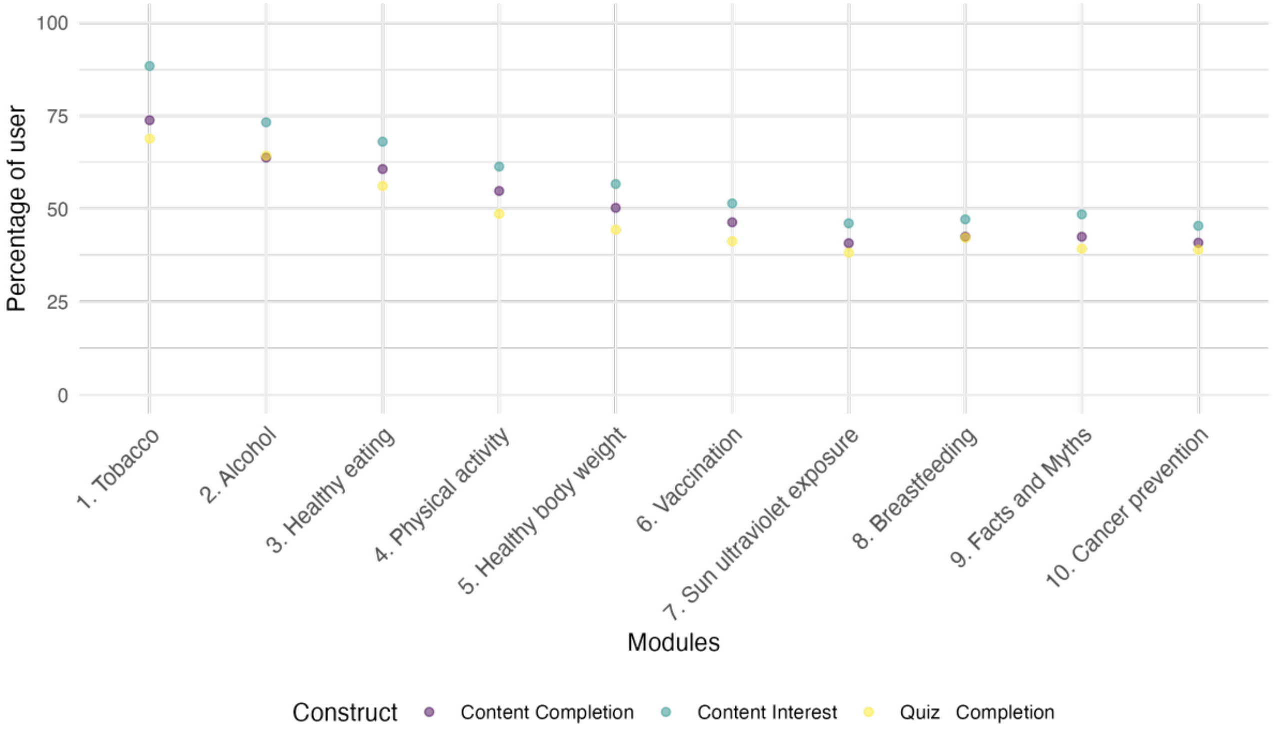
Principal Findings

The results of the WASABY app pilot study have demonstrated the potential of an mHealth app to promote evidence-based cancer prevention recommendations to European adolescents. While most mHealth apps addressing cancer prevention have focused on specific risk factors (such as body weight [43]) or specific cancer sites (such as breast cancer [44]) and a plethora of interventions targeting patients with cancer and survivors of cancer have been developed [45], there is currently no other comprehensive app based on the ECAC that specifically targets adolescents aged between 14 and 19 years, to the best of our knowledge.

The app was successful in engaging a large proportion of users across all its modules, with 40.8% (305/748) of users visiting all 10 modules. Similarly, 36.9% (276/748) of users completed each module, and 34.5% (258/748) completed the entire app autoevaluation assessment, indicating that over one-third of users in the pilot study completed the app. Given that the content of the app covers a wide range of cancer risk factors and protective measures as outlined in the ECAC, this encouraging result suggests that covering multiple domains of cancer prevention is feasible without deterring user interest and adherence.

As shown in Figure 2, a decreasing linear relationship was observed in the app's completion across the 10 individual modules, with the highest level of interest and completion reported for module 1 (focused on tobacco), which gradually decreased until module 10 (focused on the ECAC). While it is reasonable to expect a decline in user retention across the modules as users progress through the app [46], the added value of the WASABY app concept lies in addressing the multiple recommendations of the ECAC. Therefore, if users discontinue using the app after completing the initial modules that focus on lifestyle-related risk factors, they will not benefit from the crucial knowledge related to cancer prevention, particularly myths and misconceptions (addressed in module 9), thereby reducing the potential impact of the app. The data from the pilot also showed that sex was a predictor of completion of the modules. This may be explained by an overrepresentation of female users, with approximately two-thirds of users identifying as female. Conversely, nonsmoker users were more likely to adhere throughout the content until the last module, underlining the importance of understanding the sociodemographics of the target audience to best target the messaging in novel digital health interventions [47]. Additionally, such characteristics shall be considered as well in the promotion and recruitment methods for app users to achieve a more representative reach among the target population.

Figure 2. WASABY app performance metrics by module (1-10) in terms of app interest, content completion, and quiz completion.



Comparing the results of this study with the findings of previous studies in the literature becomes difficult when considering the small population sizes and heterogeneous designs of mHealth interventions. A systematic review and meta-analysis reported that eHealth school-based interventions addressing multiple lifestyle risk factors can be effective in improving physical activity and fruit and vegetable consumption, indicating the potential for multirisk factor application targeting adolescents

[48]. An earlier scoping review on apps to promote healthy lifestyle among adolescents concluded that the ability to set personal goals enhances self-monitoring and increases awareness [49]. The review also determined that most apps were implemented as part of therapy or to strengthen school programs, supporting the original conceptual design of the pilot intervention for the WASABY app [49]. Additionally, a total of 2 umbrella reviews published in 2023 on digital interventions to moderate alcohol consumption in young people and physical inactivity and nutrition in young people [50] identified the potential of digital interventions to increase physical activity and improve nutrition in school-age children and reduce alcohol consumption in certain subpopulations of younger people, especially if active feedback is provided by the mHealth intervention. The overall body of evidence is characterized by substantial heterogeneity, inconsistent population groups, and intervention definitions. This indicates that the effectiveness of mHealth tools for health promotion may suffer from the small effects of interventions, which remain detectable for a short period of time after the conclusion of the intervention.

Finally, during the pilot period, the promotion strategy of the app relied partially on the support of nongovernmental organizations (NGOs) to increase awareness and ultimately integrate the app into their existing multidimensional health education programs. Cancer leagues are key NGOs acting as primary promoters of the ECAC at the national, regional, and local levels, marking them out as ideal promoters of the app. Cancer leagues were involved in the cocreation process from the early stages of the app's development. Notably, the number of downloads was particularly influenced by the endorsement and promotion of the app through the national leagues, with users in Slovenia demonstrating the highest engagement rates across all modules. They were most likely to access all modules (190/392, 48.5%), read the modules' contents (167/392, 42.6%), and complete the quizzes (145/392, 37%). This highlights the success of the Zveza slovenskih društev za boj proti raku (Association of Slovenian Cancer Societies) in adopting the WASABY app for youth-targeted initiatives and demonstrates that with committed support from a key stakeholder for the promotion of the app, it is possible to achieve good uptake.

Limitations

There are several limitations that should be acknowledged. First, as this study was designed to evaluate the outcomes of the design, development, and dissemination of the WASABY app, the evaluation framework's scope was limited in terms of time and reach. As a result, certain dimensions, such as knowledge acquisition and user retention, could not be adequately evaluated due to the lack of monitoring of KPIs over a longer period (ie, at 6 and 12 months after completion). Additionally, the fidelity of the tool implementation was impacted by the COVID-19 pandemic. The initial plan was to pilot the tool through in-person demonstration at existing health education outreach programs organized by cancer leagues in 6 European countries. However, the app's promotion and dissemination had to be conducted entirely through social media channels. Therefore, much of the data collected for this study relied on self-reporting, and no measures were in place to validate user app registration. Additionally, due to the scope of the study analysis, which was rather exploratory, no adjustments by age or sex groups were conducted in the statistical analysis. Lastly, the data reported were insufficient to determine whether the app promotion was only reaching health-literate populations within the target group. It is, therefore, not possible to determine whether the app's pilot reached a representative cross-section of the population or if it was installed and completed by individuals who were already more likely to comply with the recommendations of the ECAC. This would be a key area of further research in future studies on mHealth tools.

Future Recommendations

The app was developed to promote and encourage adolescents to follow the ECAC recommendations. Evidence suggests that the ECAC is not well-known among the general public [51]. Therefore, the app could help to improve awareness and, subsequently, knowledge and adherence to these recommendations. With this objective in mind, the European Commission has mandated the development of the "EU Mobile App for Cancer Prevention" under Europe's Beating Cancer Plan [52]. The results and lessons learned from the WASABY app should be taken into account for this new EU endeavor. To improve adherence and retention, future iterations of the app or comparable tools should further gamify its content, providing motivation and incentives to complete each module. It is also essential to consider the sociodemographic characteristics of the target population when promoting apps to ensure they reach a more diverse and representative population. Engaging with NGOs to cocreate and promote the WASABY app was beneficial, but further research is required to assess the feasibility of embedding the app as an intervention within a broader health education program. Furthermore, it is necessary to evaluate the impact of knowledge acquisition of the ECAC recommendations on the intention to adopt the recommendations in daily life.

Conclusions

The experience gained from designing, developing, and promoting the WASABY app provides a valuable case study on the effective dissemination of evidence-based recommendations on cancer prevention within the ECAC through an innovative digital health tool aimed at European adolescents. The data obtained from this study show the potential of an mHealth app that addresses multiple risk factors, thus laying the groundwork for the creation of new tools to encourage healthy lifestyles and mitigate NCDs. The insights derived from the study also hold significance for the implementation of Europe's Beating Cancer Plan, particularly the development of the "EU Mobile App for Cancer Prevention" [52].

Acknowledgments

The authors would like to thank the following individuals within the cancer leagues who participated in the collaborative process of creating the content for the WASABY app: Sebastian del Busto (Asociación Española Contra el Cáncer); Gerry McElwee (Cancer Focus Northern Ireland); Maja Primic-Žakelj, Urška Ivanuš, and Katja Jarm (Zveza slovenskih društev za boj proti raku); Annick de Gaulle (La Ligue contre le Cancer); Florian Suter (Krebsliga); and Adriana Melnic (Societatea Română de Cancer). Additionally, the authors extend their acknowledgment to the Association of European Cancer Leagues (ECL) Youth Ambassadors for the European Code Against Cancer (ECAC), whose pivotal role in disseminating and promoting the WASABY app on social media is highly appreciated. The development of the app was overseen by the ECL secretariat team, with technical assistance provided by Adhere Health Inc (formerly Salumedia Tecnologías S.L.U.) and graphic design work executed by Outcrowd Studio as subcontractors.

The project through which the WASABY mobile app was developed and this paper was submitted for publication has received funding from the European Commission's Pilot Projects scheme under grant agreement PP-2-5-2016 (#769767). The opinions and findings presented in this publication are those of the authors and do not necessarily reflect the views of the European Commission. The European Commission and its agencies are not responsible for any use that may be made of the information it contains.

Data Availability

The WASABY app's content is available on GitHub [53]. The data that support the findings of this study are available from the corresponding author upon reasonable request.

Authors' Contributions

MML contributed to conceptualization, methodology, formal analysis, writing, and original draft preparation. GP was involved in project implementation, writing, reviewing, and editing. AT performed writing, reviewing, and editing. DR contributed to conceptualization, supervision, project administration, methodology, writing, reviewing, and editing.

Conflicts of Interest

None declared.

Multimedia Appendix 1
WASABY App testing results from a web-supported 19-item questionnaire to assess comprehension and suitability of the App's content.
[PDF File (Adobe PDF File), 10205 KB - cancer_v9i1e48040_app1.pdf]

Multimedia Appendix 2
Privacy policy, legal notice, and terms of use.
[DOCX File , 40 KB - cancer_v9i1e48040_app2.docx]

Multimedia Appendix 3
App stores' key performance indicators.
[DOCX File , 13 KB - cancer_v9i1e48040_app3.docx]

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Abbreviations

ECAC: European Code Against Cancer
ECL: Association of European Cancer Leagues
EU: European Union
GDPR: General Data Protection Regulation
HBM: health belief model
KPI: key performance indicator
mHealth: mobile health
NCD: noncommunicable disease
NGO: nongovernmental organization
OR: odds ratio
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology
WHO: World Health Organization

Edited by T de Azevedo Cardoso; submitted 09.04.23; peer-reviewed by N Ribeiro, M Brinzac; comments to author 16.06.23; revised version received 09.09.23; accepted 27.10.23; published 28.11.23.

Please cite as:
Mallafré-Larrosa M, Papi G, Trilla A, Ritchie D
Development and Promotion of an mHealth App for Adolescents Based on the European Code Against Cancer: Retrospective Cohort Study
JMIR Cancer 2023;9:e48040
URL: https://cancer.jmir.org/2023/1/e48040
doi:10.2196/48040
PMID:38015612

Original Paper

Exploring the Incorporation of a Novel Cardiotoxicity Mobile Health App Into Care of Patients With Cancer: Qualitative Study of Patient and Provider Perspectives

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Abstract

Background: Cardiotoxicity is a limitation of several cancer therapies and early recognition improves outcomes. Symptom-tracking mobile health (mHealth) apps are feasible and beneficial, but key elements for mHealth symptom-tracking to indicate early signs of cardiotoxicity are unknown.

Objective: We explored considerations for the design of, and implementation into a large academic medical center, an mHealth symptom-tracking tool for early recognition of cardiotoxicity in patients with cancer after cancer therapy initiation.

Methods: We conducted semistructured interviews of >50% of the providers (oncologists, cardio-oncologists, and radiation oncologists) who manage cancer treatment-related cardiotoxicity in the participating institution (n=11), and either interviews or co-design or both with 6 patients. Data were coded and analyzed using thematic analysis.

Results: Providers indicated that there was no existing process to enable early recognition of cardiotoxicity and felt the app could reduce delays in diagnosis and lead to better patient outcomes. Signs and symptoms providers recommended for tracking included chest pain or tightness, shortness of breath, heart racing or palpitations, syncope, lightheadedness, edema, and excessive fatigue. Implementation barriers included determining who would receive symptom reports, ensuring all members of the patient's care team (eg, oncologist, cardiologist, and primary care) were informed of the symptom reports and could collaborate on care plans, and how to best integrate the app data into the electronic health record. Patients (n=6, 100%) agreed that the app would be useful for enhanced symptom capture and education and indicated willingness to use it.

Conclusions: Providers and patients agree that a patient-facing, cancer treatment-related cardiotoxicity symptom-tracking mHealth app would be beneficial. Additional studies evaluating the role of mHealth as a potential strategy for targeted early cardioprotective therapy initiation are needed.

(JMIR Cancer 2023;9:e46481) doi:10.2196/46481

KEYWORDS

cancer, cardiology, implementation science, mobile app, oncology; mobile phone; cancer patient; patient care; mobile health application; application; implementation; design; development; symptom tracking; cardiotoxicity; cancer therapy; symptom; primary care

Introduction

Overview

There has been a rapid increase in novel anticancer therapies, with >150 new approvals since 2000 alone [1,2]. Many of these have been associated with dramatic improvements in survival [3,4]. However, concurrently, cardiotoxicity is a potentially severe adverse effect of novel cancer therapies which limits the use of several effective cancer therapies. Cardiovascular disease has become increasingly common among patients with cancer receiving novel cancer therapies, with a reported incidence of up to 38% [5,6]. Patients with cancer who develop concurrent cardiovascular disease, including cardiotoxic arrhythmias, heart failure, hypertension, and myocarditis, have worse long-term quality of life (QOL) and poorer outcomes [1,7]. Yet, most of these events are missed until severe morbidity or death occurs [6,8]. Thus, early recognition of cardiotoxic events in high-risk patients with cancer is paramount [9-16].

Mobile health (mHealth) has been investigated to screen for cancer-related symptomatology (eg, pain and chemotherapy side effects) and to improve QOL and outcomes in patients with cancer. In particular, mHealth apps and symptom-reporting systems are powerful tools to improve QOL, symptom detection, and survival [17-24]. Prior work shows that patients with cancer are willing to use mHealth apps and tend to be compliant with electronic symptom reporting [25]. Yet, to date, there have been no studies examining mHealth for symptom-tracking for cancer-related cardiotoxicity [26]. Given the severe consequences of cardiotoxicity, there may be a role for mHealth in screening for this complication and improving QOL among patients at high risk for cardiotoxicity.

Goal of the Study

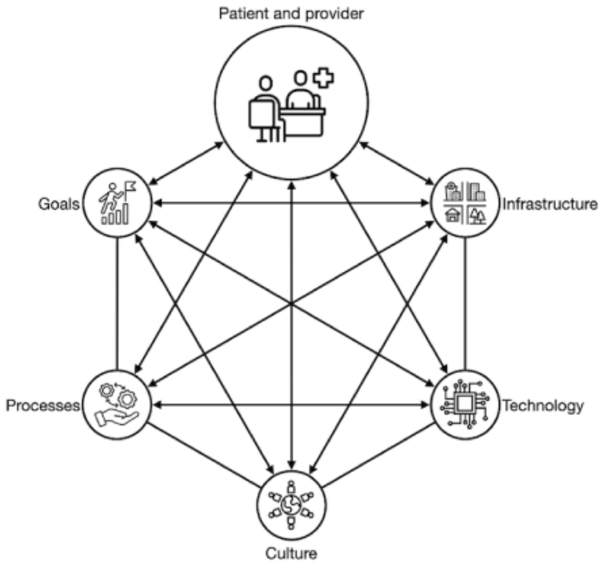
As a first step to closing this gap, we sought to determine considerations for the design and implementation of an mHealth symptom-tracking tool for early recognition of cardiotoxicity in patients with cancer. We explored this issue using the socio-technical systems (STS) framework to model complex interactions between goals, people, processes, infrastructure, culture, and technology.

STS Framework

Health care systems operate within complex adaptive environments that are constantly evolving, particularly in the high-pressure context of care delivery [27]. This dynamic setting makes the implementation of Health Information Technology interventions, such as mHealth apps, a formidable challenge. While several conceptual models exist that examine the implementation of technology innovations in health care, they are usually limited in scope [27]. Importantly, many of these models fail to address the intricate relationships that exist between different dimensions of implementing technology innovations in a health care setting such as those related to the deployment of an mHealth app.

The STS framework offers a systems-oriented perspective on organizations (Figure 1). Within this framework, readiness and implementation are considered within the context of various interconnected subsystems. Overcoming barriers to the implementation of digital tools in health care, including mHealth apps, involves addressing challenges like organizational readiness and the alignment between the tool and existing workflows [28]. Sociotechnical theory asserts that the successful implementation of mHealth interventions is contingent on both technical factors, such as ease of use, and social and organizational factors, including leadership support.

Figure 1. STS framework. STS: socio-technical systems.



Sociotechnical theory posits that the successful implementation of mHealth is a function of both technical (eg, ease of use) and social and organizational factors (eg, leadership support) [29-31]. The associated STS framework [32] is composed of six domains [33]: (1) goals: This encompasses performance metrics and objectives that guide the implementation efforts. (2) People: This refers to individuals within the system, including their attitudes, behaviors, skills, and competencies. (3) Infrastructure: Physical and financial assets necessary for the implementation, ensuring adequate resources. (4) Technology: The technological components, tools, and equipment required for the intervention. (5) Culture: Shared norms, beliefs, and values that influence the organizational environment. (6) Processes: Work practices and organizational structure that influence how the intervention is integrated.

We selected this framework to explore the design and possibility of implementation of the app into a health system. Further, our approach emphasizes a strong focus on user-centeredness. Specifically, we have applied the STS framework in relation to patients, who are the primary end users. Their perspectives offer valuable insights into critical factors such as design preferences, expected features, and the willingness to adopt the app. Additionally, we have also engaged health care providers, who play a significant role not only in receiving the app's data but also in the early identification of cardiotoxicity. By considering viewpoints from both patients and providers, our study aims to provide a deeper understanding of how mHealth implementations can be aligned with the specific needs of these essential stakeholders.

Our research addresses a significant gap in the current literature. While numerous studies have separately investigated the viewpoints of patients or providers in the context of mHealth, the synergistic interaction between these perspectives has often been overlooked [34-36].

Our study seeks to bridge this gap by acknowledging the essential interdependence between the perspectives of patients and providers within the intricate domain of mHealth. By using this approach, we intend to enhance the comprehension of effectively integrating the sociotechnical complexities of mHealth with the distinct requirements of these crucial stakeholders.

Methods

Participants

Providers

Leveraging a large, university-affiliated comprehensive cancer center, we recruited cardiotoxicity providers from our health system. In 2022, the health system managed over 58,000 patient admissions and over 2.25 million outpatient visits. Using convenience sampling, we sought clinical providers who worked with patients at risk of cancer treatment-related cardiotoxicity (ie, board-certified cardiologists, oncologists, radiation oncologists and cardio-oncologists).

Patients

We recruited patients using ResearchMatch.org and via convenience sampling. Research Match (Vanderbilt University) is a web-based service that connects researchers from over 200 US academic institutions to volunteers, living in the United States, and who are willing to participate in research studies. Volunteers sign up and create a profile by providing their demographics, contact information, and information about their health. Researchers can search the Research Match database for registered volunteers who match the study inclusion criteria. For this study, we required that patients were older than 18 years of age with the capacity to give consent, were English-speaking, owned or used a smartphone, and had a cancer diagnosis. To improve generalizability, we did not require participants to be part of our institution or reside in a specific part of the United States. Participants who fit our criteria and indicated that they were interested in participating were contacted by a study team member via telephone to confirm all inclusion criteria and eligibility, and to set up a time for a web-based meeting to conduct the study procedures.

Ethical Considerations

This study was approved by The Ohio State Cancer Institutional Review Board (#2021C0018). All participants consented verbally before any study procedures. Patients were also provided the consent document via email before beginning any study procedures. All study documents were deidentified and files were saved to a secure server behind institutional firewalls. Study documents were saved with the date and time of the interview rather than participants' names, and names were replaced with codes (eg, Participant 1 and cardiologist 1).

Procedure

Providers

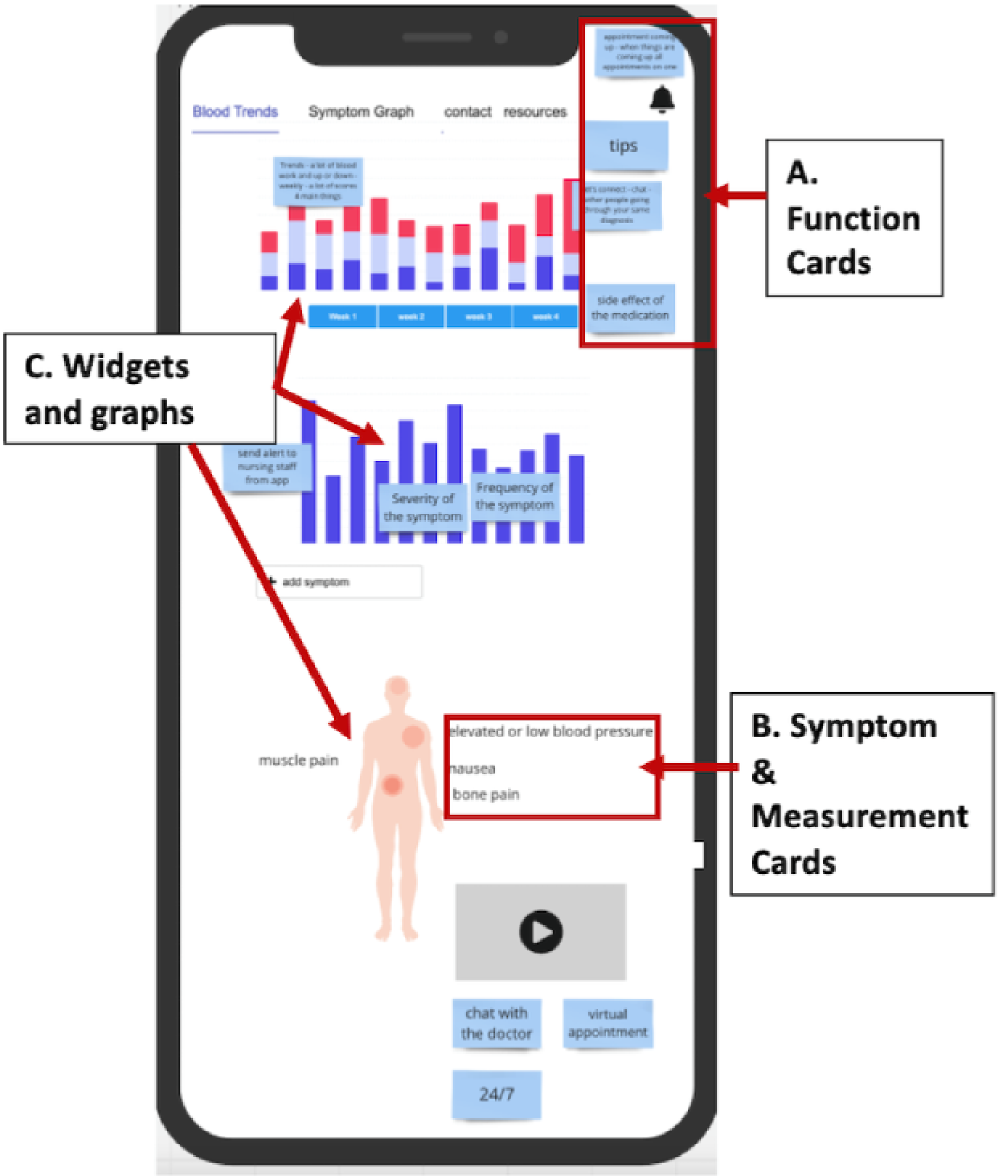
We conducted 15- to 30-minute semistructured web-based interviews with providers. Topics were related to the STS domains and included: the provider's role (eg, "What type of cancer patients do you work with?"), opinions on app design (eg, features; anticipated challenges with patient uptake; eg, "If patients were to use an app to help you understand and manage their condition, what features do you think would be most helpful?"), signs and symptoms indicating cardiotoxicities (eg, "What pieces of information (eg, symptoms) would you like to see?"), and electronic health record (EHR) integration (eg, "If the app could push data to the patients' EHR, would this be helpful to you?"). Demographic information, including role, how long participants had been in their role, and the type of cancer the participants treated, was asked during the interview. The interview guide was codeveloped by a team member experienced in qualitative methods and a cardio-oncology physician. The cardio-oncology physician team member piloted the guide before other participants were interviewed.

Patients

We conducted 30-minute semistructured web-based interviews. The interview guide was developed by the research team and focused on 3 primary topics that were related to STS domains: the patient's cancer, treatment, and symptoms (eg, "What information about your condition do you keep track of and report to your doctor?"); perspectives on the potential app (eg, "How could this app work best for you? For example, would you like to receive reminders or notifications from it?"); and positive and negative prior experiences with mobile apps (eg, "I want you to think of an app you have used or are currently using that you have particularly enjoyed. Can you describe features of the app that you particularly like [liked], that are [were] easy to use, or that help [helped] achieve what you want [wanted]?"). During the interview, the following demographic information was collected: age, gender, race, ethnicity, cancer treatment status (active treatment or survivor), cancer type, and when cancer was diagnosed. Interviews were recorded and transcribed. Patients received a digital gift card (US $25) for participation in this phase.

We also subsequently engaged patients in a 60-minute co-design process using a web-based whiteboard, wherein they interfaced with a blank mobile app screen to design their ideal app display and mock-up a prototype app. Each co-design session involved only 1 participant. These sessions were facilitated by a team member experienced in co-design. Working virtually with the facilitator, participants were provided a link to the web-based whiteboard and were asked to share their screen. There, they were given several precompleted function cards (sticky notes describing features such as "send alert to message staff from app," "tips," "chat with the doctor," etc); symptom and measurement cards (textboxes and potential icon displays of the symptoms to be tracked in the app); and widgets and graphs (allowing for choices between bar charts, line graphs, choropleth diagrams, pie charts, and several other graph types). They were informed that they could drag any of these options into the blank screen and design their ideal app for symptom tracking, including their desired graphical display of symptoms, and they were encouraged to add in any other app features that they would like to see (see Figure 2). They could also add their own blank sticky note to indicate a different feature, look, or option that was not provided. Patients received a digital gift card (US $50) for participation in this phase. The co-design sessions were recorded and transcribed.

Figure 2. Example of patient app design from co-design process.



Analysis

Provider Data

Provider data were thematically analyzed [37,38] following a combined inductive-deductive process [39]. First, we developed a codebook with code categories predefined, based on sociotechnical theory to consider both technical (eg, app features) and social and organizational factors (eg, workflow). The codebook subsequently evolved wherein new codes emerged and definitions were clarified [40,41]. The coding team was trained and led by the lead author, who is experienced in qualitative methods and analysis. Coding was done independently, with each transcript coded by 1 team member, but the principal investigator reviewed all coding.

Patient Data

Patient data were analyzed following an inductive approach using thematic analysis [37,38]. We reviewed the interview and co-design transcripts and coded comments into common themes (including app features desired, such as medication tracking, ability to contact provider, and other themes, such as the desire for the ability to customize the app). These data were supported with the patient app mock-ups and were used together to determine frequencies of desired features and options for the app, the desired look of the app, patient demographics, and patient symptoms. Noteworthy quotations that helped contextualize these findings were marked for potential inclusion in the study. Each transcript was coded by 1 team member, with the principal investigator reviewing all coding.

Results

Demographics

Providers

We interviewed 11 providers, including 3 cardio-oncology physicians, 2 oncologists, 3 oncologists or hematologists, 1 radiation oncologist, and 2 general cardiologists. Providers included cardiotoxicity fellows (n=2) and attendings (n=9).

Patients

A total of 6 patients participated, with 5 (83%) participating in a semistructured interview, and 6 (100%) in co-design; including 67% (n=4) with multiple active cardiotoxicity symptoms. Demographics are shown in Table 1.

Table 1. Patient demographics.

Variable	Values
Age (years), mean (SD; range)	55 (9.68; 46-66; 2[a])
Race or ethnicity, n (%)	
White	4 (67)
Black	1 (17)
Not reported	1 (17)
Gender, n (%)	
Male	1 (17)
Female	5 (83)
Cancer type, n (%)	
Breast	5 (83)
Prostate	1 (17)
Treatment status, n (%)	
Active treatment	1 (17)
Survivor	5 (83)
Treatment type[b], n (%)	
Chemotherapy	4 (67)
Radiation	2 (33)
Surgery	5 (83)
Other	1 (17)
Potential cardiotoxic treatment-related symptoms experienced[b], n (%)	
Chest pain or tightness	0 (0)
Shortness of breath	1 (17)
Heart palpitations	2 (33)
Abnormal heart rate	1 (17)
Abnormal blood pressure	1 (17)
Edema	2 (33)
Lightheadedness	1 (17)
Syncope	0 (0)
Excessive fatigue	2 (33)
Total number of patients reporting >1 symptom	4 (67)
Mobile health used[b], n (%)	
Patient portal	4 (67)
Health apps	3 (50)
Other	1 (17)

[a] Number of participants who did not report.

[b] May sum to >6 as some participants reported multiple.

Providers' Perspectives: Current State

Table 2 describes the current state of cardiotoxicity symptom tracking and reporting at the institution, mapped onto the STS framework. There is no systematic process for patients to report potential cardiotoxicity symptoms. Rather, it is up to patients to recognize and choose to contact their provider via phone or patient portal. Alternatively, symptoms may go unreported until a patient has a clinic visit, causing delays in cardiotoxicity recognition. Providers also reported that patients may not recall symptoms during their appointment, and thus it may go unreported entirely. There is no standardized process for incorporating symptom information into the EHR, and no process for providers or staff to regularly manage symptom reports. Cardiologist 1 expounded upon this by describing a potential barrier to such a process, wherein providers and staff would need billable time for this:

> *...nurse practitioners could [receive symptom reports]. They're fully capable of it, but it's if it's all non-billable time...I mean with the way that the health care system is designed right now...pretty much if you're not billing...*

Table 2. Current states of potential serious cardiotoxic symptom capture and treatment.

Domain	Current state: patients report symptoms at visit or call in	Representative quotations
Goals	Cardio-oncology issues reported at appointments	*If somebody comes to my clinic every three months...symptoms...might not have risen to the test threshold of them calling you...[and] that day they might not be feeling shortness of breath [and therefore it goes unreported].* [Cardio-oncologist 1]
Culture	Organization's EHR[a] largely precludes integration of app data into EHR	*...if you could get Epic to play along, sure, but...there's going to be some barriers...* [Oncologist 1]
People	Some patients are higher risk for cardiotoxicity and would benefit from providers having more timely information	*Groups of patients that have received large doses of anthracyclines, combination of cardiotoxic chemotherapy plus radiation, high dose radiation...who we know are at an increased risk and we want to kind of keep a closer eye on...having more information may be helpful to their care.* [Cardiologist 1]
Technology	Current technology is not amenable to early reporting of symptoms	*Symptoms outside of those acute encounters is going to be beneficial for patient care.* [Cardiologist 2]
Infrastructure	Current infrastructure requires patients to actively choose to contact providers about symptoms outside of appointments	*Our patients use MyChart on Epic, and if there's something serious they just put in a message and so someone from our team receives it.* [Oncologist/hematologist 3]
Processes	No current process for a provider or staff member to receive regular reports of symptom data	*From a patient perspective, it would be great to know that someone was like watching your vital signs all the time, but from a physician standpoint we just don't have the resources to do that.* [Oncologist 1]

[a] EHR: electronic health record.

Providers' Perspectives: Goal State

Table 3 describes the goal state of a more robust, timely cardiotoxicity symptom reporting and recognition process leveraging mHealth. Providers posited it would give patients an alternative method to report symptoms, and patients would be motivated to use the app if they understood that it was a faster way to communicate with their provider. Providers suggested that the app could also prompt discussion during appointments:

> *[with the app] if I would have seen their click, the shortness of breath button 200 times in between the previous visit and now and ask them...like, 'you seem to be reporting this quite a bit...Is it something which you're really feeling or you not just feeling it today?' That might be a question which I might then ask, which I would have not asked before.* [Cardio-oncologist 1]

Providers cautioned that to ensure adoption, the app should be straightforward and simple, and not ask too much of patients, for example,

> *That may be a bit discouraging, like if you had them log their blood pressure every hour or something...if there's a lot of busy work that the patients having to put into the app, that may be a barrier.* [Cardiologist 1]

Providers suggested that patients should be able to customize the app, such as whether they wanted it to send them reminders to report symptoms.

Table 3. The goal states to improve the integration and effectiveness of mobile apps into cardio-oncology care.

Domain	Goal state: addition of mobile app to facilitate earlier recognition	Representative quotations
Goals	- Earlier recognition of emergent or worsening cardio-oncology issues	- If someone's having a side effect of the treatment you want to know about it as soon as possible to help prevent further harm. [Oncologist 1] - When it would be helpful for me to get that information? I think probably realistically in real time, you know as soon as we encounter a major problem. [Oncologist/hematologist 1] - If they had some event that happened between appointments and they just were like 'oh, I wouldn't get through to somebody. So I'd rather just log in through the app,' that would be helpful. [Oncologist/hematologist 3]
Culture	- Working within cultural constraints to incorporate patient-facing technology into EHR[a] without writing to EHR	- As long as it doesn't interfere with something...algorithms can mess up with each other, so as long as it doesn't disrupt the functioning of our EHR, I think it should be helpful. [Oncologist/hematologist 2]
People	- Getting patient buy-in to use the app will be crucial for this to work	- That's going to kind of be a game changer for patients if they understand that… this is potentially a faster and more efficient way for me to communicate with my doctor or their office. It changes the calculus as far as how much effort somebody's gonna put into things. [Cardio-oncologist 2]
Technology	- Mobile app to track regularly reported symptoms - Keeping the app simple is important - Patients should have options to tailor the technology (eg, turn off reminders)	- People who aren't...technically savvy are still willing to use [technology]...Just you can't make it overly complicated because I think people get overwhelmed fairly quickly. [Radiation oncologist 1] - Maybe like tailoring...like they can toggle the reminders on or off if there were anxious person that doesn't want a reminder...turn it off. [Oncologist/hematologist 3]
Infrastructure	- Work within existing infrastructure to facilitate transfer of data from mobile app to providers or staff (eg, EHR inbox)	- ...if it could be linked to MyChart. It would beep or send an alert to the MyChart that at this time, patient had went into >30 seconds a-fib or something like that... [Oncologist/hematologist 2] - It'd be nice if it would go to my in-basket, and I would get paged at the same time. Just so someone looks at it quickly if it's a serious event. [Radiation oncologist 1]
Processes	- App facilitates more timely and efficient symptom reporting - Looping in all providers (cardiology, oncology, and primary care) is crucial	- I think eventually clinically this is going to be potentially used in the same way we use MyChart. Right now for Epic, basically patients are told at the time of their initial engagement with the office, even before they speak to the physician, that they have this electronic mode to communicate with more efficiently and they don't have to make phone calls every time they have an issue. [Cardio-oncologist 2] - ...maybe like a co-management model with oncology and cardio-oncology...Even if cardio-oncology is getting that data, I still have to decide whether to hold their treatment or not...I can't think of a situation where it would work solely with cardiology leading it. [Oncologist 2] - I think we would, between the cardiologist and the oncologist, figure out what needed to be adjusted together...can we hold this oncology medication? Is it safe to or not? So those are conversations we would have. [Oncologist/hematologist 3]

[a] EHR: electronic health record.

Providers mentioned that oncology, cardiology, and primary care should all be involved when a patient shows potential signs of cardiotoxicity, to allow them to codevelop a plan. This is explained here:

> *...it's really important that you guys think about oncology being in the mix for sure. Also, primary care...or if they have a previous relationship with the cardiologist...thinking of a team-based model rather than their results going to one person.* [Oncologist 2]

In terms of EHR integration, the institution requires that data from external apps be reviewed by a clinician before adding it to the patient record, challenging the idea of a full EHR-app integration. Providers described how a similar goal could be achieved while working within this constraint, such as having concerning patient symptom data trigger an alert in the patient portal or provider in-basket.

Providers' Perspectives: Signs and Symptoms to Report in the App

Providers indicated that signs and symptoms indicative of cardiotoxicity, that should be added to the symptom-tracking app, included: chest pain or tightness, shortness of breath, heart racing or palpitations, syncope, lightheadedness, edema, and excessive fatigue.

Patients' Perspectives: Current State

There was no current standardized process for patients to report symptoms. Most patients indicated waiting until appointments to discuss symptoms, unless they felt that it was urgent, in which case they would call or message their provider's office. For example, 1 patient stated (Table S1 in Multimedia Appendix 1):

> *I don't write [my symptoms] down. I just know, OK, it started a couple weeks ago...and I kind of just keep a mental note, and then if I feel like it's something I need to tell [the doctor], then I do*

Patients' Perspectives: Goal State

As shown in Table 4, all patients indicated an interest in tracking symptoms via a mobile app. Participants foresaw using these data in 2 ways: first, by allowing them to see trends in their symptoms and symptom severity, and second, to communicate symptoms to their provider. Toward the former, patients desired a bar chart display to see their (cardiotoxicity) symptoms over weekly, monthly, and yearly time periods. Toward the latter, participants expressed interest in sending their symptoms and related questions via the app, to get their providers' feedback and interpretations. Some also hoped that the app could alert them and their provider if a concern needed to be addressed immediately.

Table 4. Patient preferences for the features of the app.

Patient preferences	Values, n (%)
Desire to track symptoms	6 (100)
See trends in symptoms: weekly, monthly, and yearly	6 (100)
Track symptom severity	6 (100)
Use app to communicate with or contact provider	6 (100)
Additional support features: community of other patients or survivors, educational resources	6 (100)

Patients indicated that an app would need to be easy to use. For example, when asked about prior apps that were disliked, 1 patient indicated the following:

> *Usually because I felt they were too complex. It was too much work to use them. For instance, to get to a certain feature that you wanna use, maybe I need to go five steps instead of two steps. It was just too cumbersome, or it takes too much time...time is important to me, I just delete those kind of apps.*

On the flip side, patients indicated liking apps that were simple. For example, when asked about an app that the patient liked, they indicated:

> *I think because it was simple, and it just was inviting. Like the colors are inviting and also has prompts for you...it was easy.*

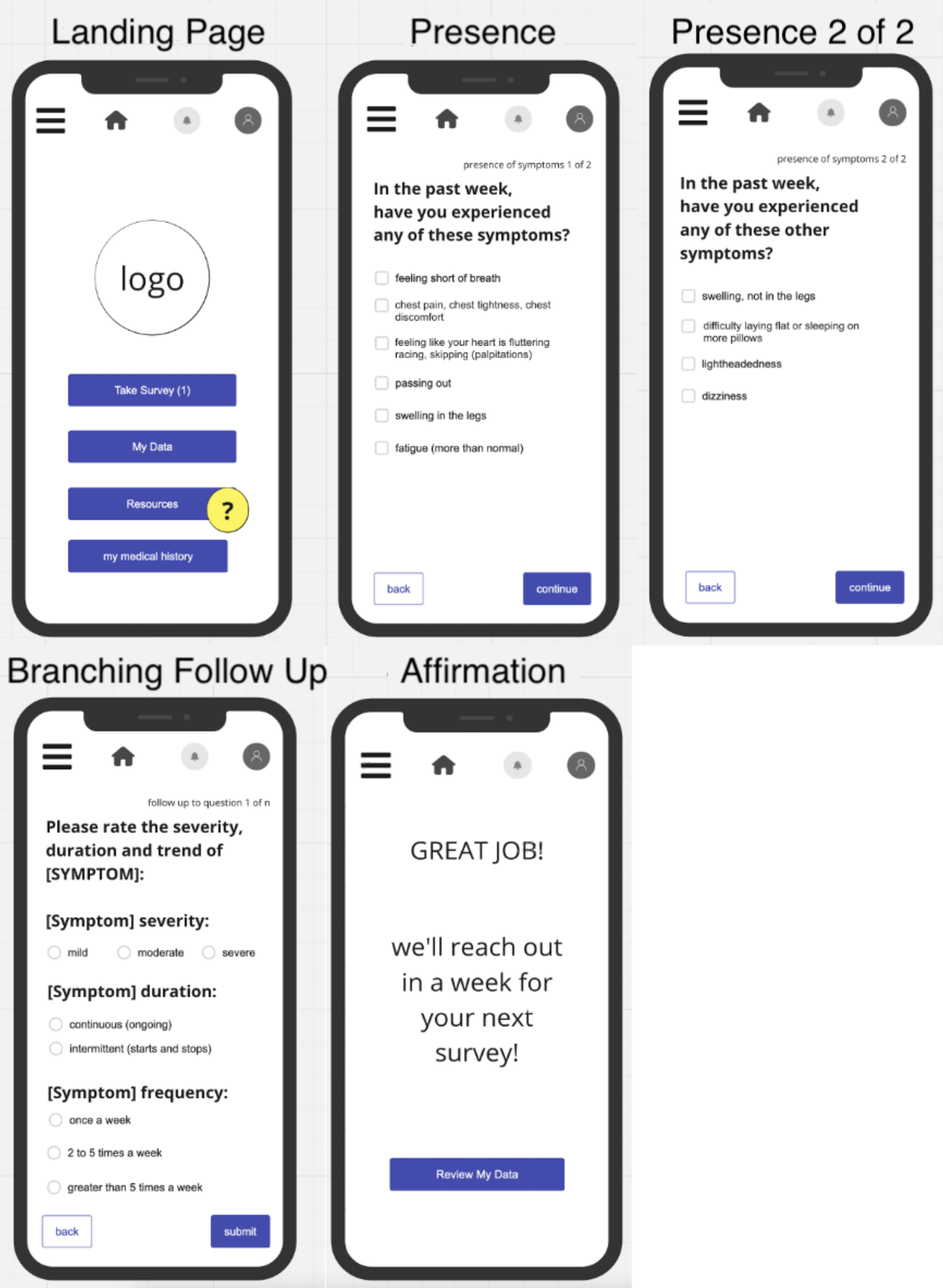
Patients' Perspectives: Additional Features Suggested in App

Participants indicated an interest in additional app features, including educational resources and the ability to build a community of other patients with cancer and survivors (eg, discussion board), as exemplified by 1 patient:

> *It would be nice if there was a good safe go-to place where you could find out more information from maybe other cancer survivors...it's nice to hear what doctors really have to say but...if there's like one other person who is experienced in that same symptom and you can have a conversation with them, that's kind of nice.*

Figures 3 and 4 show the app design resulting from the co-design process. Figure 3 displays the front page of the app, as well as the symptom tracking feature wherein participants can indicate and rate their symptoms. These ratings would ideally serve 2 purposes: first, to provide an early alert to providers of concerning symptoms indicative of potential cardiotoxicity via regular transmission of these data to clinical staff and second, to be maintained within the app to inform a chart to allow for visualizing patterns over time. Toward the latter, Figure 4 shows the graph display preferred by patients (a bar chart style) which allows patients to view their symptoms and severity of symptoms over time. Patients indicated being interested in viewing this for their own knowledge, and both patients and providers indicated interest in using these graphs during clinic visits to inform clinical care.

Figure 3. Display of front page of app and symptom logging feature based on patient input and provider symptom list.



presence of symptoms 1 of 2

In the past week, have you experienced any of these symptoms?

- ☐ feeling short of breath
- ☐ chest pain, chest tightness, chest discomfort
- ☐ feeling like your heart is fluttering racing, skipping (palpitations)
- ☐ passing out
- ☐ swelling in the legs
- ☐ fatigue (more than normal)

presence of symptoms 2 of 2

In the past week, have you experienced any of these other symptoms?

- ☐ swelling, not in the legs
- ☐ difficulty laying flat or sleeping on more pillows
- ☐ lightheadedness
- ☐ dizziness

follow up to question 1 of n

Please rate the severity, duration and trend of [SYMPTOM]:

[Symptom] severity:

○ mild ○ moderate ○ severe

[Symptom] duration:

- ○ continuous (ongoing)
- ○ intermittent (starts and stops)

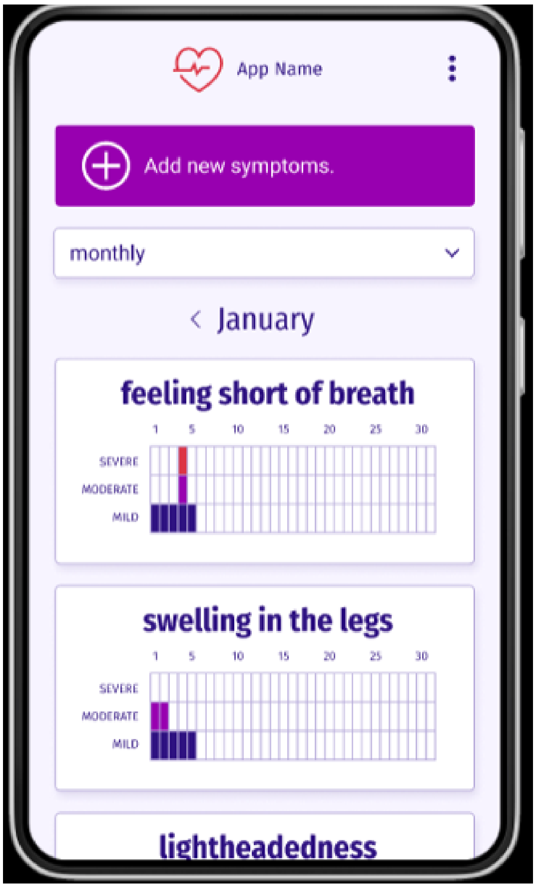
[Symptom] frequency:

- ○ once a week
- ○ 2 to 5 times a week
- ○ greater than 5 times a week

GREAT JOB!

we'll reach out in a week for your next survey!

Figure 4. Finalized display of chart feature based on patient input.



Discussion

Principal Findings

This study evaluated providers' and patients' perspectives on the design and implementation of a novel cardio-oncology mHealth app (for symptom reporting and early cardiotoxicity recognition). Providers and patients expressed positive attitudes and described barriers to early cardiotoxicity reporting. Findings suggest that the app should be designed for patients with cancer at higher risk for cardiotoxicity, should motivate patients to log symptoms, and should allow providers to collaboratively comanage symptoms efficiently.

A key factor of success identified is to motivate the users to engage in symptom-logging behaviors for an extended period [42]. Both patients and providers suggested that designing the app to be simple, and to allow patients to tailor the app to their preferences, would facilitate app engagement. Further, providers suggested that explaining the benefits of the app (eg, more efficient communication) would help motivate patients to adhere to symptom logging.

Our findings are in agreement with prior work [34,35] showing that digital solutions have the potential to address unmet needs, such as facilitating symptom monitoring, detecting adverse effects, improving cancer self-management, and empowering patients. However, similar to prior work [42], providers suggested that a lack of billable time assigned to monitoring and managing app symptom reports would be a barrier. Similar to prior work [43], providers expressed that it would be ideal to incorporate app data into the EHR to enhance patient-centered care. However, cultural and infrastructure-related barriers complicate this. Alternative modes (eg, in-basket messages and linking to the patient portal) could be considered. Providers also indicated that the app could facilitate face-to-face doctor-patient communication (eg, reviewing symptom logs during appointments). Data generated and recorded from mHealth apps may be considered billable or admissible to the patient health care record, given the potentially significant influence on patient outcomes. This would leverage the current insurance bundled health care delivery mode, with the patient's desire for quick and effective ways to communicate with providers via verifiable and self-reported information. Practically, patients may be allowed to opt-in to having their mHealth data recorded within the EHR (eg, similar to Epic's "MyChart" system).

Providers have previously expressed concerns that during critical situations, patients may report severe symptoms to an app, expecting that it is being actively monitored [35]. This concern seems well-founded based on our data. It is unlikely that this would be the case without additional personnel for this role. Thus, we suggest the app include notifications and that urgent or severe symptom should be reported another way (eg, by calling the provider's office, going to the emergency room, or calling 911).

The STS framework played a significant role in understanding the implementation of the cardio-oncology mHealth app. The six domains of the STS framework were instrumental in guiding our study: (1) goals: The study focused on understanding performance metrics and objectives, aiming to design an app that effectively addresses the needs of both providers and patients for early cardiotoxicity recognition. (2) People: Providers and patients—the pivotal end users—were the lens through which the STS framework was operationalized in this study. Their attitudes, behaviors, and competencies shaped the app's design. Providers expressed the need for patient motivation to engage in symptom-logging behavior over an extended period, emphasizing simplicity and personalization. Patient adherence was seen to be fostered by explaining the benefits of efficient communication enabled by the app. (3) Infrastructure: The study recognized the significance of sufficient physical and financial resources for implementing the app effectively. Challenges in allocating billable time for monitoring app reports were acknowledged as a potential barrier, indicating a need for resource allocation. (4) Technology: The technological components required for the mHealth app were central to the study's evaluation. It was emphasized that the app should not replace urgent traditional communication methods for severe symptoms, suggesting a need for clear technological boundaries. (5) Culture: Shared norms and values influence the organizational environment. Integrating app data into the EHR was identified as a cultural challenge at this institution. As part of a broader organizational culture around information security [44], the institution had organizational policies that disallowed external apps to write data to the EHR. Alternative methods, like in-basket messages or patient portal links, were proposed. (6) Processes: Work practices and organizational structure were taken into account. The study highlighted the potential role of the app in facilitating doctor-patient communication, allowing for symptom review during appointments and potentially integrating app-generated data into patient records.

Consistent with prior research, the study found that mHealth apps have the potential to address unmet health care needs by enhancing symptom monitoring, supporting patient self-management, and improving communication. However, the study also underscored challenges related to resource allocation and integration with existing health care practices. The findings suggest that for successful implementation, the app should be carefully tailored to address these technical, organizational, and behavioral considerations.

Concerns raised by providers about patients expecting active monitoring of severe symptoms through the app were acknowledged. To address this, we recommended incorporating notifications within the app to guide patients on reporting urgent or severe symptoms through appropriate channels, such as calling the provider's office, seeking emergency care, or dialing 911. The STS framework facilitated a comprehensive understanding of the app's potential, its challenges, and strategies to ensure successful adoption and use within the health care ecosystem.

Study Limitations

While this study leveraged a multidisciplinary group of cardio-oncology specialists, the providers were from 1 hospital, and our sample size was small. However, our small sample was largely due to a small population, which was widely represented: participants included 2 out of 3 (67%) of the institution's cardio-oncologists, and over half of the physicians affiliated with the clinical cardio-oncology program. Implementation in other types of institutions should also be explored, as sociotechnical factors likely vary in relation to organizational size and resources. This evaluation focused on cardiotoxicity given the serious consequences to patients. In addition, most transcripts were coded by only 1 individual, although all coding was reviewed by the first author. Further, patient recruitment was challenging, and thus we were limited in obtaining information from patients who have experience with more novel cancer therapies with higher rates of cardiotoxic effects. In future work, we will be better resourced to selectively recruit this specialized group. Regardless, 67% (n=4) of our patients sampled did indicate having 1 or more indicators of potential cardiotoxicity related to cancer therapy, with 1 reporting having developed a cardiac condition. We also acknowledge that the decision to recruit patients from outside the institution may have limited what we were able to learn about how to implement the app in this particular organization.

This study focused solely on symptom trackers or monitors. However, we acknowledge that some patients see cardiotoxic injury well before the onset of symptoms. We also note that emerging biomarkers, including blood or imaging-based biomarkers for example, may further advance the ability to detect and track cancer treatment-induced cardiotoxicity well before the onset of clinical symptoms and the manifestation of more advanced disease. In future work, we plan to consider the concurrent leveraging of other clinical tests with this app. With many at-home, single-lead electrocardiogram (ECG) machines and wearable smartwatches with single-lead ECG functionality, it may be possible to incorporate such data into an app. These data could be logged with other clinical data in the app alongside home blood pressure readings and heart rate monitoring data from wearable technology to facilitate rapid triage of new, potentially worrisome symptoms of cardiotoxicity. We will consider further integration with emerging smartwatch application data.

Clinical Implications

mHealth can play a role in early recognition of clinical complications of cancer treatment, such as cardiotoxicity. However, incorporation of mobile apps into clinical care requires working through persons, systems, and technology-related barriers to ensure success.

Conclusions

Providers and patients perceived that a patient-facing symptom-reporting app would be beneficial to increase early recognition of cancer treatment-related cardiotoxicity, as current processes are perceived to lead to delays in recognition and treatment. However, sociotechnical barriers include the lack of a process for multidisciplinary providers to have allocated time to review app data and collaborate on care plans, infrastructure-related challenges limiting how mHealth data can be incorporated into the EHR, and designing an app that is simple and tailored to patients to motivate use.

Acknowledgments

This work was supported in part by a pilot grant award from The Ohio State University College of Medicine, Department of Biomedical Informatics and by The Ohio State University Center for Clinical and Translational Science (CTSA grant UL1TR002733). We thank Rob Strouse and Amanda Robinson for their assistance with the co-design process. This work was also supported in part by the National Institutes of Health (P30 CA16058). DA is supported by National Institutes of Health grant (K23-HL155890 and R01HL170038), and an American Heart Association - Robert Wood Johnson Foundation grant.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Patient perceived barriers and needs for cardiotoxicity symptom capture.
[DOCX File , 13 KB - cancer_v9i1e46481_app1.docx]

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Abbreviations

ECG: electrocardiogram
EHR: electronic health record
mHealth: mobile health
QOL: quality of life
STS: socio-technical systems

Edited by J Bender; submitted 13.02.23; peer-reviewed by P Postigo-Martin, C Jacob, JH Rajendran; comments to author 28.06.23; revised version received 05.09.23; accepted 08.11.23; published 12.12.23.

Please cite as:
Gregory ME, Cao W, Rahurkar S, Jonnalagadda P, Stock JC, Ghazi SM, Reid E, Berk AL, Hebert C, Li L, Addison D
Exploring the Incorporation of a Novel Cardiotoxicity Mobile Health App Into Care of Patients With Cancer: Qualitative Study of Patient and Provider Perspectives
JMIR Cancer 2023;9:e46481
URL: https://cancer.jmir.org/2023/1/e46481
doi:10.2196/46481
PMID:38085565

Original Paper

A Web-Based Cancer Self-Management Program (I-Can Manage) Targeting Treatment Toxicities and Health Behaviors: Human-Centered Co-design Approach and Cognitive Think-Aloud Usability Testing

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Abstract

Background: Patients with cancer require adequate preparation in self-management of treatment toxicities to reduce morbidity that can be achieved through well-designed digital technologies that are developed in co-design with patients and end users.

Objective: We undertook a user-centered co-design process in partnership with patients and other knowledge end users to develop and iteratively test an evidence-based and theoretically informed web-based cancer self-management program (I-Can Manage). The specific study aims addressed in 2 phases were to (1) identify from the perspective of patients with cancer and clinicians the desired content, features, and functionalities for an online self-management education and support (SMES) program to enable patient self-management of treatment toxicities (phase 1); (2) develop the SMES prototype based on human-centered, health literate design principles and co-design processes; and (3) evaluate usability of the I-Can Manage prototype through user-centered testing (phase 2).

Methods: We developed the I-Can Manage program using multiperspective data sources and based on humanistic and co-design principles with end users engaged through 5 phases of development. We recruited adult patients with lung, colorectal, and lymphoma cancer receiving systemic treatments from ambulatory clinics in 2 regional cancer programs for the qualitative inquiry phase. The design of the program was informed by data from qualitative interviews and focus groups, persona and journey mapping, theoretical underpinnings of social cognitive learning theory, and formalized usability testing using a cognitive think-aloud process and user satisfaction survey. A co-design team comprising key stakeholders (human design experts, patients/caregiver, clinicians, knowledge end users, and e-learning and digital design experts) was involved in the developmental process. We used a cognitive think-aloud process to test usability and participants completed the Post-Study System Usability Questionnaire (PSSUQ).

Results: In the initial qualitative inquiry phase, 16 patients participated in interviews and 19 clinicians participated in interviews or focus groups and 12 key stakeholders participated in a persona journey mapping workshop to inform development of the program prototype. The I-Can Manage program integrates evidence-based information and strategies for the self-management of treatment toxicities and health-promoting behaviors in 6 e-learning modules (lay termed “chapters”), starting with an orientation to self-management. Behavioral exercises, patient written and video stories, downloadable learning resources, and online completion of goals and action plans were integrated across chapters. Patient participants (n=5) with different cancers, gender, and age worked through the program in the human factors laboratory using a cognitive think-aloud process and all key stakeholders reviewed each chapter of the program and approved revisions. Results of the PSSUQ (mean total score: 3.75) completed following the cognitive think-aloud process (n=5) suggest patient satisfaction with the usability of I-Can Manage.

Conclusions: The I-Can Manage program has the potential for activating patients in self-management of cancer and treatment toxicities but requires testing in a larger randomized controlled trial.

(JMIR Cancer 2023;9:e44914) doi:10.2196/44914

KEYWORDS

web-based program; self-management; cancer treatment; digital technology; co-design; usability

Introduction

Background

The burden of cancer and its treatment is a major cause of morbidity and growing health care costs worldwide [1,2]. Systemic therapies remain highly effective treatments for cancer [3] but are associated with a myriad of treatment-related toxicities, including fatigue, myalgia, gastrointestinal disturbances (nausea, vomiting, diarrhea), that can range from mild and temporary to severe, chronic, and debilitating [4-6]. Treatment toxicities (also called treatment side effects) are highly distressing [7], can lead to poor treatment adherence [8], and high rates of costly emergency department visits [9-11]. Ultimately, it is patients and their caregivers that shoulder responsibility for self-management (SM) of treatment toxicities and the effects of cancer at home between clinic visits with minimal support from health care providers. Access to high-quality education tools and resources that enable patients to effectively manage complex treatment-related toxicities in routine care are lacking [12,13], leaving patients vulnerable to potentially life-threatening severe adverse events, poorer functioning in daily life, long-term disability, and possibly worse survival [14,15].

Similar to the posttreatment survivorship phase [16], the acute treatment phase of cancer should be considered a “teachable moment” in which self-management education and support (SMES) are leveraged to optimize patients’ well-being and strengthen their use of core SM skills (ie, goal setting/action plans, problem solving, decision-making, communication with providers, self-monitoring) [17] and behaviors specific to treatment side effect management. SM is defined as involving the day-to-day tasks, problem-specific strategies, and behaviors individuals must undertake for self-monitoring and management of their disease and symptoms [18]. People living with cancer often feel anxious, overwhelmed, and confused by the sheer volume of information and medical jargon they must digest [19] and need educational materials, including verbal instructions augmented by written documentation, and multimedia learning tools to support their learning and retention [20,21]. In this context, SMES that enables patients to gain self-efficacy in the use of core SM skills (ie, goal setting/action plans, problem solving, decision-making, communication with providers, self-monitoring) [22,23] and behaviors specific to toxicity management and to optimize health [24] are essential early in the diagnosis and treatment phase of cancer and across the cancer trajectory.

Digital technologies are fast emerging for the delivery of SMES for chronic illness outside the walls of hospitals and clinics [25] and are a necessity in the context of constrained health care resources [26]. Digital delivery of SMES is also timely in the context of the COVID-19 pandemic, which has helped put in place the infrastructure necessary to support virtual care [27]. Systematic reviews of digital self-management interventions (DSMIs) in cancer populations show benefits for reducing symptom severity and improving quality of life [28,29]. However, heterogeneity in SMES interventions [30] and what should be translated into DSMIs support components and functionalities has led to some uncertainty about effectiveness [31]. Moreover, many DSMIs are developed without a guiding theoretical framework [32,33], focus on passive dissemination of information [34], and seldom include functionalities that promote patient activation or application of SM behaviors and uptake of health behaviors. Many have not been developed using a co-design approach or best practices in usability testing and seldom target the active treatment phase of cancer [35]. DSMIs seldom focus on active involvement of patients in the early SM of cancer and treatment toxicities [36] or develop programs that address eHealth literacy, which plays a significant role in the uptake of health interventions [37].

Objectives

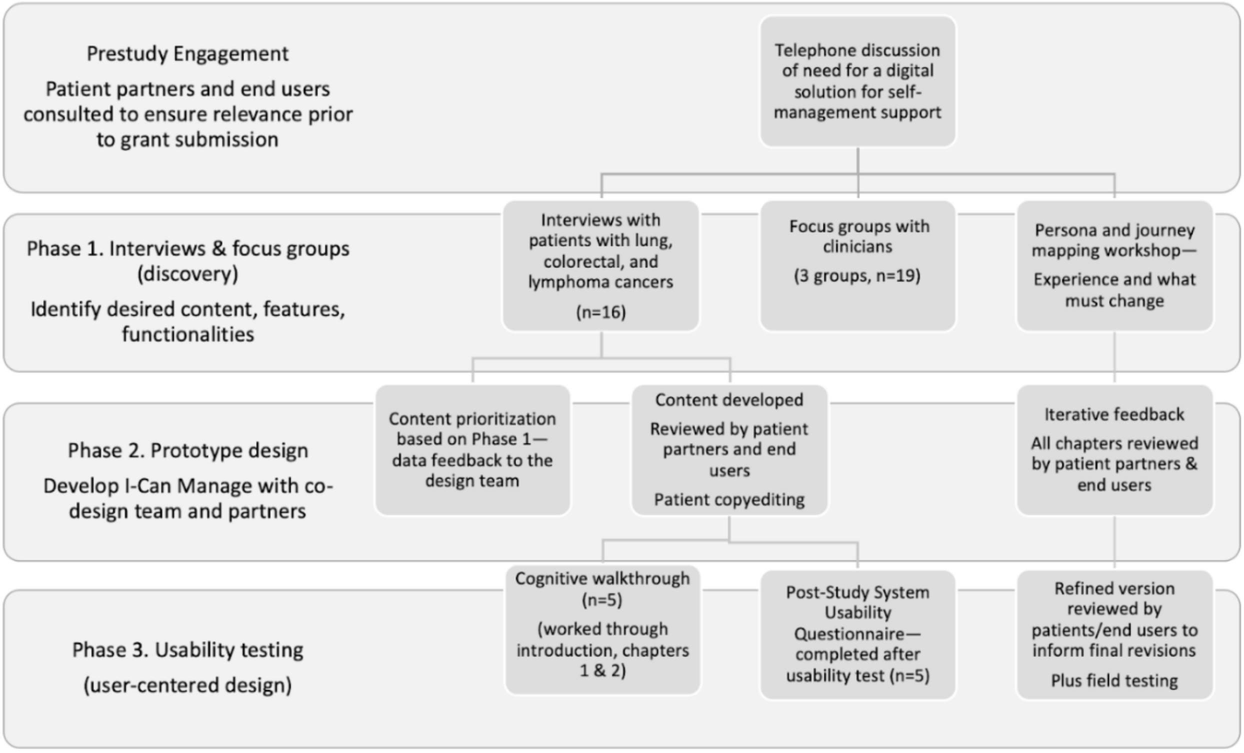
Our work addresses these gaps in digital SM programs through the development of the I-Can Manage program, an evidence-based and theoretically informed online SMES program that targets the acute diagnostic and systemic treatment phase of cancer. The overall aim of this study was to ensure usability, uptake, and potential effectiveness of the I-Can Manage program through engagement of patient partners and knowledge end users in its co-design. The specific study aims addressed in 2 phases were to (1) identify from the perspective of patients with cancer and clinicians the desired content, features, and functionalities for an online SMES program to enable patient SM of treatment toxicities (phase 1); (2) develop the SMES prototype based on human-centered [38], health literate design principles [37] and co-design processes [39]; and (3) evaluate initial usability of the I-Can Manage prototype through user-centered testing (phase 2). In this paper, we describe the development of the I-Can Manage prototype, co-design approach, and results of usability testing.

Methods

Study Design

The overall study design was descriptive, sequential mixed methods (qualitative interviews and usability survey) [40]. Study participants (patients and clinicians) were recruited from ambulatory cancer clinics at a large comprehensive cancer, Princess Margaret Cancer Centre (Toronto, ON), and a regional cancer program (Juravinski Cancer Centre, Hamilton, ON). The methods and qualitative data insights (results) are presented together reflecting the iterative nature of the co-design process and the multiple perspectives that informed development of the I-Can Manage program. The overall co-design approach and the multisources of data that informed the prototype development are shown in Figure 1. The specific methods and results are further elaborated for each phase of the development and design below.

Figure 1. Multiperspective data sources.



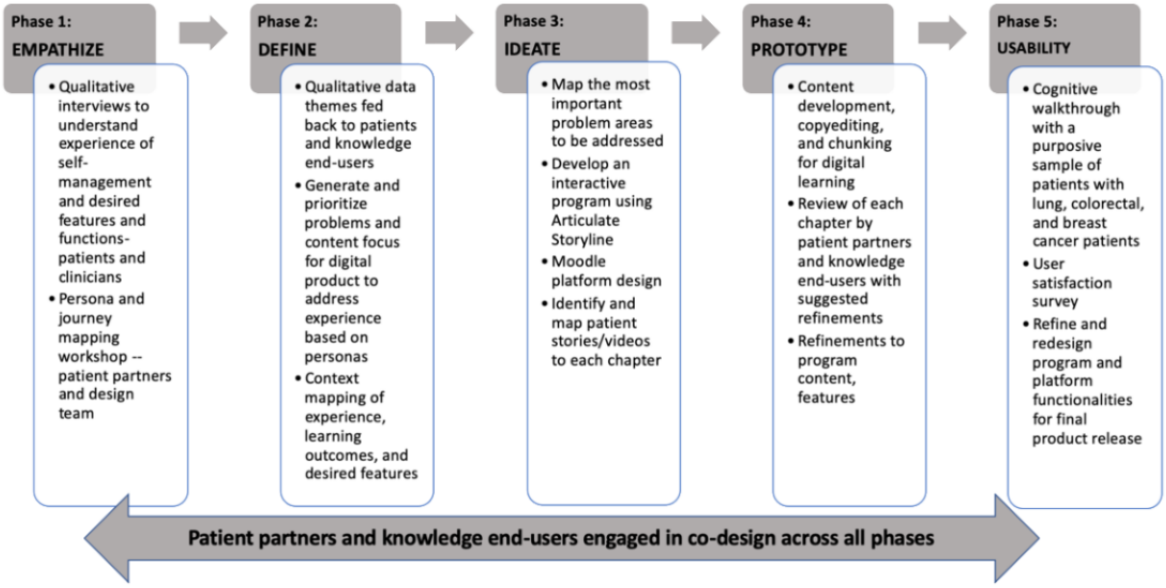
Ethical Considerations

The study was approved by the Research Ethics Board of the University Health Network (Toronto, ON; 17-5533.7) and the Juravinski Cancer Center (Hamilton, ON; 3624). Written informed consent was provided by all participants (patients, clinicians) recruited for the qualitative interviews, focus groups, and usability testing phase of the prototype development. Demographic information was collected from participants including age, type of cancer, gender, date since last treatment, type of treatment received, and comfort with use of digital technology. All data were deidentified including the data obtained in a persona mapping workshop that included members of the design team. Patient participants in the design team meetings and usability testing phase of the study received reimbursement for travel expenses and parking costs. We adhered to local, national, regional, and international law and regulations regarding protection of personal information, privacy, and human rights as required for digital technology. Ethics approval number for this study is 17-5533.7.

Overview of the Development Process

As shown in Figure 2, we followed a 5-phase human-centered and co-design thinking process [41,42] to develop the I-Can Manage program with engagement of patients as end user partners and other knowledge end users (eg, clinicians, administrators, cancer support service leaders) throughout all stages of the research process from inception of the research question to prototype completion. Persons with lived experience of cancer or their caregivers interested in participating in the research were recruited from a provincial cancer agency through an email blast sent from the program administrator to their list of volunteers as patient partners. The email blast described the proposed research and invited them to engage as partners in the co-design of the digital SM learning platform, I-Can Manage. Interested patients or caregivers were then contacted by telephone to further discuss the proposed research and confirm their interest in participating and the need for the proposed program.

Figure 2. Phases of human centred and co-design approach.



Our design team comprised 6 patients (3 females with breast cancer [1 Aboriginal], 2 males with lymphoma, and 1 male with lung cancer), 1 caregiver, 3 digital designers, 2 clinicians (nurses), 1 PhD student experienced in adolescents and young adults populations, and knowledge end users (medical oncologist, national cancer services director, cancer information specialist, eHealth literacy expert, and experts in patient education) with diverse cancer experiences who were engaged to provide input throughout the program development and design phases.

Phases of Development and Design

Phase 1: Empathize

To understand user needs in the empathize phase, a qualitative inquiry was conducted based on a qualitative descriptive methodology [43]. The goal of qualitative description is to provide a rich description of an experience in an easily understandable language and focus on who, what, how, and where questions regarding a phenomenon of interest (ie, SM of treatment side effects). It is particularly suited for health service research [44]. The goal of the qualitative inquiry was to gain insights into the experience of patients with lymphoma, lung, and colorectal cancer (n=16) and clinicians (n=19) on SM, views of desired content, features/functionalities, and optimal timing for the SMES program during systemic treatment. The full methods and results of the qualitative inquiry were previously published [45].

Patient Recruitment

Briefly, adult patients (aged ≥18 years) with lymphoma, lung, and colorectal cancer were recruited from ambulatory cancer clinics in a comprehensive cancer center and regional cancer program if they met the study eligibility criteria (not more than 3 months from the completion of systemic cancer treatment or currently receiving systemic cancer treatment, English speaking, Eastern Cooperative Oncology Group status of 0-2 such that self-care was possible, familiar with the internet or use of a phone). Potentially eligible patients were identified by members of the circle of care. Clinicians were invited to participate using email correspondence sent from their program manager and included oncologists, nurses, social workers, allied health, and psychologists. Individual qualitative interviews were conducted with patients and focus groups were conducted with clinicians.

Qualitative Data Insights

Overview

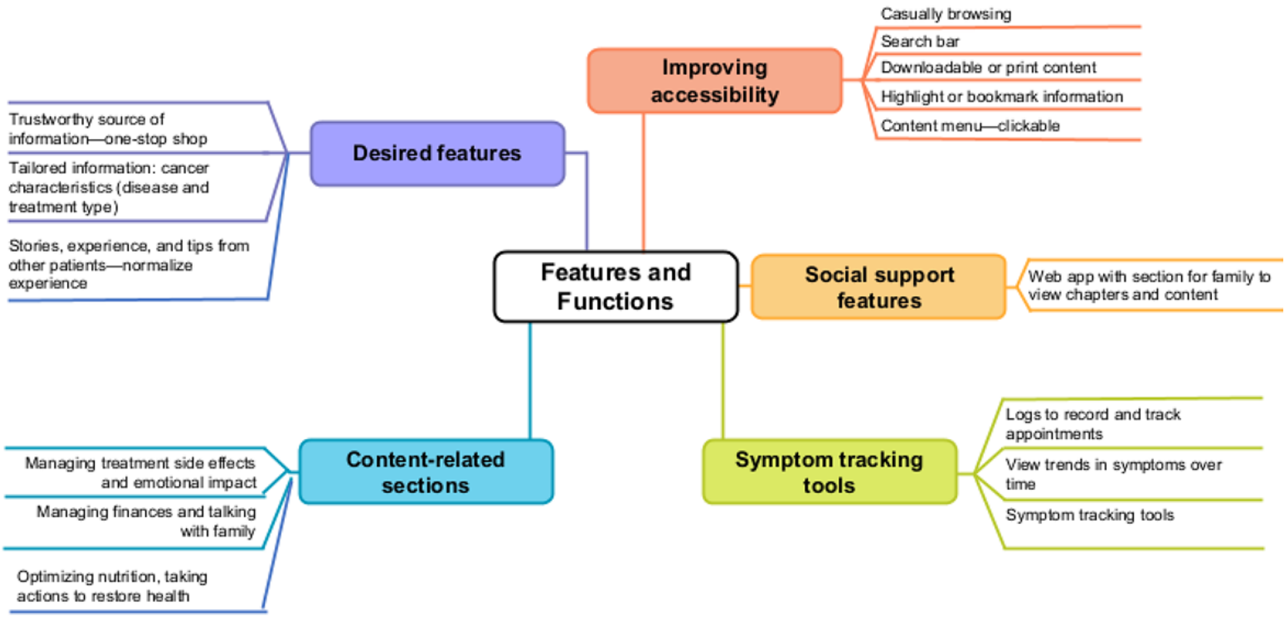
Results that are highlighted herein are to show how these data informed the design of I-Can Manage and to ensure we took into consideration the patients' experience of cancer as essential for a humanistic design approach. Briefly, analysis of the data revealed managing cancer and treatment as "hard work." Patients wanted information tailored to their personal context, to learn from other patients with cancer in the hopes of "normalizing" their experience, and support for managing emotional consequences, which they reported as "neglected" in the active treatment phase of cancer. For instance, as part of normalizing the experience, in the treatment toxicity module we described the experience of symptoms from the perspective of patients as a way to normalize the experience (ie, myalgia feels like aching in the bone and joints). The desired features and functionalities derived from qualitative interviews are shown here to establish the context for how I-Can Manage was designed (Figure 3).

Following the qualitative inquiry, patients, caregivers, clinicians, knowledge end users, and digital design experts (n=12) were invited to a persona mapping workshop. Persona mapping is the creation of fictional, but realistic profiles of the users of the program and their journey [46]. In the persona mapping workshop, participants were engaged in persona and cancer experience journey mapping to develop a deeper understanding of their real-world experience of being diagnosed with cancer, managing treatment toxicities, and participating in health recovery; their perspectives of what they needed to know and their hopes for a digital solution to improve their experience; and the challenges they experienced.

Most participants in the persona mapping workshop were patients (n=6) and caregiver (n=1), clinicians (n=2), designers (n=2), and knowledge end users (n=1) who were able to attend (reimbursed for travel) from our design group described earlier in the paper. Groups of patient partners, clinicians, end users were mixed in small working groups to ensure all perspectives were voiced and heard and a facilitator was assigned to each group. Participants described the defining moments that stood out across phases of their cancer journey and care. These defining moments included experiences of not knowing how to talk to family and friends about the diagnosis or not knowing whether their emotional reactions or treatment side effects were normal, and the devastating effects of dealing with the life-altering nature of cancer (Multimedia Appendix 1). One participant remembering the day of diagnosis stated, “today my life has changed.”

Participants were asked to describe what they needed to learn, know, and do. Participants also expressed the need for a single source of trustworthy information to manage treatment side effects, to learn from experiences of other patients, and to know what actions they could take to help themselves to persevere, endure cancer and treatment, and recover health. Persona data were then used to inform the content of the I-Can Manage program. This was operationalized as co-design by sharing key topics and desired content based on qualitative data that were provided back to participants and our design team before we further developed the program to ensure the content “held true” for their experience and to identify “SM support needs” to be met by our digital solution. For example, in this workshop, participants were asked about what they needed to know and understand about how to tell their family regarding their diagnosis as a defining moment and what they hoped could change with the online program. Thus, for example, in module (chapter) 1 we provided specific information about sharing the diagnosis and considerations for “who” and “how to tell” (eg, a work colleague vs a young child or older child) and this was linked to patient’s stories and other resources about how to talk to family members including children about a cancer diagnosis.

Figure 3. Desired features and functions.



Phase 2: Define

In addition to data from the persona and journey mapping, themes from qualitative data were reported back to the design team. Consequently, core problems in managing cancer treatment toxicities and side effects were identified and key content and features for the “I-Can Manage” program to address these problems were prioritized for inclusion by the design team. Additionally, an experienced oncology nurse (DH) developed content based on her experience and knowledge of working with cancer populations and evidence-based guidelines [47,48], including patient versions of symptom SM guidance documents [49]. A patient partner experienced in digital design was engaged to further chunk content for digital delivery and copyediting to ensure use of plain language and a coherent flow of information. The design team was involved in iterative development and design cycles that included reviewing and providing feedback for each program chapter to inform refinements and iterative development.

Phase 3: Ideate

The I-Can Manage program was specifically designed to target the active treatment phase of cancer. Using what we learned from these multiperspective data sources including the qualitative inquiry and the journey mapping workshop, we developed a context-mapping approach [41] to develop a framework that would guide development of the prototype, expected learning outcomes, features, and functions (Table 1).

Table 1. The I-Can Manage components at a glance to address patient experience from multiperspective data sources, including behavioral exercises to build self-management skills/efficacy.

Focus	Module 1: Regaining your balance	Module 2: Managing treatment side effects	Module 3: Coping with stress and emotions	Module 4: Balancing fatigue and activities	Module 5: Optimizing health and quality of life
Patient experience	• Shock and crisis • Fears of incapacitation/death/telling family • Information overload • Psychosocial impact forgotten in the acute phase	• Anxiety/fears about treatment and side effects. What do they feel like • Concerns about the effectiveness of treatment • Anticipating/managing side effects. What works for recovery	• Stress/roller coaster of emotions • Feelings of uncertainty/sense of vulnerability • Need new ways of coping • Change in roles and family/friend relationships	• Overwhelmed with fatigue • Vicious cycles of fatigue, rest, deconditioning, insomnia, PA[a] • Adjust PA to acute treatment effects	• Interrupted functioning in daily life and work • Illness intrusiveness, self-esteem, body image, sexual health, relationships • Restoring quality of life
Learning outcomes	• Knowledge of emotional reactions to diagnosis • Able to identify desired role as partner in health care and personal strengths • Able to apply mindful breathing to reduce anxiety early in diagnosis • Confident in communication with family/friends/providers	• Knowledge about what to expect regarding chemotherapy side effects/normal pattern of side effects/recovery • Able to differentiate between normal and adverse effects to report to providers (health team) • Apply symptom self-monitoring for tailoring daily behaviors • Confident in the use of self-management behaviors to prevent/reduce side effects	• Knowledge of physiological reactions to stress and mind/body connections • Able to apply positive coping skills and problem-solving to manage emotions and uncertainty • Able to differentiate between normal emotions and depression/anxiety to report to providers • Confident in the use of stress-reducing behaviors	• Knowledge of energy-bank model of fatigue and body capacity • Able to differentiate between usual and cancer fatigue • Able to apply energy conservation and adaptive pacing in daily life • Confident in the use of behaviors and PA to manage fatigue	• Knowledge of healthy lifestyle behaviors and influence on cancer recovery • Taking action on smoking cessation and health behaviors • Able to apply healthy eating to manage specific problems (eg, weight gain or loss) • Confident in the use of behaviors to optimize quality of life
Select program content	• Regaining your balance • Strategies to manage initial anxiety and fear • Desired role in and making decisions aligned with health values • Forming a partnership with health team • Being effective in self-management • Mobilizing personal strengths/support systems • Talking with others about your diagnosis	• Overview of chemotherapy and other types of cancer treatment • Chemotherapy side effects (pattern, type, normalize how they feel, self-management strategies/specific behaviors to reduce effects on daily function) • Titrating medications to optimize effectiveness • Avoiding and recognizing signs and symptoms of infection • Adjusting work and life activities • What can family and friends do to support you through treatment	• Stress and crisis reactions • Reframing of beliefs about illness • Normalize emotional turbulence and emotional reactions (emphasize positive emotions) • Practical tools for coping (ie, relaxation, mindfulness, meditation, self-talk) • Mobilizing peer support • Breaking vicious cycles of negative emotions and symptoms • Application of positive coping skills including problem-solving	• Adaptive pacing for energy conservation • Graded physical activity (avoid boom and bust) to tolerance • Developing a physical activity plan during treatment • Breaking vicious cycles of fatigue, rest, and insomnia • Scaling fatigue for self-management and behavior adjustment • Application of sleep hygiene to address insomnia	• Recognizing health values • Healthful nutrition during treatment • Taking action on healthy lifestyle behaviors • Restoring quality of life, putting wellness in the foreground • Restoring meaning and purpose in life/leisure activities • Adjusting to change in work, vocational, and other life roles • Dealing with cancer worry/fear of recurrence • Sexuality and intimacy

Focus	Module 1: Regaining your balance	Module 2: Managing treatment side effects	Module 3: Coping with stress and emotions	Module 4: Balancing fatigue and activities	Module 5: Optimizing health and quality of life
Behavioral exercises to build core self-management skills and self-efficacy	• Recognizing your personal strengths and resources • Vicarious learning (deep breathing, active relaxation, positive self-talk) • What is your decision-making style tool? How to make decisions • Partner in health scale • Decision balance tool (weighing the pros and cons of treatment options) • Goal and action plan	• Self-monitoring of symptoms and side effects; tracking severity with sliding scale and graph over time • Self-assessment of confidence in managing treatment side effects • Daily decisions (eg, adherence to medications) • Tailoring of behaviors to manage effects • Specific strategies for managing common treatment side effects • Goal and action plan	• Recognize and manage your cancer stressors worksheet • Dealing with anxiety and panic (5-4-3-2-1 exercise) • Recognizing and breaking vicious cycles between your thoughts, emotions, and behaviors • Self-assessment of coping skills and which skills to strengthen • Problem-solving practice worksheet • Building on your coping skills • Goal and action plan	• Problem-solving barriers to activity • Developing your FITT[b]-graded physical activity plan • Scaling severity of fatigue using a 0-10-word scale • Monitoring fatigue using a daily diary for adjusting physical activity • Using a Perceived Exertion Scale • Goal and action plan	• Identify your 4 quadrants of quality of life • A balanced life (the wellness wheel) • Build a healthy eating plan • Goal and action plans

[a] PA: physical activity.

[b] FITT: frequency, intensity, time, and type.

Additionally, the design of the platform adhered to eHealth literacy principles including intuitive navigation, plain language, and iterative testing with end users. The design of the I-Can Manage program was theoretically underpinned by social cognitive learning theory and the construct of self-efficacy, which relates to an individual's belief in their own capability [50]. This was achieved by incorporating action-oriented information and behavioral exercises as a core feature of the program to promote application of core SM skills (ie, problem solving, goal setting/taking action, decision-making, symptom self-monitoring using tracking and diaries, resource use, collaborative communication, and partnering with health care providers) [22], problem-specific SM strategies (ie, physical activity for fatigue), and health behaviors to optimize health and wellness (ie, eating healthy, smoking cessation).

Program features incorporated the 4 main sources of self-efficacy information [51] including (1) mastery learning (ie, symptom self-monitoring and learning how to adjust behaviors based on symptom severity, goal setting/action planning); (2) vicarious experiences through the inclusion of videos that modeled a behavior (ie, how to do mindful breathing, physical activity demonstrations, and patients talking about emotions and how they coped); (3) social persuasion through the inclusion of patient stories (video and written) and also to normalize their experience (ie, what does cancer fatigue feel like); and (4) emotional and physiological states through the inclusion of downloadable patient exercises to identify personal strengths and coping skills, reframing negative emotional states, and breaking vicious symptom cycles (ie, avoiding boom and bust in managing cancer fatigue).

Phase 4: Prototype

We used the e-learning authoring software Articulate 360 storyline [52] to produce interactive and video-based content; and the Moodle learning management system (Moodle Community) [53] as the web-based learning platform to host the content, register patients, and track usage patterns. Links to other sites were integrated for deeper learning and to facilitate tailoring of information to the needs of user and to ensure access to trustworthy information sources such as the American Society of Clinical Oncology (ASCO; clinician-approved patient fact sheets) [54]. The final prototype of the I-Can Manage web-based program comprised a welcome and introductory chapter, and 5 learning chapters with 4-5 sections per chapter (Figure 4), and core elements to support uptake of SM strategies and behavior change supported through completion of downloadable worksheets embedded in each chapter (Figure 5). Participants are given suggestions at the start of the program as to what modules they may want to complete first and the order of the modules. However, the program allowed patients to move around the modules as they desired, as we learned in usability testing that patients want to skip modules that were not relevant to them and to complete modules in a particular order relevant to their needs. Additionally, they desired modules to be open and accessible throughout their cancer treatment journey (ie, not locked so they have to complete 1 chapter to get to the next chapter). For instance, some patients described only scanning the treatment toxicities module as this was a recurrent cancer and so wanted to go directly to the chapter on coping as this was more relevant. As described earlier, each chapter was developed to incorporate core elements and functionalities that focused on building knowledge and use of behaviors to address the multifaceted medical, emotional, and lifestyle tasks of cancer SM [55]. Best practices were used for providing interactive content that would facilitate uptake of SM strategies, behaviors, and behavior change [35]. I-Can Manage emphasizes building of self-efficacy and core SM skills including completion of goal setting and action planning and activation of behaviors including symptom self-monitoring skills using symptom severity scales to inform daily tailoring and adjustment of behaviors.

Figure 4. Overview of the I-Can Manage program.

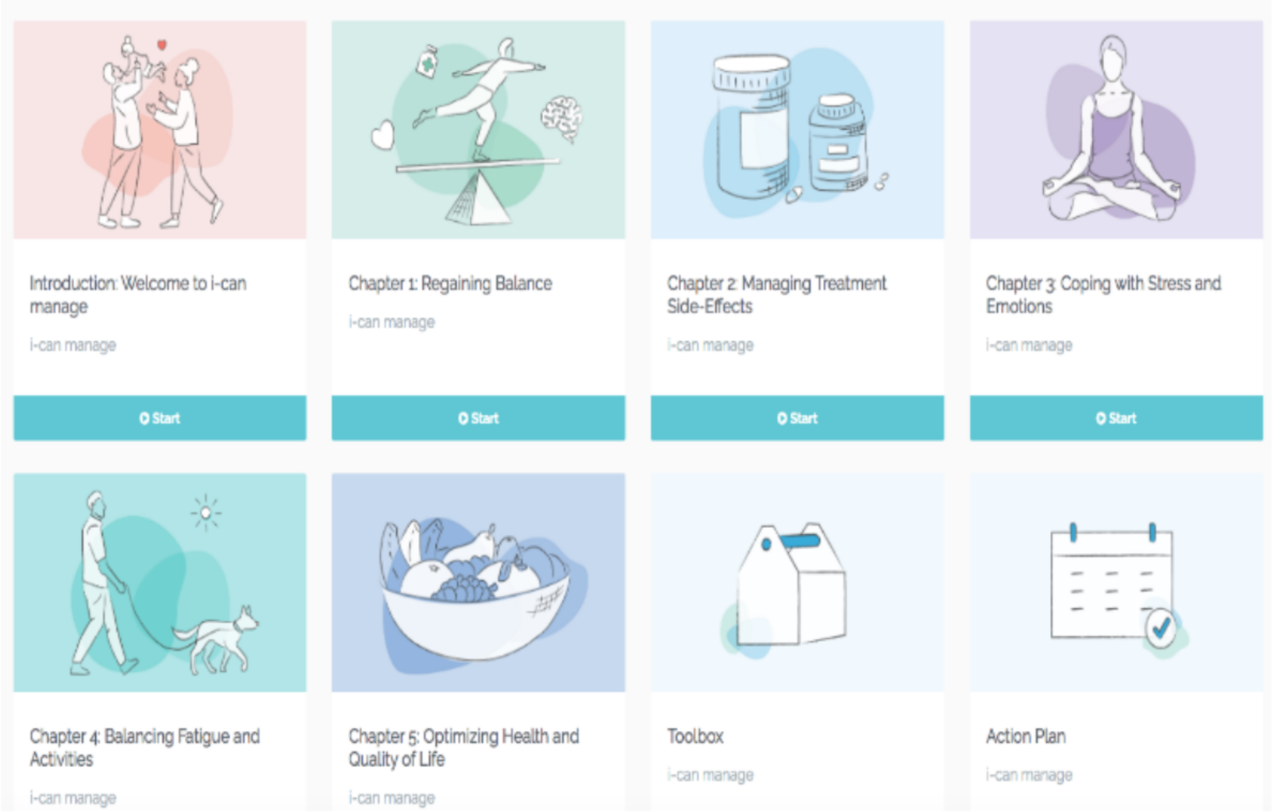
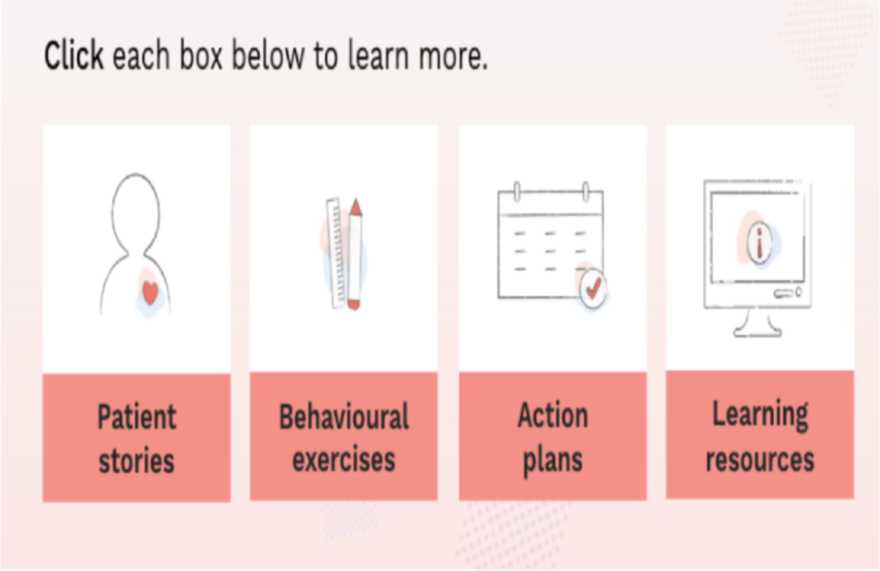


Figure 5. Cross-cutting elements for each chapter to support behavior change.


Click each box below to learn more.

Thus, we incorporated learning to support use of SM core skills and build self-efficacy including (1) evidence-based content about the best practice strategies and behaviors to manage treatment side effects; (2) patient stories in written and video formats interspersed throughout the program to humanize and normalize their experience, and to deepen their learning about how to apply SM strategies and behaviors to manage treatment toxicities and the emotional effects of cancer; (3) behavioral exercises to build core SM skills (ie, goal setting and action planning); and (4) links to other trustworthy sources such as the ASCO and the Canadian Cancer Society or peer support networks for access to additional support. In addition to evidence-based information, tips for managing treatment side effects from peers and their descriptions of how a symptom felt were used to normalize symptoms and enable patients to hear the voice of experienced others who had traveled this journey before them. Select screenshots portraying a selected sample of the components of Chapter 4 “Balancing Fatigue and Activities” are shown in Multimedia Appendices 2 and 3. Additionally, we show a sample of a downloadable work sheet for tracking cancer fatigue (Multimedia Appendix 4) and one of the number of downloadable education information sheets (Multimedia Appendix 5).

Phase 5: Usability (User Interface/User Experience Design) Testing

We used convenience sampling to recruit adult patients (aged 18 and over) diagnosed with diverse cancers (breast, lymphoma, and colorectal; n=5) at a large comprehensive cancer center for participation in usability testing in the digital design laboratory. The eligibility criteria were the same as the qualitative inquiry phase of the study and we attempted to purposively sample for maximal variation in age, type of cancer, gender, culture, and race. Nearly 80% of usability problems can be identified with 5 participants, which is considered an adequate sample for usability testing [56]. Ideally, it is recommended that maximal variation in sampling for usability testing be used in digital design to ensure the program addresses usability from the perspective of different users with different cancer diagnoses, ages (younger and older), gender, diverse cultures, and race. Prospective participants were not previously exposed to the program and agreed to take part in this formalized user interface/user experience design testing using a cognitive walkthrough of the program in the laboratory.

A cognitive walkthrough was used to identify user experiences related to how the content was presented and ease of use of functionalities [57], with user experiences and feedback manually recorded in a spreadsheet. Participants worked through the program in our human factors digital laboratory while being observed and made comments aloud as they worked through the program that was recorded verbatim by the observer. Assigned task included talking aloud to reflect the participants thoughts while working through the “Introduction: Welcome to I-Can Manage” (overview of the program and orientation to SM and their role) and the first 2 chapters (Chapter 1: “Regaining Balance” and Chapter 2: “Managing Treatment Side-Effects”). Participants were also instructed to use the Hamburger Menu and other design elements (buttons to click through the program; Moodle Platform) to navigate to other program chapters in order to determine ease of use of the program. These data were used to inform refinements to the program and finalize the prototype (Multimedia Appendix 6). The Moodle learning platform was further optimized based on usability feedback.

Results

Usability phase participants ranged in ages from 53 to 67 years; most were married, college/university educated, had diverse cancers, and all were comfortable using the internet (Table 2).

Suggestions for refinements to the program focused mainly on improving navigation through the program (eg, more visible hamburger menu), reducing the number of clicks to move forward in the program, and enabling users to go back to chapters. Additionally, suggestions were made for minor changes to the program content such as lessening the amount of content on each page. Participants described the content as relevant and engaging, but thought there was a lot of content, so we further chunked or eliminated content and placed reminders throughout the program for patients to take a break; and added information about how long it would take to complete chapters so that patients could plan accordingly (Multimedia Appendix 2). Besides, our patient partners and knowledge end users were given open access to the program and asked to provide feedback on each chapter and its content. Their feedback was also used to further refine the program prior to release of the prototype. A specific member of our team did field testing of the prototype across computers and iPads (Apple Inc.) to check links and functionality and to ensure fixes prior to final product release.

Usability patient participants (n=5) also completed the Post-Study System Usability Questionnaire (PSSUQ) [58] to assess their experience and perceived usability of the I-Can Manage program on a 7-point Likert scale of Strongly Agree to Strongly Disagree, with a lower score denoting greater performance and satisfaction with usability of the system. The global mean score for the PSSUQ was 3.75 and for system usefulness, information quality, interface quality this was 3.54, 4.1, and 3.5, respectively (Table 3).

Table 2. Participant characteristics for usability testing (N=5).

Characteristic	Frequency
Age (years), mean	50.4
Sex (female), n (%)	3 (60)
Married, n (%)	4 (80)
Cancer type, n (%)	
Breast	2 (40)
Lung	1 (20)
Colorectal	1 (20)
Hematological	1 (20)
Education, n (%)	
High school	1 (20)
College/university	4 (80)
Income (CAD[a]), n (%)	
<90,000	2 (40)
>90,001	2 (40)
Did not want to answer	1 (20)
Ethnicity, n (%)	
Canadian	3 (60)
Asian	1 (20)
Jewish	1 (20)
Very comfortable in using the internet, n (%)	5 (100)

[a] CAD $1 =US $0.75.

Table 3. Mean scores for the Post-Study System Usability Questionnaire.[a]

Item	Median score	Mean score
Overall score	3.20	3.75
System usefulness	2.83	3.54
Information quality	4.00	4.16
Interface quality	2.75	3.55

[a] Lower scores indicate better performance and satisfaction.

Discussion

Summary of Key Results

We developed the content, features, and functions of a web-based SM program, I-Can Manage, iteratively in co-design with patient partners and knowledge end users (eg, cancer peer support program leaders, clinicians) using multiperspective data sources and a 5-phase human-centered development process that included formalized usability testing. The I-Can Manage program was positively viewed by our end users. Satisfaction with the system was high, and it was viewed as an easily navigable SMES program that could be integrated early in the acute diagnosis and acute treatment phase of cancer. Our work addresses a gap in knowledge about the application of an iterative co-design and demonstrates a user-centered digital design process that could be used by other researchers in the development of similar programs.

Comparison With Prior Work

Digital technology to deliver SMES is increasingly recognized as important for reaching people living with cancer on a wider scale in their own homes and communities and is complementary to guidance by health care professionals and can enhance health system capacity [59,60]. Little research has focused on the potential effectiveness of digitally delivered SMES to enable activation of patients in the SM of treatment-related toxicities, and the psychosocial and lifestyle changes that accompany a cancer diagnosis. A recent review identified 19 studies evaluating DSMIs in cancer populations, with 11 studies focused on the active phase of cancer treatment (population range 34-752 patients) [31]. Most digital programs identified were focused on dissemination of information, patient education, self-care advice, or collection of patient-reported outcomes, symptom data for the purpose of communicating or alerting health care providers versus features and functions to support the application of SM strategies and behaviors. Moreover, there is enormous diversity in intervention content in digital SMES programs and the emphasis placed on uptake of behaviors. Further, many were not developed in co-design with end users or using best practices in usability testing. Thus, not surprisingly, the findings for effectiveness of DSMIs have been mixed, with some studies showing positive effects on quality of life and anxiety and depression, whereas other studies showed no effect. Other systematic reviews showed positive benefits of DSMIs in improving adherence to oral treatment regimens [61], symptom distress [62], and healthy lifestyle behaviors [63]. However, considerable heterogeneity in intervention components tested and outcomes measured are noted for cancer SM interventions in general [32] and for digital programs [59]. Few of these programs include features and functionalities that enable the activation of SM behaviors, core SM skills, and building self-efficacy as key mechanisms for achieving a change in behaviors and improvement in health outcomes [60]. Most focus on dissemination of information or education that may improve knowledge but is inadequate to promote uptake of health behaviors particularly for patients with complex and dynamic illnesses such as cancer. By contrast, I-Can Manage specifically focuses on the behavioral aspects of SM reinforced through the way that information is provided (ie, action oriented) and completion of behavioral exercises by users (eg, steps to follow to develop a graded activity plan, healthy meal plates, breaking vicious cycles of fatigue and negative emotions, coping strategies, goal setting and action planning for each module, and building of self-efficacy).

Broader Implications

Patient engagement in SM is a desired standard of quality cancer care [64] that has not yet been integrated in routine practice [65] and patients describe poor access to SM in ambulatory care [66]. The I-Can Manage program has universal applicability for systemic (chemotherapy and immunotherapy) or oral cancer treatments as it is agnostic to cancer type. It is intended to capitalize on the diagnosis and treatment phase of cancer as a “teachable moment” to support patients in managing the multiple tasks of cancer and treatment early in the continuum. SM is particularly challenging during the acute phase of cancer because people are learning a new medical language and how to manage toxicities for often complex treatment regimens alongside dealing with the emotional sequalae of cancer, and seldom realize they can take actions to optimize health.

We envision future chapters and functionalities that support tailoring to cancer type, treatment modalities, phases of cancer care (ie, posttreatment survivorship), and differing needs of younger and older patient populations, as well as cultural, ethnic, and race diversity. For example, social media and peer support are considered essential to young adults with cancer [67], and future iterations will need to optimize Moodle functionalities or a native app-based format to offer these components. The I-Can Manage program provided direct links to other reputable organizations whose mandate was peer support. It is also recognized that older individuals may require tailored SM support programs that address multimorbidity [68] and changes in cognitive capacity that occur with aging and can impact on learning [69].

Chronic diseases such as cancer place a significant burden on health care systems globally and are a major source of health care expenditure. Disease SM programs are advocated as a solution to this problem; however, little progress has been made in the redesign of health care systems to ensure integration of these programs in routine cancer care [12]. Digital technology to support patient activation in disease and health SM leveraging programs such as the I-Can Manage program may be more widely scalable than trying to redesign complex care systems, which have largely failed to date [70].

Digital SMES should be considered an essential component of routine clinical care that is financed and integrated in a comprehensive program of SM support [71,72], particularly in the context of episodic ambulatory cancer care that is characterized by high-volume patient loads and short rapid visits without scheduled follow-up for SM training or support. Thus, implementation of SMS in cancer care settings has been challenging and progress lags compared with other chronic diseases. Future research should also identify the essential components of digital SM support solutions that translate into behavior change and clinicians will need to gain comfort in prescribing digital therapeutics as part of their treatment approach; besides, implementation research will be crucial to promote uptake in practice.

Future research should focus on formal testing of the I-Can Manage program on SM behaviors and health outcomes and adaptations for tailoring to different treatment modalities, cancer types, socioeconomic and cultural diversity, and older and younger age groups. We expect that the I-Can Manage program would result in improved self-efficacy, uptake of SM strategies, and better quality of life and wellness that requires testing in a clinical trial.

Limitations

There are some limitations in our work to consider such as the inclusion of patients and clinicians from only 2 cancer centers in the qualitative inquiry. Although our patient partners were from rural/remote and urban regions, most had high levels of education and income that could have introduced some selection bias in the study. Additionally, convenience sampling was used for recruiting patients for usability testing, the sample size was small, and only patients were included and not caregivers. This could have introduced some selection bias given that those interested in digital solutions or more computer literate may have been more willing to participate. Our usability testing focused on tasks for completion that only included the Introduction, and Chapters 1 and 2 and not all chapters given the time that would be required to complete them in a single session.

Conclusions

Suboptimal management of cancer treatment toxicities can lead to serious complications and negative effects on quality of life and worse survival. Patients/families require education and SM support to apply the SM strategies and behaviors necessary to effectively manage the medical, emotional, and lifestyle changes that are necessary to adapt to cancer and treatment. Digital SMES is a promising solution that requires future testing for its effectiveness on improving health outcomes.

Acknowledgments

We take the opportunity to thank our 7 patient partners and knowledge end users who freely shared their stories and gave their time to assist in the co-design of this program and also both patients and clinicians who were interviewed and shared their personal stories and cancer experience. This study was funded by a grant from the Canadian Institute for Health Research (CIHR) grant 379110 and CIHR grant 151292.

Data Availability

Data can be made available upon request to the corresponding author.

Conflicts of Interest

DH reports a consultant and scientific advisory board relationship with CAREVIVE, Inc. and has received institutional grant/research funding from AstraZeneca unrelated to this study. MKK has received grant/research support from EISAI, Ipsen, Eli Lilly, and Exelixis; and received honoraria from EISAI, Ipsen, and Eli Lilly unrelated to this study. The remaining authors do not have any conflicts to declare and have disclosed that they have not received any financial considerations from any person or organization to support the preparation, analysis, results, or discussion of this article.

Multimedia Appendix 1
Summarized themes of experience, defining moments, and needs from persona and cancer journey mapping.
[DOCX File , 20 KB - cancer_v9i1e44914_app1.docx]

Multimedia Appendix 2
Select screenshots for Chapter 4: "Balancing Fatigue and Activity.".
[PNG File , 488 KB - cancer_v9i1e44914_app2.png]

Multimedia Appendix 3
Additional screenshots for Chapter 4: "Balancing Fatigue and Activity.".
[PNG File , 313 KB - cancer_v9i1e44914_app3.png]

Multimedia Appendix 4
Downloadable fatigue diary for symptom monitoring.
[PNG File , 72 KB - cancer_v9i1e44914_app4.png]

Multimedia Appendix 5
Downloadable information sheet—sleep hygiene behavior tips.
[PDF File (Adobe PDF File), 124 KB - cancer_v9i1e44914_app5.pdf]

Multimedia Appendix 6
Summary of user feedback.
[PDF File (Adobe PDF File), 83 KB - cancer_v9i1e44914_app6.pdf]

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Abbreviations

ASCO: American Society of Clinical Oncology
DSMI: digital self-management intervention

PSSUQ: Post-Study System Usability Questionnaire
SM: self-management
SMES: self-management education and support

Edited by A Mavragani; submitted 09.12.22; peer-reviewed by N Fridriksdottir, K Devine, N Jiwani; comments to author 16.02.23; revised version received 26.03.23; accepted 23.05.23; published 21.07.23.

Please cite as:
Howell D, Bryant Lukosius D, Avery J, Santaguida A, Powis M, Papadakos T, Addario V, Lovas M, Kukreti V, Haase K, Mayo SJ, Papadakos J, Moradian S, Krzyzanowska MK
A Web-Based Cancer Self-Management Program (I-Can Manage) Targeting Treatment Toxicities and Health Behaviors: Human-Centered Co-design Approach and Cognitive Think-Aloud Usability Testing
JMIR Cancer 2023;9:e44914
URL: https://cancer.jmir.org/2023/1/e44914
doi:10.2196/44914
PMID:37477968

Original Paper

Data-Efficient Computational Pathology Platform for Faster and Cheaper Breast Cancer Subtype Identifications: Development of a Deep Learning Model

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Abstract

Background: Breast cancer subtyping is a crucial step in determining therapeutic options, but the molecular examination based on immunohistochemical staining is expensive and time-consuming. Deep learning opens up the possibility to predict the subtypes based on the morphological information from hematoxylin and eosin staining, a much cheaper and faster alternative. However, training the predictive model conventionally requires a large number of histology images, which is challenging to collect by a single institute.

Objective: We aimed to develop a data-efficient computational pathology platform, 3DHistoNet, which is capable of learning from z-stacked histology images to accurately predict breast cancer subtypes with a small sample size.

Methods: We retrospectively examined 401 cases of patients with primary breast carcinoma diagnosed between 2018 and 2020 at the Department of Pathology, National Cancer Center, South Korea. Pathology slides of the patients with breast carcinoma were prepared according to the standard protocols. Age, gender, histologic grade, hormone receptor (estrogen receptor [ER], progesterone receptor [PR], and androgen receptor [AR]) status, erb-B2 receptor tyrosine kinase 2 (HER2) status, and Ki-67 index were evaluated by reviewing medical charts and pathological records.

Results: The area under the receiver operating characteristic curve and decision curve were analyzed to evaluate the performance of our 3DHistoNet platform for predicting the ER, PR, AR, HER2, and Ki67 subtype biomarkers with 5-fold cross-validation. We demonstrated that 3DHistoNet can predict all clinically important biomarkers (ER, PR, AR, HER2, and Ki67) with performance exceeding the conventional multiple instance learning models by a considerable margin (area under the receiver operating characteristic curve: 0.75-0.91 vs 0.67-0.8). We further showed that our z-stack histology scanning method can make up for insufficient training data sets without any additional cost incurred. Finally, 3DHistoNet offered an additional capability to generate attention maps that reveal correlations between Ki67 and histomorphological features, which renders the hematoxylin and eosin image in higher fidelity to the pathologist.

Conclusions: Our stand-alone, data-efficient pathology platform that can both generate z-stacked images and predict key biomarkers is an appealing tool for breast cancer diagnosis. Its development would encourage morphology-based diagnosis, which is faster, cheaper, and less error-prone compared to the protein quantification method based on immunohistochemical staining.

(JMIR Cancer 2023;9:e45547) doi:10.2196/45547

KEYWORDS

deep learning; self-supervised learning; immunohistochemical staining; machine learning; histology; pathology; computation; predict; diagnosis; diagnose; carcinoma; cancer; oncology; breast cancer

Introduction

Rationale

Breast cancer is the fourth most frequent cause of death worldwide [1]. Invasive breast cancer from the heterogeneous group of breast epithelial malignancies shows distinct outcomes and responses to therapy due to the presence of subtypes, which can be defined based on the biomarker expression status [2]. These biomarkers include estrogen receptor (ER), progesterone receptor (PR), androgen receptor (AR), erb-B2 receptor tyrosine kinase 2 (ERBB2 or commonly called HER2), and antigen Ki67. In clinical practice, biomarker expressions in invasive breast cancer can be evaluated using immunohistochemical (IHC) staining. IHC has been a routine clinical process for a long time, but it is still susceptible to the pathologist's subjectivity and human errors [3]. Besides, due to the high specificity of IHC staining that can only identify a single biomarker at a time, multiple rounds of IHC staining are often required and, thus, deemed to be costly and time-consuming.

Hematoxylin and eosin (H&E) staining is another routine clinical procedure for primary cancer diagnosis (eg, cancer vs benign) and is generally performed prior to IHC staining. Although it has been suspected that H&E-stained slides may reflect the characteristic phenotypes of the prognostic biomarkers [4,5], recent deep learning models show the possibility of capturing latent features from H&E images and achieving reasonably accurate prediction of the subtype biomarkers [6-8], potentially saving clinical resources. However, these models rely on a massive number of training samples that often require data collection from multiple institutes. In practice, this approach is challenging due to a number of reasons: (1) there are inevitable data variations among institutes due to differences in equipment models and protocols adopted by each institute, and (2) data sharing across institutes faces data privacy and security issues. Such a dilemma may be overcome by developing a data-efficient model that is capable of learning from smaller training samples that still maintains high prediction accuracy.

Recent deep learning research has been focusing on the analysis of 3D medical images [9-12]. This is because 3D images offer additional information that may not be unveiled in the 2D images, leading to a more accurate classification of tissues. Likewise, 3D visualization at the cellular level is able to capture the complete morphology of nuclei, which is closely associated with cancer pathology and medical complications [13,14]. However, 3D histology images are less popular, as 3D histomorphological features rarely appear intuitive to human eyes. Hence, 2D histology image-based cancer prediction models have thus far been proposed [6-8]. Nevertheless, we hypothesized that these 3D features carry useful information that can help our proposed deep learning model to learn more effectively, even from a small set of data.

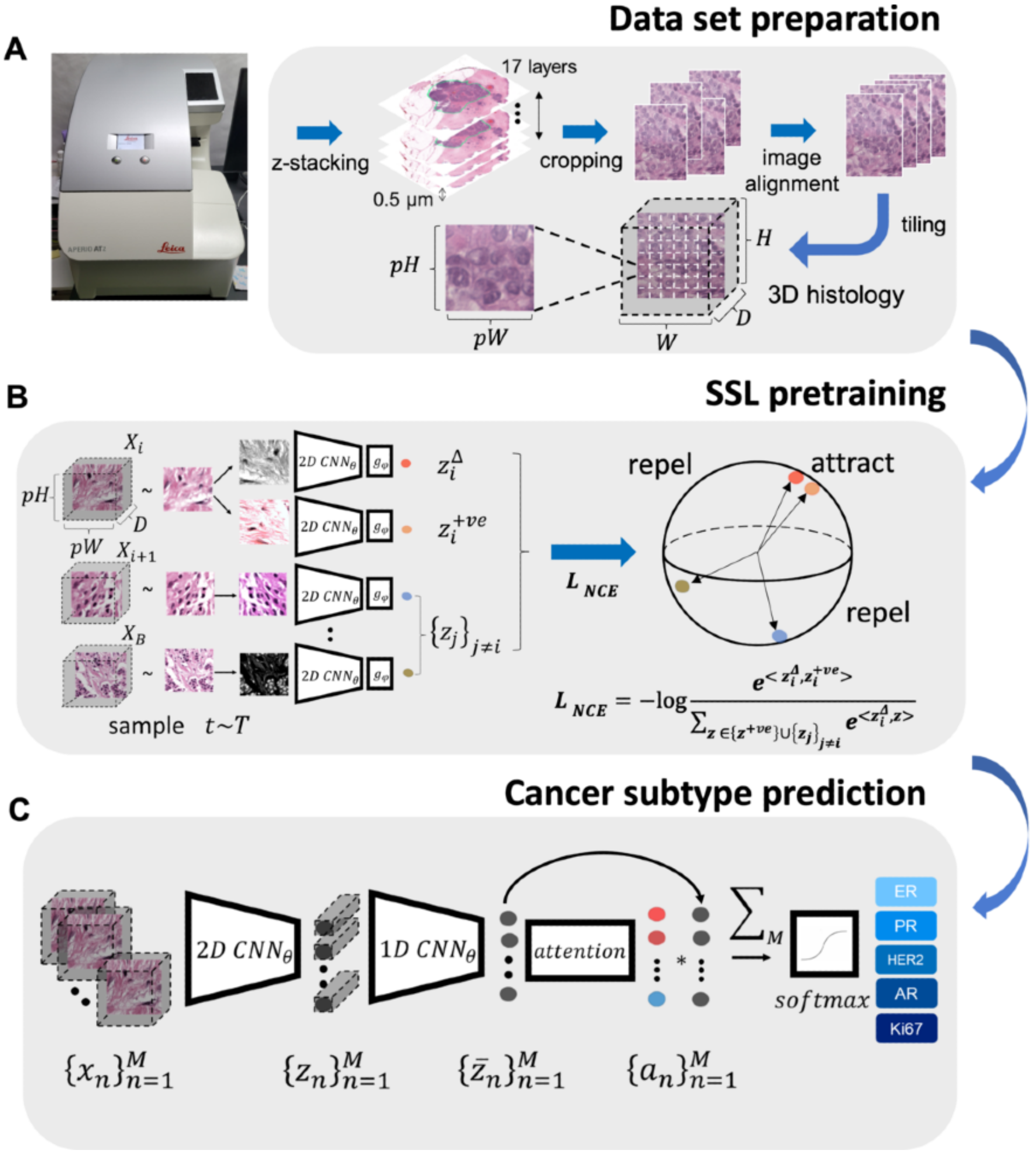
Objectives

In this study, we developed a data-efficient computational pathology platform, 3DHistoNet, to identify all 5 biomarkers (ER, PR, AR, HER2, and Ki67) associated with breast cancer subtypes. We aimed to demonstrate that our model can (1) generate z-stacked histology images suitable as a 3D data set for the training of our model; (2) harness a 3D data set to achieve improved prediction performance even with a smaller sample size; and (3) additionally produce attention maps that visualize the morphological characteristics of various prognostic biomarkers, thereby allowing pathologists to directly gain molecular information from H&E slides alone.

Methods

As shown in Figure 1, our pathology platform is composed of 3 stages: the preparation of the z-stacked whole slide tissue image data set (Figure 1A), self-supervised feature extraction from z-stacked tissue images (Figure 1B), and an attention-based prediction model (Figure 1C). The following subsections describe each of the stages. This study is reported according to the Guidelines for Developing and Reporting Machine Learning Predictive Models in Biomedical Research [15].

Figure 1. Schematics of 3DHistoNet for the prediction of prognostic biomarkers from hematoxylin and eosin slides. The model consists of 3 stages: (A) the preparation of z-stacked whole slide tissue images, (B) self-supervised feature extraction from z-stacked tissue images, and (C) attention-based prediction model. AR: androgen receptor; CNN: convolutional neural network; ER: estrogen receptor; HER2: erb-B2 receptor tyrosine kinase 2; PR: progesterone receptor; SSL: self-supervised learning.



Data Source

We retrospectively examined 401 cases of patients with primary breast carcinoma diagnosed between 2018 and 2020 at the Department of Pathology, National Cancer Center, South Korea. Pathological diagnoses of the specimens were performed by a breast pathologist following the World Health Organization guidelines and the American Joint Committee on Cancer staging manual (8th edition). Glass slides; medical charts; and pathological records including histologic grade, hormone receptor (ER, PR, and AR) status, HER2 status, and Ki-67 index were reviewed by another pathologist before collecting cases. Patients who meet any of the following conditions were excluded: (1) whole slide images were not available, (2) malignant lesions were not found, and (3) diagnosed as having breast cancer. Positive ratios for each biomarker were as follows: ER (313/401, 78.1%), PR (279/401, 69.6%), AR (353/401, 88%), HER2 (305/401, 76%), and Ki67 (258/401, 64.3%).

Ethics Approval

The retrospective study protocol was approved by the Institutional Review Board of the National Cancer Center (NCC2021-0283).

Preparation of z-Stacked Whole Slide Images for Model Building

We scanned the entire morphology of the H&E-stained tissue specimens using a pathology slide scanner (Aperio AT2, Leica Biosystems) set at a magnification of 40× (pixel size of 0.25 µm). At each focal plane, the lateral (x-y) dimensions were scanned. After completion, the focal plane was shifted by moving the objective lens axially at an interval of 0.5 µm to stack the whole slide scanning. To cover the entire depth of focus determined by the tissue thickness (3-4 µm) and further extended by the axial resolution (~2 µm) of the objective lens, 17 z-stack layers (~8 µm) were obtained. Due to the insufficient precision of the translational stage in the scanner, misalignment along the stack layer may occur. As a correction, we used an image registration algorithm with affine transformation provided by ImageJ. As breast cancer subtypes are a subset of cancer, we confined our region of interest to the cancer region as annotated by trained, certified pathologists. The region was then cropped into 256×256 image tiles without any overlap for a multiple instance learning (MIL) approach. The total number of tiles obtained was 187,921 from 401 specimens.

Predictive Models

We used a self-supervised learning (SSL) approach to train a neural network that extracts low-dimensional features from z-stacked H&E image stacks in a label-free way. Specifically, we adopted the recently proposed Simple Framework for Contrastive Learning of Visual Representations (SimCLR) [16] as our SSL framework. SimCLR learns to extract abstract features from H&E scans by maximizing the "agreement" between the altered views of the same input and minimizing it otherwise.

Figure 1B illustrates the application of SimCLR to our task of extracting features from z-stacked H&E tiles. First, we generated altered views for each z-stacked H&E tile by applying a set of mild image transformations, such as affine transform, color jittering, resizing, and cropping, which still preserved most of the key semantics of the original input tile. These altered views were then passed through a neural network, referred to as 2D convolutional neural network (CNN) in the figure, which outputs low-dimensional features for each of the views, shown as colored dots in the figure. We used InfoNCE loss [17] as the training objective that "attracts" the features generated from the same input tile and "repels" the features from different input tile sources. This "attract" and "repel" process is visualized in the figure as the proximity of colored points within a sphere. A more formal explanation that accompanies mathematical notations and definitions is available in Multimedia Appendix 1 [16-19].

After training the feature extractor neural network 2D CNN as described in the previous subsection, the next step was to use the extracted features to train another set of neural networks for the actual cancer subtypes prediction task. The overview is shown in Figure 1C. First, we extracted features from z-stacked input tiles using the SSL pretrained neural network 2D CNN. The extracted features were passed through a set of prediction modules comprising 3 submodules: (1) a 1D CNN module that integrates z-stacked representations into a single representation; (2) an attention module that generates a heatmap, which assigns a higher value to the representations that contribute strongly to prediction; and (3) a classifier layer that produces a probability of different cancer subtypes.

Regarding the z-stacked representations as multichannel 1D signals that may contain informative interactions across the signals, we applied 1D CNN to find such interactions across the stacks and integrated them into a single representation, represented as gray dots in the figure. The 1D CNN is comprised of 2 CNN blocks. Each block contains a 1D convolutional layer and a rectified linear unit layer. Taking the set of integrated representations as inputs, an attention module generates scores that measure the relative importance of each representation to the final prediction. The attention module not only helps to accelerate the model training but also assists health care practitioners in identifying potential areas that may require further focus.

Finally, the computed attention scores were used to perform a weighted average across the representations set and subsequently fed into a classifier module comprised of a fully connected layer and a softmax layer to produce cancer subtype probabilities. All 3 submodules were trained based on latent features of the H&E image stack in an end-to-end fashion with a cross-entropy loss function that matches the prediction with the ground-truth cancer subtype labels (ER, PR, AR, HER2, and Ki67). A more formal explanation that accompanies mathematical notations and definitions is available in Multimedia Appendix 1.

Model Training Setting

We used ResNet50 as our feature extractor neural network [18]. During SSL pretraining, we set the tile size to 256,set the training batch size to 256, and trained for 250 epochs. For generating different views from a source tile, we applied random cropping with a scale between a factor of 0.4 to 1; rotations of 0°, 90°, 180°, and 270°; horizontal flipping; color jittering; RGB to grayscale; gaussian blur; and solarization. Additionally, to accelerate the training speed and reduce large memory consumption, we used mixed-precision training, which combines single precision (32 bit) and half precision (16 bit). We optimize the model using the Adam optimizer [20] with a learning rate of 0.0003.

In the cancer subtype prediction task, we trained the 3 modules of our model with a batch size of 1 because each specimen has a varying tile number depending on the specimen size. No augmentation is applied to the features extracted from the tiles as the features are no longer humanly interpretable, making it difficult to know which augmentation preserves the key contents of the representation. We oversampled minority labels to address the class imbalance issue. We optimized the model using Adam optimizer [20] with a learning rate of 0.0001. We measured the variability of the model prediction with 5-fold cross-validation as internal validation. We also implemented an identical 5-fold split during the SSL pretraining step to ensure that there is no bias favoring our proposed approach over other baseline approaches. The average receiver operating characteristic curve and its area under the curve (AUC) over the 5-fold validation results were used to measure the model performance. Our 3DHistoNet was implemented in PyTorch [21] (version >1.9.0) and trained on a single NVIDIA Tesla V100 GPU with 32GB memory.

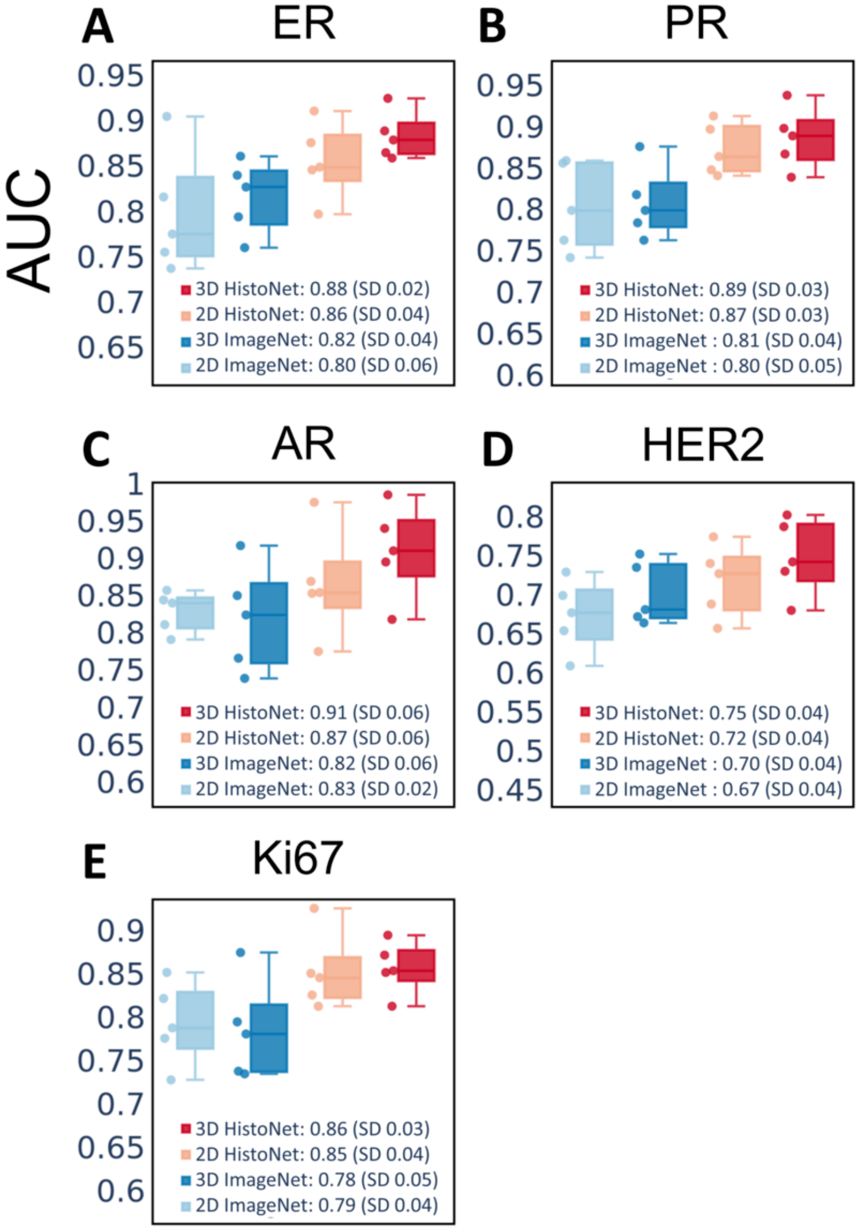
For comparison with our model, we used ImageNet-pretrained ResNet50 (IMAGENET), which is officially available in PyTorch as the baseline feature extractor. During the IMAGENET pretraining, a standard set of data augmentation techniques (random crop, resize, rotation, and intensity adjustments) were applied. For model optimization, stochastic gradient descent was applied with a learning rate of 0.1, momentum of 0.9, and decay rate of 0.99998. A minibatch size of 256 was used during pretraining.

Results

Evaluation of the Model Performance of 3DHistoNet

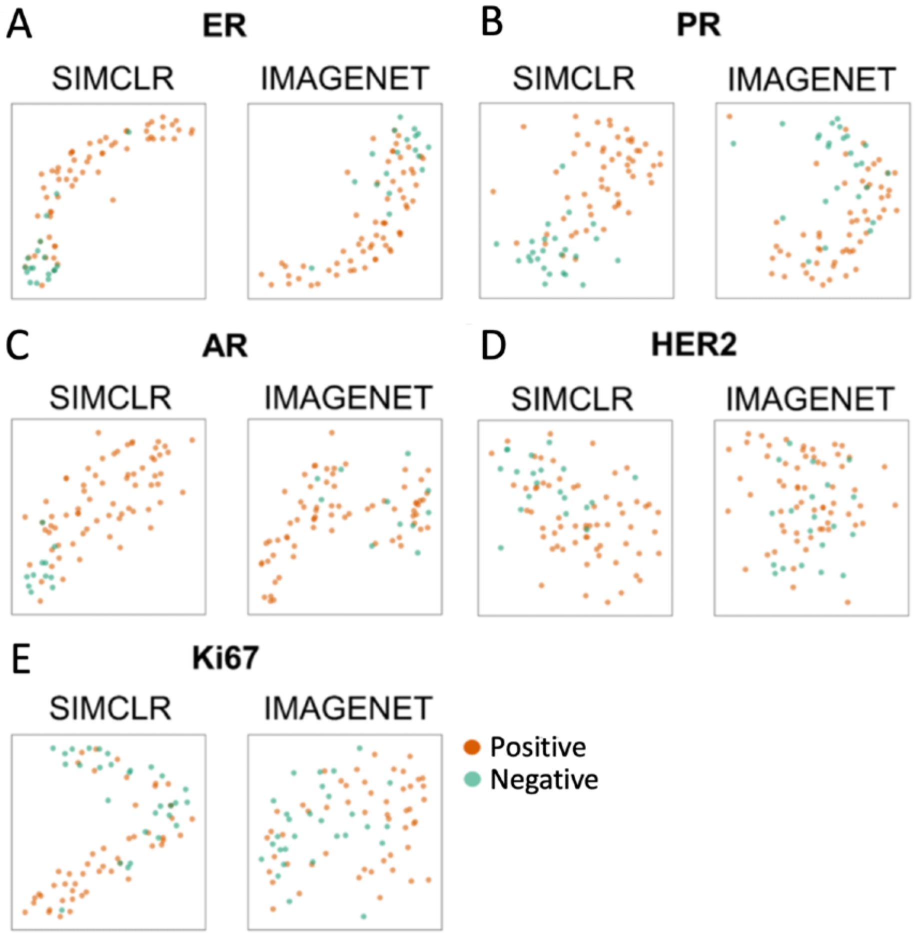
The classification capability of 3DHistoNet for all prognostic biomarkers, including ER, PR, AR, HER2, and Ki67, is shown in Figure 2. The AUC ranged from 0.75 to 0.91, demonstrating outstanding prediction accuracy despite being trained with a small data set (n=401). For comparison, we repeated the experiments with a single best-focused image from the image stack as representative of a 2D data set or with an IMAGENET model in place of SimCLR. We found that 3DHistoNet significantly outperformed IMAGENET regardless of the data type and target class, suggesting the superiority of the SSL model over the conventional supervised learning model. Our results also showed that the use of the image stack generally enhanced the classification performance compared to the 2D counterparts. On the other hand, both 3DHistoNet and IMAGENET scored an ascending order of AR, PR, ER, Ki67, and HER2 in terms of prediction performance, implying that the difficulty of the classification task is dependent on the characteristic features associated with the biomarkers.

Figure 2. 3DHistoNet shows superior performance in the prediction of prognostic biomarkers (ER, PR, AR, HER2, and Ki67) in comparison with the conventional supervised learning model. Box plots of the area under the curve (AUC) are plotted to compare the performance of 3DHistoNet with ImageNet-pretrained ResNet50 model (IMAGENET) when trained with 2D and 3D histology data sets, respectively (n=401). AR: androgen receptor; ER: estrogen receptor; HER2: erb-B2 receptor tyrosine kinase 2; PR: progesterone receptor.



We further performed a t-Distributed Stochastic Neighbor Embedding analysis (Figure 3) to compare the discrimination power of the 2 models without the confounding effects from the downstream layers (ie, prediction model). The results showed that 3DHistoNet forms more distinguishable clusters compared to IMAGENET, confirming the higher discrimination capability of the former. This trend is consistent with Figure 2, whereby AR showed the most contrasting clusters (Figure 3C) and HER2 showed the most overlapping features (Figure 3D).

Figure 3. t-Distributed Stochastic Neighbor Embedding (tSNE) analysis on low-dimensional features of the 3D data set from feature extraction modules of 3DHistoNet (SimCLR) and IMAGENET. 3DHistoNet attained higher discrimination power at the feature extraction stage. AR: androgen receptor; ER: estrogen receptor; HER2: erb-B2 receptor tyrosine kinase 2; IMAGENET: ImageNet-pretrained ResNet50; PR: progesterone receptor; SimCLR: Simple Framework for Contrastive Learning of Visual Representations.



It has been shown that the MIL approach is suitable for the classification of histology images [22,23]. The aggregation of the prediction results of patch images can effectively diagnose the whole slide image that these patches belong to. With a few choices of MIL algorithms (MeanPool, MaxPool, and Attention) given [24], we investigated the optimal algorithm for our classification task (Table 1). In general, the attention algorithm scored the highest accuracy for AR, PR, and HER2; although overall, no statistical significance in the performance of the 3 algorithms was observed. The result could imply that the high classification performance is mainly attributed to our SSL module. However, further validation with a sufficiently large data set remains to be done in the future. For our implementation, we chose the attention algorithm owning to its additional visualization function to highlight key diagnostic features.

Table 1. Comparison of the 3DHistoNet performance with different multiple instance learning algorithms (MeanPool, MaxPool, and Attention).

Biomarker	MeanPool, mean (SD)	MaxPool, mean (SD)	Attention, mean (SD)
ER[a]	0.882 (0.041)	*0.89 (0.044)* [b]	0.883 (0.026)
PR[c]	0.882 (0.04)	0.875 (0.032)	*0.888 (0.036)*
AR[d]	0.879 (0.093)	0.893 (0.082)	*0.906 (0.075)*
HER2[e]	0.732 (0.054)	0.739 (0.053)	*0.748 (0.049)*
Ki67	*0.861 (0.033)*	0.823 (0.012)	0.857 (0.03)

[a] ER: estrogen receptor.

[b] Italicization represents the multiple instance learning algorithm with the highest performance for each biomarker.

[c] PR: progesterone receptor.

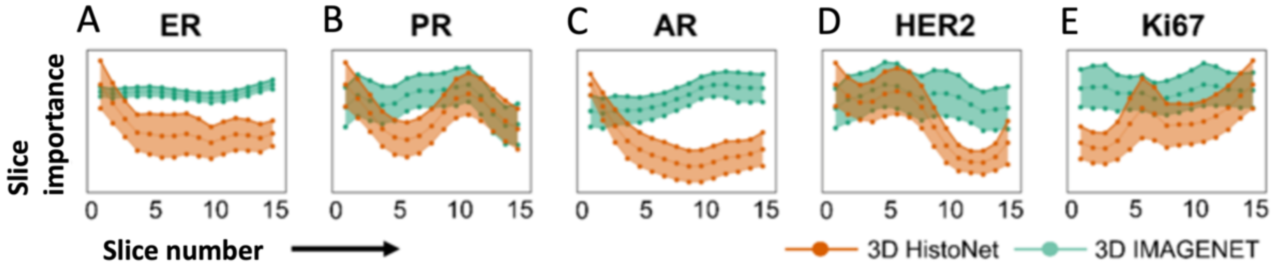
[d] AR: androgen receptor.

[e] HER2: erb-B2 receptor tyrosine kinase 2.

Assessment of the Data Efficiency of 3DHistoNet

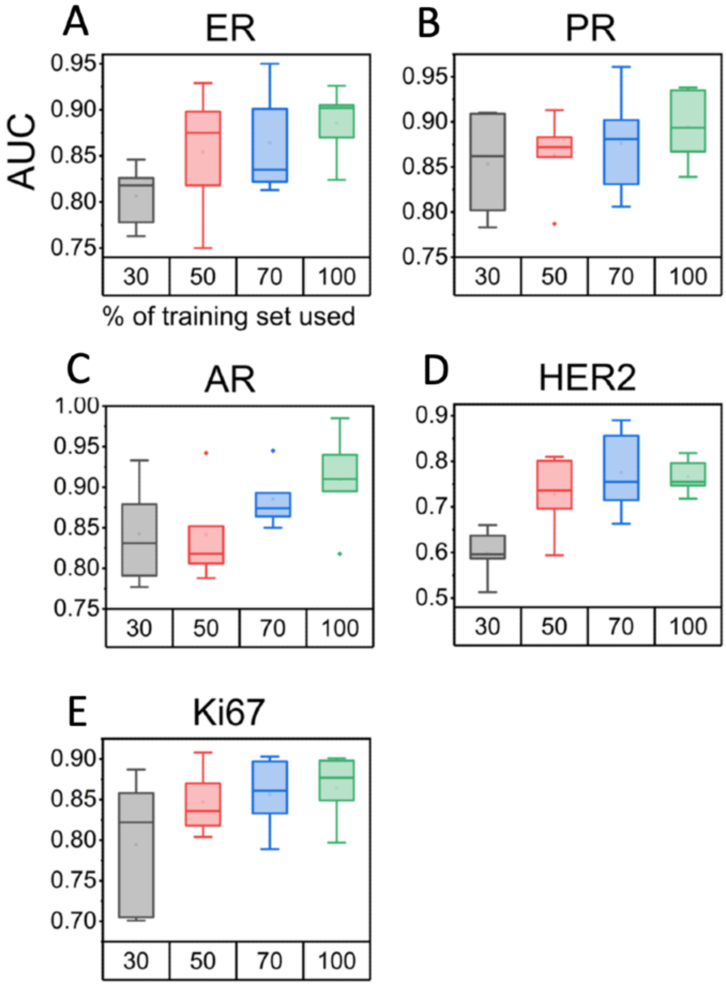
The results in Figure 2 imply that the benefit of using the image stack is greater with 3DHistoNet than with IMAGENET, suggesting that 3DHistoNet is more efficient in the extraction of relevant information from the image stack. To prove this, we evaluated the average contributions of z-slices to the biomarker prediction (Figure 4). The result shows that 3DHistoNet referred to more significant slices at different levels, whereas IMAGENET assigned equal importance to all layers, implying that it cannot extract significant information from the multiple layers. Further, we also noticed that 3DHistoNet showed different referencing patterns depending on the biomarkers, substantiating its capability to predict different biomarkers with the same architecture.

Figure 4. A graph that indicates the slice-wise feature importance in predicting biomarkers, which is computed by aggregating the Gradient-weighted Class Activation Mapping (Grad-CAM) score across all spatial axes (height and width) and tiles (A-E). The shaded region indicates the empirical SD of the slice-wise feature importance estimated using a held-out test set. AR: androgen receptor; ER: estrogen receptor; HER2: erb-B2 receptor tyrosine kinase 2; IMAGENET: ImageNet-pretrained ResNet50; PR: progesterone receptor.



We also proved that the z-stacked histology image helped overcome the shortage of training data set, which is encountered as a common limitation imposed on model performance. We sequentially sampled subsets of the training data set in the proportion of 30%, 50%, and 70% of the total number of cases in the training set (Figure 5). The performance of 3DHistoNet generally reached the optimal level with 70% of the data set except for AR (Figure 5C), implying that 3D information can make up for the shortage of the training data set, thereby contributing to the higher prediction capability. Note that since we obtained the 3D data set merely by z-stacking the same H&E tissue samples, no additional cases were added to increase the training data set, thus demonstrating the cost-effectiveness of 3DHistoNet.

Figure 5. Box plots based on the area under the curve (AUC) to show the data set size–dependent performance of 3DHistoNet in terms of the 5-fold average AUCs. The model was independently trained with 30% (n=120 cases), 50% (n=200 cases), 70% (n=280 cases), and 100% (n=401 cases) of the 3D histology data set. AR: androgen receptor; ER: estrogen receptor; HER2: erb-B2 receptor tyrosine kinase 2; PR: progesterone receptor.

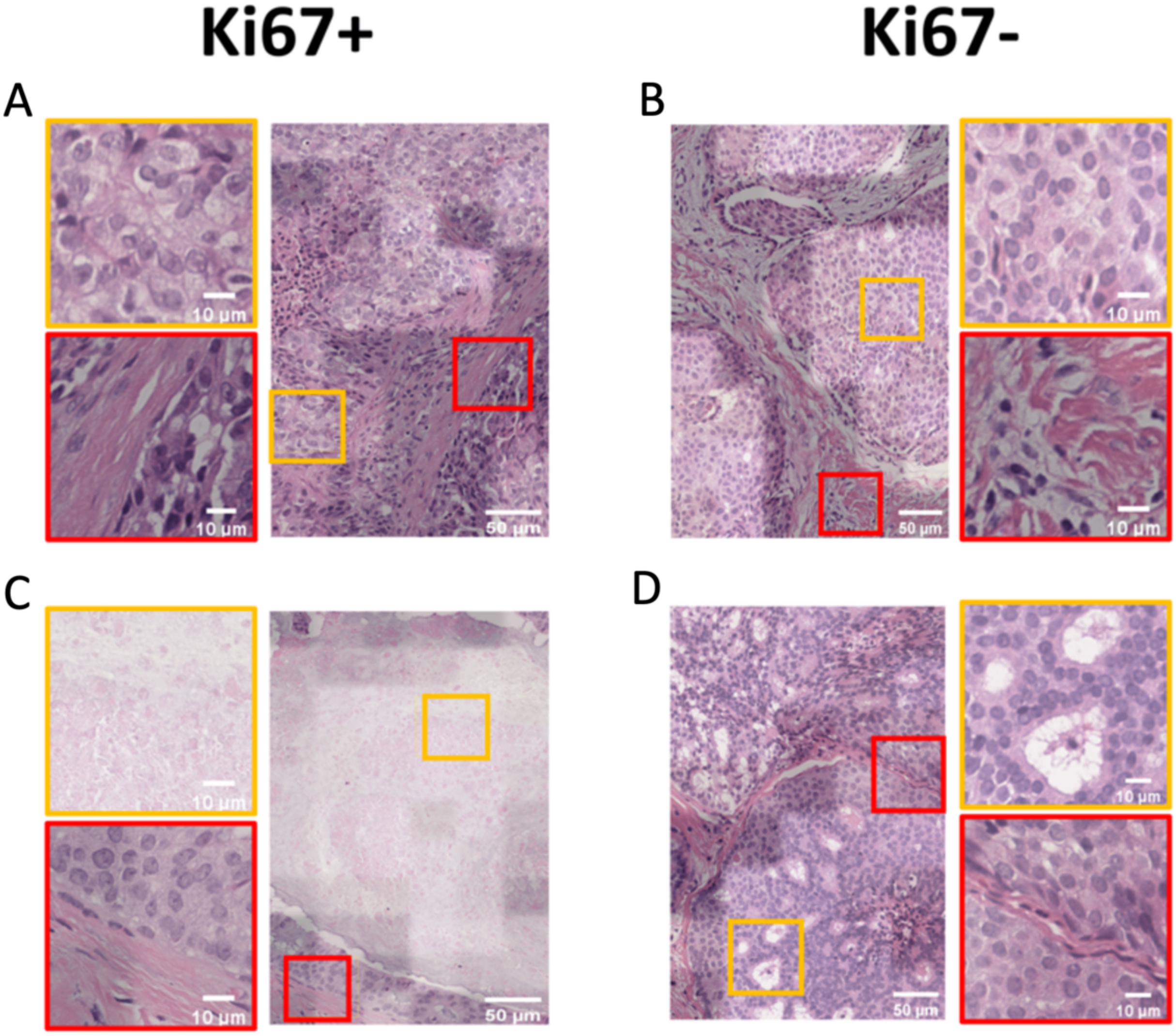


Morphological Examination of Prognostic Biomarkers Using Attention Visualization

We assessed the interpretability of the model prediction by reviewing the attention maps produced together with the classification results. In the attention map consisting of the raw histology image and the corresponding heatmap, regions giving major contributions to the classification are highlighted brighter, whereas darker regions suggest fewer contributions. A certified pathologist manually reviewed the attention maps of Ki67 expression. This cell proliferation marker is known to have strong associations with cell morphology [25], thereby explaining possible correlations between characteristic phenotypes and model prediction.

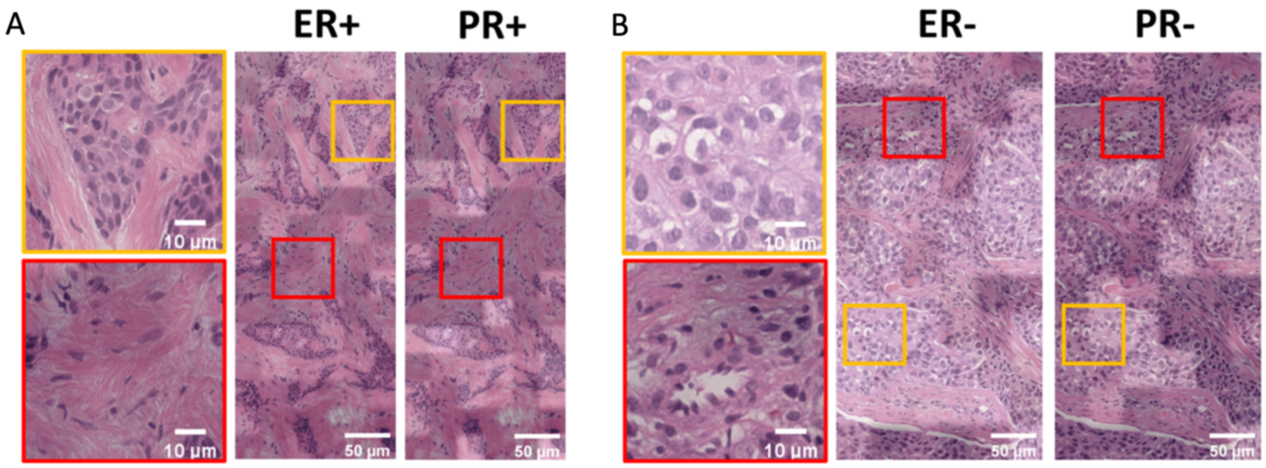
In some Ki67+ tiles, brighter regions generally consisted of high-grade cells whose nucleoli are prominent with a large nucleus, irregular nuclear membrane, and vesicular chromatin (Figure 6A—orange box), thus indicating an active cell cycle. In contrast, the brighter regions of the Ki67– images depict smaller, round nuclei with smooth contours, suggesting cells in the dormant (G0) phase (Figure 6B—orange box). Another interesting observation is that fibrosis, a ubiquitous feature in both Ki67+/– tiles (Figure 6A, C, and D—red boxes) and adipocyte (Figure 6B—red box), which lacks characteristic morphology, are assigned lower weights (darker regions). This result suggests a high specificity of the attention map module. Other Ki67+ tiles are characterized by coagulative necrosis (Figure 6C—orange box), which occurs as a result of cell proliferation occurring faster than neovascularization, leading to localized ischemia [26]. On the other hand, Ki67– maps highlight the lumen as a unique feature (Figure 6D—orange box). Such differentiable features can also be observed in AR (Multimedia Appendix 2).

Figure 6. 3DHistoNet can highlight discriminatory features between Ki67+ and Ki67– images by overlapping raw images with corresponding heatmaps. (A) and (B) Orange boxes show distinct cellular features for differentiation between Ki67+/– cases, which were highlighted with brighter coloration in the heatmap. The orange box in (C) highlights coagulative necrosis as a unique feature in Ki67+ cases, whereas (D) shows the lumen as a characteristic feature of the Ki67– group. Less discriminative features such as fibrosis and adipocyte were highlighted with darker coloration (red boxes in A to D).



Further, given that ER expression has high positive correlations with PR [27], the attention maps of the 2 biomarkers over the same image can also identify the common features accounting for their correlation (Figure 7). In the ER+/PR+ image, the pair of attention maps assigned high weightage to the region consisting of low-grade cancer cells with lumen formation (orange box). In contrast, the stroma and fibroblast were paid less attention in both attention maps. In the case of the ER–/PR– image, high-grade cell features (enlarged nucleus, prominent nucleoli, and coarse chromatin) were highlighted, whereas cells aligned along the blood vessels were disregarded. This result supports the consistency of our attention maps with useful clinical interpretation of 3DHistoNet.

Figure 7. 3DHistoNet can identify common features responsible for the strong positive correlation between ER and PR expressions. (A) In the ER+/PR+ image, low-grade cancer cells with ductal differentiation were commonly highlighted (orange box), whereas amorphous features of fibroblast and stroma were paid less attention (red box). (B) In the ER–/PR– image, the less growth pattern of the high-grade tumor cells was assigned brighter coloration (higher weightage, orange box), whereas cells along the blood vessels were assigned darker coloration (red box). ER: estrogen receptor; PR: progesterone receptor.



Discussion

Principal Findings

Breast cancer subtyping is a crucial step in determining therapeutic options, but the molecular examination based on IHC staining is expensive and time-consuming. Our data-efficient computational pathology platform, 3DHistoNet, demonstrates the capability to generate z-stacked histology images, based on which the model is trained to predict the set of all breast cancer subtypes. The main advantages of our model are that our prediction accuracy surpasses the conventional MIL model by 0.11 in terms of AUC and that such outstanding performance can be achieved with a small training data set. Finally, our platform can concurrently generate attention maps over H&E images for histopathological interpretations on the results, thereby strengthening our model's clinical validity.

Techniques to Improve the Generalizability of the Deep Learning Model

Training an end-to-end deep neural network to predict subtype biomarkers from z-stacked H&E scans poses challenges due to 2 factors: the large image size and the absence of pixel-level annotations corresponding to each subtype. The limited memory capacity of GPUs makes it impractical to fully use the high-resolution 3D image tiles from each specimen during training [7]. Moreover, cancer subtype prediction relies on local features that are not uniformly spread across the tissues but rather locally confined [28]. Consequently, learning features that robustly characterize cancer subtypes without manual annotations to guide pixel-level model training becomes challenging. As a result, a standard end-to-end trained deep neural network for subtype prediction is prone to suffering from memory capacity issues as well as overfitting.

To improve the memory and computational efficiency, we deployed the SSL module into our 3DHistoNet, which offers an alternative approach to extracting low-dimensional features without supervision from either specimen-level or patch-level subtype labels. Therefore, without having to feed all the patches from the whole slide image, SSL techniques can flexibly adjust the number of patches according to the given memory size of GPUs. The extracted features are shown to generalize well on all 5 prognostic biomarkers. Consequently, separate training for feature extraction of each biomarker is unnecessary, leading to higher computational efficiency.

We designed our model to be robust against the overfitting issue commonly observed in deep learning models for pathology images. First, in contrast to the standard neural network–based classification model that learns both the feature embedding and probability nodes for final end-to-end prediction, we adopted a 2-step training approach by separating the training of the embedding module from the cancer subtype prediction module, so that the number of parameters involved during each training can be reduced. Additionally, our SSL pretrained ResNet50 maps each 3D image tile from 256×256×3×17 to 1024×17, reducing the feature dimension by 192 times. Even if a sample has 50 such patches, the total number of features is only 50×1024×17, which is merely twice the number of features in a standard image with a size of 256×256×3. Therefore, despite the high dimensionality of the stacked image, the encoded features are manageable.

Further, by using a 1D convolution layer to integrate the z-stacked features, we kept the complexity of our model low, even with the large size of the image stack used. In contrast to a fully connected layer, where the number of trainable weights is directly associated with the input feature size, the 1D convolution layer allows weight sharing by traversing a small weight kernel across the feature. Therefore, when comparing the number of parameters between the models used for 2D and 3D pathology data sets, the 3D instance is only twice as large as the 2D instance. Consequently, the model complexity of the 3D instance, which impacts the risk of overfitting, is not significantly increased compared to the 2D instance.

Validation on Performance Improvement by Histology Stack

The theoretical axial (z-axis) resolution of our whole slide scanner is about 2 μm, which is insufficient to visualize 3D tissue morphology with high resolution. Consequently, the upper or lower layers of our z-stack images show an overlap between the "in-focus" image of the upper or lower layers and the "out-of-focus" image of the middle layer, leading to an apparent blur in our image stack. Nevertheless, our results (Figures 2-5) draw a consensus that the image stack carries additional latent information that can contribute to the model performance. To verify our idea, we trained 3DHistoNet with a virtual image stack, which was prepared by blurring the "in-focus" image using an image-processing technique such that it appears to be the same as our histology image stack but empty of axial information (Multimedia Appendices 3-4). Multimedia Appendix 5 shows that our raw data set gives higher model performance compared to the virtual one, thus supporting our claim.

Clinical Implications

The dual functions of our model to predict subtype biomarkers and generate attention maps hold several clinical values. First, the prediction of the biomarkers using H&E slides eliminates the necessity of IHC staining, saving up a substantial amount of the pathologist's time and clinical resources. This benefit is especially valuable in the case of Ki67, whose diagnosis is time-consuming due to the manual counting of stained nuclei. On the other hand, the heatmap generated by our model identifies the characteristic features of the target biomarkers, rendering the prediction mechanism explainable and, thus, increasing the fidelity of our model to the pathologist.

Limitations

The discriminative power of the features learned using SSL heavily depends on the choice of augmentation techniques. The augmented views from the same image should neither share too much nor too little mutual information [29]. However, finding the sweet spot is nontrivial, as it varies with both the data type [30,31] and downstream prediction task [32]. In our case, where prediction relies on cell morphology, the potential variations in morphological features across different biomarkers are unknown. If we knew such morphological discriminative features beforehand, we could further improve our model's performance by injecting the prior knowledge during the SSL pretraining. This could be achieved either by removing augmentations that potentially "destroy" the morphological features or by adding augmentations that amplify the learning of morphological features. Hence, additional research is required to explore the optimal combination of augmentation methods that can further enhance the discriminability of the learned features.

Implementing data augmentation in our prediction module (Figure 1C) poses another challenge, as the inputs to the classifier module are low-dimensional abstract representations of image patches that we can hardly interpret. Thus, it is difficult to determine the adequate augmentations that still preserve the key discriminative features. One way to overcome the issue is to freeze the parameters in the feature extraction module (Figure 1B) and attach them to the classifier module. This way, we can perform augmentations on images and feed them directly to the classifier module; however, this would be at the cost of increased computation time and memory consumption. Therefore, it is encouraged to seek other alternatives, such as directly augmenting representations with interpolation and extrapolation [33] or turning the outputs of the feature extraction module to follow a tractable distribution with more control [34].

Conclusion

In conclusion, we developed a data-efficient, stand-alone pathology platform, 3DHistoNet, which enables the generation of a z-stacked histology image data set and SimCLR-based prediction for 5 breast cancer subtype biomarkers.

We show that 3DHistoNet significantly outperformed the IMAGENET-pretrained supervised model in the prediction of all biomarkers, even with a limited sample size. Our model simultaneously generates attention heatmaps that are indicative of the correlation between biomarker expression and histomorphological characteristics, which would render the H&E image with higher interpretability to promote the morphology-based diagnosis among pathologists. The implementation of 3DHistoNet would encourage morphology-based diagnosis, which is faster, cheaper, and less error-prone compared to the protein quantification method based on IHC staining.

Acknowledgments

This work was supported by the National Research Foundation Singapore under the AI Singapore Programme (award AISG-GC-2019-001-2A), the National Medical Research Council Singapore under the Health Service Research Grant (award MOH-HSRG-OC17Nov-0001), the Korea Health Industry Development Institute (grant HI21C1137), and the Ministry of Health and Welfare (grant 11-65-0-090-091-4800-4848-501).

Data Availability

All code was implemented in Python with PyTorch being the primary deep learning package. Code, trained models, and scripts to reproduce the experimental result of this paper are available on the web [35]. All source code is provided under the GNU GPLv3 free software license.

Authors' Contributions

KB, YSJ, NH, and MF conceived the study, designed the experiments, and prepared the manuscript. KB developed the z-stacked whole slide imaging technique. KB and NH curated the in-house data sets and performed experimental analysis. YSJ developed and evaluated 3DHistoNet. NH and MF supervised the research. KB and YSJ contributed equally as joint first authors. MF and NH contributed equally as joint senior authors.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Mathematical definitions.
[DOCX File , 24 KB - cancer_v9i1e45547_app1.docx]

Multimedia Appendix 2
3DHistoNet can highlight discriminatory features between AR+ and AR– images. (A) In the AR+ image, abundant granular eosinophilic or vacuolated cytoplasm with distinct cell borders were highlighted as distinct features that contribute to the prediction of the image as AR+ (orange box). In contrast, regions consisting of fibroblast, stroma, and cells with high nucleus-to-cytoplasm ratio were not identified as characteristic features (red box). (B) In the AR– image, basal-like or medullary patterns with high-grade cancer cells were the key features (orange box), whereas blood vessel and condensed tumor cells were highlighted as being less prominent (red box). AR: androgen receptor.
[PNG File , 1495 KB - cancer_v9i1e45547_app2.png]

Multimedia Appendix 3
Examples of a raw histology image stack.
[MP4 File (MP4 Video), 604 KB - cancer_v9i1e45547_app3.mp4]

Multimedia Appendix 4
Examples of a virtual image stack prepared by blurring the "in-focus" image of a raw stack to an increasing degree. Note that despite their similar appearance, the raw stack should contain more morphological information than the virtual stack.
[MP4 File (MP4 Video), 399 KB - cancer_v9i1e45547_app4.mp4]

Multimedia Appendix 5
Comparison of the 3DhistoNet performance with z-scanned and virtual image stack in terms of ROC-AUC. In general, training with the z-stacked image gives higher model performance compared to the virtual dataset.
[PNG File , 213 KB - cancer_v9i1e45547_app5.png]

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Abbreviations

AR: androgen receptor
AUC: area under the curve
CNN: convolutional neural network
ER: estrogen receptor
H&E: hematoxylin and eosin
HER2: erb-B2 receptor tyrosine kinase 2
IHC: immunohistochemistry
IMAGENET: ImageNet-pretrained ResNet50
MIL: multiple instance learning
PR: progesterone receptor
SimCLR: Simple Framework for Contrastive Learning of Visual Representations
SSL: self-supervised learning

Edited by T de Azevedo Cardoso; submitted 15.01.23; peer-reviewed by T Camargo, D Hu; comments to author 16.06.23; revised version received 07.07.23; accepted 21.07.23; published 05.09.23.

Please cite as:
Bae K, Jeon YS, Hwangbo Y, Yoo CW, Han N, Feng M
Data-Efficient Computational Pathology Platform for Faster and Cheaper Breast Cancer Subtype Identifications: Development of a Deep Learning Model
JMIR Cancer 2023;9:e45547
URL: https://cancer.jmir.org/2023/1/e45547
doi:10.2196/45547
PMID:37669090

Original Paper

Content Quality of YouTube Videos About Metastatic Breast Cancer in Young Women: Systematic Assessment

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Abstract

Background: Young women with metastatic breast cancer (MBC) are part of a digitally connected generation yet are underserved in terms of information needs. YouTube is widely used to find and identify health information. The accessibility of health-related content on social media together with the rare and marginalized experiences of young women with MBC and the digital media practices of younger generations imply a considerable likelihood that young women with MBC will seek information and community on the internet.

Objective: This study aims to assess the content quality of MBC YouTube videos and to identify themes in the experiences of young women with MBC based on YouTube videos.

Methods: A systematic assessment of MBC YouTube videos using the search term "metastatic breast cancer young" was conducted in August 2021. The search was performed in an incognito browser and with no associated YouTube or Google account. Search results were placed in order from most to least views. Title, date uploaded, length, poster identity, number of likes, and number of comments were collected. Understandability and actionability were assessed using the Patient Education Materials Assessment Tool (PEMAT); information reliability and quality were assessed with DISCERN. Themes, sponsorships, and health care professionals' and patients' narratives were reported.

Results: A total of 101 videos were identified. Of these, 78.2% (n=79) included sponsorships. The mean PEMAT scores were 78.8% (SD 15.3%) and 43.1% (SD 45.2%) for understandability and actionability, respectively. The mean DISCERN score was 2.44 (SD 0.7) out of 5. Identified themes included treatment (n=67, 66.3%), family relationship (n=46, 45.5%), and motherhood (n=38, 37.6%).

Conclusions: YouTube videos about young women with MBC are highly understandable but demonstrate moderate rates of actionability, with low reliability and quality scores. Many have a commercial bias. While web-based materials have limitations, their potential to provide patient support is not fully developed. By acknowledging their patients' media habits, health care professionals can further develop a trusting bond with their patients, provide a space for open and honest discussions of web-based materials, and avoid any potential instances of confusion caused by misleading, inaccurate, or false web-based materials.

(JMIR Cancer 2023;9:e45101) doi:10.2196/45101

KEYWORDS

social media; YouTube; metastatic breast cancer; breast cancer; patient education; health education; patient literacy; media literacy; health literacy; consumer health information; assessment tool; treatment; false information; women; videos; web-based

Introduction

Breast cancer is uncommon among young women, a population that is more likely to be diagnosed with more advanced and aggressive cancer than postmenopausal women [1]. Young women diagnosed with metastatic breast cancer (MBC) under the age of 40 years are marginalized from more common presentations of breast cancer (ie, early stage, postmenopausal, or non-metastatic), and therefore bear informational vulnerability. This refers to one's risk of encountering and being affected by information that is false, inaccurate, or taken out of context, which can be exacerbated by low media literacy levels. In a context where their diagnoses and disease experiences are rare and understudied, young women with MBC often turn to social media and web-based forums to find MBC-related information and community. Young women with MBC actively seek information about their diagnoses and turn to scientific research that is then discussed in web-based settings [2-5].

The accessibility of health-related content on social media together with the rare and marginalized experiences of young women with MBC and the digital media practices of younger generations imply a considerable likelihood that young women with MBC will seek information and community in web-based contexts, including forums and social media platforms. These factors pose a risk that young women with MBC will encounter health information that is incorrect, misleading, false, or removed from the appropriate context. Health information on social media is largely unregulated; its impact on patients' understanding is difficult to measure and is largely dependent on one's own literacy skills. YouTube is a video sharing company and social media platform that is widely used to find and identify health information [6].

The purpose of this study is to assess the content quality of YouTube videos about and by young women with MBC and to identify common themes in MBC experiences based on video content. Identifying common themes contributes to knowledge of the emotional, social, and financial effects imposed on young women with MBC, which can help to better define priorities in patient-centered research. The outcomes of this study include knowledge of the content quality of YouTube videos, including their strengths and weaknesses, and further understanding of the experiences of young women with MBC, which may provide indications as to their reasons for seeking information and community in web-based spaces. Situated within a broader framework of the impact of social media on health care decisions, this study offers a perspective on the potential of social media regarding information circulation in cancer care among members of a vulnerable population.

Methods

Ethical Considerations

Ethics approval was not required as research involving publicly available data is exempt from McGill University's Research Ethics Board review [7].

Data Collection

A systematic assessment of YouTube videos with the search term "metastatic breast cancer young" was conducted on August 3, 2021. The search was performed in an incognito browser with no associated YouTube or Google account. Search results were placed in order from most to least views. The title, date uploaded, length, poster identity, number of likes, and number of comments were collected in a spreadsheet.

Several video characteristics were recorded. Videos included in playlists were recorded. Playlists are a collection of audio and video files created by users; they tend to be grouped together by theme and are intended to be watched in sequential order. Videos were also classified as information-based or experience-based. Information-based videos were driven by information and knowledge transfer, such as instances of health care professionals explaining a particular element of care or delivering a research presentation. Experience-based videos were driven by people's experiences and stories, such as interviews with survivors or patients. The two were not mutually exclusive; a video could be described as both information- and experience-based. Reviewers took note of the presence of information and experience in order to account for the types of perspectives being offered in each video. In addition, reviewers noted whether videos included personal narrative, were educational, or offered advice. Personal narrative was defined as the presence of details about one's lived experience; this differed from an experience-based video in that a video might be information-based but include mention of someone's personal experience (eg, a physician giving a research talk who tells a short, personal anecdote). If a video was educational, this means it included the presence of knowledge transfer; this differed from a video being information-based in that a video might be experience-based but include some element of knowledge transfer (eg, a panel led by survivors or patients who discuss their experience of illness but also discuss how their treatment works or what their diagnoses mean). For a video to offer advice, it had to suggest that the viewer take some sort of action. Moreover, reviewers noted whether a video was part of a news media broadcast.

Assessment Using the Patient Education Materials Assessment Tool and DISCERN

A review of selected videos was performed by a communication studies researcher and two health care professionals. All reviewers were trained to use the scoring instruments by the same person, including theme identification. Reviewers scored a small sample of videos collaboratively to establish reliability. Any major disagreements were resolved through consensus.

Content quality of the YouTube videos was assessed using the Patient Education Materials Assessment Tool (PEMAT) and DISCERN instruments. Understandability and actionability were scored using the PEMAT for audio-visual materials [8,9]. The PEMAT instrument offers a score for understandability and a score for actionability. Actionability refers to whether the material describes an action the viewer can take and whether it describes and explains steps toward taking that action. Each item in the PEMAT instrument was assessed and given a score of 0 (disagree) or 1 (agree). Scores were then added up and averaged to determine overall understandability and actionability. Information reliability and quality were assessed with DISCERN [10,11]. When assessing material using DISCERN, reviewers assigned a score that ranged from 1 to 5, where 1 was low and 5 was high. In both instruments, a higher score indicated higher quality levels. The PEMAT and DISCERN were only applied to the YouTube videos in the data set and not to the surrounding materials, such as titles, captions, or comments.

Themes, Narratives, and Sponsorships

For each video, the themes addressed, presence of sponsorships, and health care professionals' and patients' narratives were also reported. Reviewers began identifying themes deductively with a predetermined list of themes of particular interest, defined in Table 1, and those that were most likely to appear in videos about the experiences of young women with MBC. The themes in Table 1 were collectively agreed upon at the research design stage. Subthemes were identified inductively based on notes taken during viewing that diverted from or were more specific than the main themes listed in Table 1. Sponsorships were identified as overt or covert. Overt sponsorships refer to explicit verbal mentions of an institution or company. Covert sponsorships refer to nonverbal instances of promotion, such as a banner, logo, or website URL appearing in the video. The presence of sponsorships was assessed in the video itself, and not in the surrounding description or caption.

Table 1. Theme definitions.

Theme	Definition
Treatment	Refers to a wide array of topics, ranging from treatment choices and side effects to the experience of receiving treatment
Family relationship	Refers to family-based experiences, such as how one may disclose their diagnosis to their family and how a diagnosis shifts the family dynamic
Motherhood	Refers to the specific relationship between mother and child, how to disclose to one's children, as well as wanting to be a mother
Terminal status	Refers to the fact that one's cancer has metastasized and may become their cause of death
Path to diagnosis	Refers to the story or experience of being diagnosed with breast cancer, such as discovering a breast lump
Spousal relationship	Refers to the patient's relationship with their spouse, including stress on the spouse who takes on a caregiving role

Results

Data Collection

In total, 101 videos were identified (Table 2). Of these, 61 (60.4%) videos were information-based and 59 (58.4%) were experience-based. The average video length was 14.9 (SD 22.5) minutes. Most videos (n=96, 95%) were created and posted by an organization. The majority of videos were uploaded by nonprofit groups and breast cancer advocacy organizations, such as Rethink Breast Cancer. The group that uploaded the most videos was Living Beyond Breast Cancer (n=16, 15.8% of total videos; Table 3). Of the 6 YouTube channels in Table 3, 5 corresponded to organizations located in the United States; Rethink Breast Cancer was the only Canadian organization with significant channel frequency. The use of hashtags was not common; only 5.9% (n=6) of videos incorporated their use. Playlists were also uncommon; 23 (22.7%) videos were listed in a playlist, while 78 (77.2%) videos were not. Many videos included personal narrative (n=67, 66.3%) and were educational (n=64, 63.3%). News media clips were not common, as only 7 (6.7%) videos consisted of news media.

Table 2. Descriptive findings of YouTube videos (N=101).

Variable	Value
Identifiable corporate sponsorships, n (%)	79 (78.2)
Patient narrative, n (%)	64 (63.3)
Health care professional narrative, n (%)	58 (57.4)
Video length (minutes), mean (SD)	14.9 (22.5)
Number of viewer comments, mean (SD)	15.5 (69.0)
Number of viewer likes, mean (SD)	92.6 (415.0)

Table 3. YouTube channels by frequency.

Channel	Frequency (N=101), n (%)
Living Beyond Breast Cancer	16 (15.8)
NCCN[a]	15 (14.8)
Vital Options International	12 (11.9)
Young Survival Coalition	11 (10.9)
Rethink Breast Cancer	7 (6.9)
Dana-Farber Cancer Institute	3 (3)
Other[b]	37 (36.6)

[a] YouTube channel of the National Comprehensive Cancer Network.

[b] Channels present <3 times, including Nalie, Good Morning America, Refinery29, Gajendra Singh, MD, TODAY, Geisinger, Metavivor Online, TEDx Talks, Today's Parent, Novartis, Susan G. Komen, Momjo, Cleveland Clinic, European Society for Medical Oncology, SELF, Rachel Leigh, Whitehead Institute for Biomedical Research, KGUN9, dailyRx, Cancer Support Community, Tigerlily Foundation, Icon Cancer Centre, Metastatic Breast Cancer Alliance, Gulf States Young Breast Cancer Survivor Network, First Coast News, vcbf1991, WTKR News 3, Breaking News, Ascension Seton, CancerFightClub, UCLA Health, Phoenix Children's Hospital, and DNA Today.

Assessment Using PEMAT and DISCERN

The mean PEMAT audio-visual scores were 78.8% (SD 15.3%) and 43.1% (SD 45.2%) for understandability and actionability, respectively (Table 4). Overall, videos had moderate reliability and quality levels, and the mean DISCERN score was 2.44 (SD 0.7) out of 5.

Table 4. Distribution of Patient Education Materials Assessment Tool (PEMAT) and DISCERN scores.

Tool	Mean (SD)	Range	Median (IQR)	Mode
PEMAT understandability				
Total points	7.6 (1.9)	3-12	7.0 (5.0-9.5)	7.0
Total possible points	9.9 (1.2)	5-12	10.0 (7.5-11.0)	10.0
Score (%)	78.8 (15.3)	30-100	77.8 (53.9-88.9)	70
PEMAT actionability				
Total points	1.4 (1.4)	0-4	1.0 (0.5-2.5)	0.0
Total possible points	3.1 (0.3)	3-4	3.0 (0-0.5)	3.0
Score (%)	43.1 (45.2)	0-100	33.3 (16.7-66.7)	0
DISCERN				
Total points	39.0 (11.1)	18-68	39.0 (28.5-53.5)	38.0
Average out of 5	2.4 (0.7)	1.1-4.3	2.4 (1.8-3.4)	1.8

Themes, Narratives, and Sponsorships

Commonly identified themes included treatment (67/101, 66.3%), family relationship (46/101, 45.5%), motherhood (38/101, 37.6%), terminal status (32/101, 31.6%), the path to diagnosis (29/101, 28.7%), and spousal relationship (25/101, 24.7%; Table 5). Subthemes included feelings of stress, anxiety, depression, and other mental health issues; racial disparities in breast cancer; making arrangements for end of life; fear of progression; explaining what it means to be "stage IV"; the "pink" movement in breast cancer; as well as participation in clinical trials and research.

Table 5. Thematic findings.

Theme	Prevalence (N=101), n (%)
Treatment	67 (63.3)
Family relationship	46 (45.5)
Motherhood	38 (37.6)
Terminal status	32 (31.6)
Path to diagnosis	29 (28.7)
Spousal relationship	25 (24.7)

Patient narratives were shared in 63.3% (64/101) and health care professional narratives in 57.4% (58/101) of videos. Of the videos that included patient narratives, 54.7% (35/64) provided a diagnosis timeline, 7.8% (5/64) were recently diagnosed (roughly within a year of the video being posted to YouTube), and 29.7% (19/64) had a diagnosis date over a year prior to the video being posted to YouTube. Advocate narratives were present in 28.7% (29/101) of videos. Scientist narratives were present in 7.9% (8/101) of videos. Scientists were distinguished from health care professionals as individuals who were identifiable (by their own introduction) as researchers who are not clinicians and do not provide care to patients directly. Overall, 78.2% (79/101) of videos were sponsored. Of the 79 sponsored videos, 22 (27.8%) were covert sponsorships and 57 (72.2%) were overt sponsorships.

Discussion

Principal Findings

Young women with MBC represent an uncommon presentation of disease among a highly digitally connected generation. We showed that YouTube videos about MBC were very understandable but demonstrated low to moderate rates of actionability, with low reliability and quality scores. Videos were also often sponsored. Our findings hold implications for the role and possible benefits of social media in cancer care. Our study contributes to a range of existing methods to assess information quality [12]. We combined the use of standardized instruments with a qualitative thematic approach in order to gain an understanding of patient experiences and concerns relative to video content quality. Given the often-unregulated nature of YouTube content and of web-based information more broadly, evaluating YouTube videos with validated instruments provided an opportunity to measure the strengths and weaknesses of YouTube videos.

The high PEMAT understandability score, which implies that videos are clear and accessible in language, is a reminder that YouTube videos are popular because they are easy to watch and understand. Patients are generally satisfied with oncology services, though research suggests that improvement in the explanation of long-term side effects, treatment options, and support with psychological, emotional, and physical elements of cancer would be beneficial [13]. While web-based materials do not represent a direct contrast to visits with one's oncologist, there are important distinctions between the two forms of information delivery. Indeed, an internet search and a conversation with one's oncologist represent vastly different information environments; the former is completely driven by the patient, is voluntary, and is readily accessible at any time, whereas the latter is scheduled, limited by time constraints, and occurs at the discretion of the oncologist. In this way, internet searches may represent an addition to the information that is provided by the oncologist and care team and do not necessarily imply that the patient is choosing to dismiss information provided by their medical care team. Internet searches may also be a way for patients to navigate complex medical information. A literacy assessment of the National Comprehensive Cancer Network (NCCN) guidelines on the management of the most common cancer diagnoses revealed that, while scoring high on the PEMAT scale, the guidelines have a reading level higher than what is considered suitable for the general adult population of the United States [14]. Therefore, internet searches do not only indicate a need for more information but also represent an opportunity for alternative or additional understandable explanations. Heavy viewership of YouTube videos might be a signal that health care professionals need to communicate more clearly, but not in terms of providing accurate information; rather, they must ensure that they are conveying information to patients in an understandable and comprehensive way. Therefore, in cases where there is a communication barrier between patients and physicians, YouTube's accessibility and clarity may act as a helpful complement to what the patient learns during their appointment.

The low levels of quality and reliability found in the videos analyzed in this study are characteristic of the overall troubling lack of regulation of web-based content and are consistent with other studies of YouTube video content quality. YouTube videos about breast cancer [15], prostate cancer [16,17], idiopathic pulmonary fibrosis [18], cleft lip and palate [19], hysterectomy [20], and neurotoxins [21] and educational videos about plastic surgery [22,23] are low in information quality. YouTube information quality is considered promising regarding food poisoning [24] and fair for orthodontic smile design [25]. YouTube videos about cosmetic surgery were shown to have high levels of bias and low levels of quality when measured with DISCERN [26]. Yuksel and colleagues [27] similarly demonstrated that YouTube videos about pregnancy and COVID-19 have many views but are low in quality and trustworthiness. Therefore, while YouTube content about health conditions is abundant, viewers should continue to be wary of its information quality. Although content moderation is part of every platform's function, it cannot account for content that is potentially misleading but that does not violate any community guidelines [28]. Information considered to be "fake news" encapsulates a wide variety of information that exceeds information that is simply false and includes misreporting and persuasive information [29]. Content moderation often occurs after a post is already shared, and the processes and justifications behind it tend to be kept secret by platforms [30]. Therefore, the lack of oversight on health information in web-based spaces is a reality that patients and health care professionals alike must contend with. In addition, many videos have a potential commercial bias. Heavy sponsorship and corporate presence are common on YouTube, though they are also common in public messaging about breast cancer. Sponsorships may not always be easily discernible or recognizable by the average viewer, a phenomenon that merits further attention and concern.

Despite the existing low levels of quality among YouTube videos, the platform holds wide potential for communicating public health information to a large audience, as we have recently witnessed with COVID-19 mitigation [31]. Low levels of web-based information quality are going to persist; therefore, health care professionals should consider providing tools to enhance patient autonomy in assessing the web-based information they consume, especially considering research that demonstrates low levels of electronic and internet health literacy among cancer survivors [32]. Rather than strictly discouraging patients from searching the internet, patients should be made aware of responsible ways of using internet sources [33]. For example, learning how to recognize sponsorships as well as the motivations behind forms of web-based content can help to alleviate the effects of a lack of content regulation and decrease informational vulnerability. Similar to the prompts of the PEMAT and DISCERN instruments, questioning the purpose behind a video and how the information in the video is presented are habits that can contribute to higher levels of media literacy [34]. Media literacy education may not originate from the oncologist, however; as Tran and colleagues [14] explain, while clinicians are always important sources of information, there is little they can do to "directly help improve patients' literacy skills." Rather, libraries and educational institutions provide guides to navigating web-based content and identifying potential misinformation. For example, on its website, the Toronto Public Library offers a guide titled "How to Spot Fake News," which also links to books, videos, and other research guides on misinformation [35].

The themes most commonly identified in our study are predominantly experiential, which may suggest that many interpersonal and relationship-based concerns—reflected in our findings as being prioritized by patients—are not being sufficiently addressed by health care professionals in structured clinical encounters, signaling an unmet need to connect to a patient community. Engaging on the internet, therefore, may act as evidence of diverging information priorities between the patient and the physician. For instance, Tran and colleagues [14] cite a survey conducted by the NCCN that demonstrated that the information in the NCCN guidelines, which are comprised mainly of treatment details, did not align with what patients were looking for [36].

That many of the identified themes are experiential also suggests that content about the lived experience of young women with MBC is both successful and desired by patients, in addition to information about the disease itself. Personal stories on social media are very common, reflecting the importance of finding community on the internet [37]. As Ginter [38] shows, young age combined with late-stage diagnosis represents specific challenges for young women with MBC who face difficulties with short- or long-term decision-making. Young women with MBC struggle with anxiety [39], are susceptible to posttraumatic stress, and need social support [40]. Social media participation has the potential to assist in alleviating patient anxiety; indeed, Attai and colleagues [41] demonstrated that breast cancer patients' "perceived knowledge increases and their anxiety decreases by participation in a Twitter social media support group." Beyond MBC, the lived experience of patients with metastatic lung cancer is understudied [42]. A study by Petrillo and colleagues [43] on the experience and supportive care needs of people with metastatic lung cancer concluded that patients with metastatic nonsmall cell lung cancer who receive targeted therapy, as well as their caregivers, "experience distress related to living with uncertainty and desire more coping support, connection with peers, information, and healthy lifestyle guidance." Their findings, which indicate the need to develop tailored support services, highlight the ways in which the experience of living with metastatic disease is understudied, unique, and requiring of specific forms of support. Moreover, assessing the themes and topics discussed in web-based spaces may prove useful for policy development or improvements to patient care [4].

Limitations

Limitations of this study include restrictions based on language, country of origin, and quality assessment. This study included only English-speaking videos, many of which originated in a US context, and therefore reflects specific social and geographical points of view. In addition, the use of the PEMAT and DISCERN instruments limited our assessment to only the videos themselves. We recognize that the surrounding content, such as captions and comments, may potentially contain rich information. This content represents an opportunity for future research, as it documents viewer reactions and may provide insight into how the viewers choose to process information that may affect their health.

Practical Implications

Our findings hold important implications for communication practices in oncology. Per policy recommendations in the realm of cancer literacy, health care professionals (oncologists in particular), where feasible, should be sensitive and receptive to the knowledge patients have gained through their internet searches and social media participation and improve their communication skills in this area [33]. By acknowledging their patients' media habits, health care professionals can potentially further develop a trusting bond with their patients by including them in setting the priorities for each appointment, providing a space for open and honest discussions of web-based materials, and avoiding any potential instances of confusion caused by misleading, inaccurate, or false web-based materials. These communication practices can help patients to be better equipped in their internet searches and social media participation and improve their ability to discern sponsorships and commercial messaging. Moreover, research indicates that trust between patient and physician is reciprocal and that communication quality has a significant influence on building that trust [44]. Furthermore, in attending to patients' media habits and practices, health care professionals can have the opportunity to stay informed on what is currently trending or popular regarding cancer in web-based spaces.

Conclusion

Social media use and participation in internet searches are widespread habits that are well-established and sure to remain an important part of the experience of disease, in particular among younger populations. While web-based materials have limitations, including high rates of sponsorship bias and low levels of information quality, their potential to provide patient support is not fully developed. More research is needed to evaluate the impact of YouTube videos on patient decisions and possible interventions provided by health care institutions. Future research may include patients' perspectives on these findings and on YouTube as a platform for information and community-seeking.

Acknowledgments

NM was supported by the Social Science and Humanities Research Council and the Fonds de recherche du Québec - Société et Culture. ANM received funding for this project from the McGill Cancer Care Quality Initiative.

Data Availability

The data sets generated and analyzed during this study are available from the corresponding author upon reasonable request.

Authors' Contributions

NM, CAR, and ANM supervised and conceptualized the study. NM, DN, CAR, and ANM developed the methodology. DN performed formal analysis and data curation. ANM acquired resources and funding. NM validated and visualized the results. NM, YA, and XW wrote the manuscript. NM and ANM reviewed and edited the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

MBC: metastatic breast cancer
NCCN: National Comprehensive Cancer Network
PEMAT: Patient Education Materials Assessment Tool

Edited by T de Azevedo Cardoso; submitted 16.12.22; peer-reviewed by AM Auvinen, B Nickel; comments to author 17.07.23; revised version received 21.08.23; accepted 19.09.23; published 14.11.23.

Please cite as:
Morena N, Ahisar Y, Wang X, Nguyen D, Rentschler CA, Meguerditchian AN
Content Quality of YouTube Videos About Metastatic Breast Cancer in Young Women: Systematic Assessment
JMIR Cancer 2023;9:e45101
URL: https://cancer.jmir.org/2023/1/e45101
doi:10.2196/45101
PMID:37737837

Original Paper

Noninvasive Staging of Lymph Node Status in Breast Cancer Using Machine Learning: External Validation and Further Model Development

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Abstract

Background: Most patients diagnosed with breast cancer present with a node-negative disease. Sentinel lymph node biopsy (SLNB) is routinely used for axillary staging, leaving patients with healthy axillary lymph nodes without therapeutic effects but at risk of morbidities from the intervention. Numerous studies have developed nodal status prediction models for noninvasive axillary staging using postoperative data or imaging features that are not part of the diagnostic workup. Lymphovascular invasion (LVI) is a top-ranked predictor of nodal metastasis; however, its preoperative assessment is challenging.

Objective: This paper aimed to externally validate a multilayer perceptron (MLP) model for noninvasive lymph node staging (NILS) in a large population-based cohort (n=18,633) and develop a new MLP in the same cohort. Data were extracted from the Swedish National Quality Register for Breast Cancer (NKBC, 2014-2017), comprising only routinely and preoperatively available documented clinicopathological variables. A secondary aim was to develop and validate an LVI MLP for imputation of missing LVI status to increase the preoperative feasibility of the original NILS model.

Methods: Three nonoverlapping cohorts were used for model development and validation. A total of 4 MLPs for nodal status and 1 LVI MLP were developed using 11 to 12 routinely available predictors. Three nodal status models were used to account for the different availabilities of LVI status in the cohorts and external validation in NKBC. The fourth nodal status model was developed for 80% (14,906/18,663) of NKBC cases and validated in the remaining 20% (3727/18,663). Three alternatives for imputation of LVI status were compared. The discriminatory capacity was evaluated using the validation area under the receiver operating characteristics curve (AUC) in 3 of the nodal status models. The clinical feasibility of the models was evaluated using calibration and decision curve analyses.

Results: External validation of the original NILS model was performed in NKBC (AUC 0.699, 95% CI 0.690-0.708) with good calibration and the potential of sparing 16% of patients with node-negative disease from SLNB. The LVI model was externally validated (AUC 0.747, 95% CI 0.694-0.799) with good calibration but did not improve the discriminatory performance of the nodal status models. A new nodal status model was developed in NKBC without information on LVI (AUC 0.709, 95% CI: 0.688-0.729), with excellent calibration in the holdout internal validation cohort, resulting in the potential omission of 24% of patients from unnecessary SLNBs.

Conclusions: The NILS model was externally validated in NKBC, where the imputation of LVI status did not improve the model’s discriminatory performance. A new nodal status model demonstrated the feasibility of using register data comprising only the variables available in the preoperative setting for NILS using machine learning. Future steps include ongoing preoperative validation of the NILS model and extending the model with, for example, mammography images.

(JMIR Cancer 2023;9:e46474) doi:10.2196/46474

KEYWORDS

breast neoplasm; sentinel lymph node biopsy; SLNB; noninvasive lymph node staging; NILS; prediction model; multilayer perceptron; MLP; register data; breast cancer; cancer; validation study; machine learning; model development; therapeutic; feasibility; diagnostic; lymph node; mammography images

Introduction

Breast cancer is the most frequently diagnosed cancer worldwide. Despite its generally favorable prognosis [1], the focus on the quality of life for affected patients is becoming increasingly important. For the last 2 decades, sentinel lymph node biopsy (SLNB) has been the standard surgical procedure for evaluating axillary status in patients with breast cancer and clinically node-negative (cN0) status [2]. The SLNB procedure causes less postoperative morbidity than axillary lymph node dissection; however, it is still associated with lymphedema, arm pain and numbness, and reduced quality of life [3]. Furthermore, in 70% to 80% of cases [4], SLNB will prove negative, without cancer cells in the sentinel lymph nodes, and surgical axillary intervention will have no therapeutic benefit.

Multiple recent studies have presented prediction models for noninvasive staging of axillary nodal (N) status with the long-term aim of replacing SLNB for subgroups of patients with breast cancer [5-17]. Only routinely and preoperatively available data should be used for a feasible noninvasive diagnosis of axillary N status aimed at clinical implementation. A limitation of the published models is that they include postoperative variables from surgical specimens, including pathological tumor size [10,14], estrogen receptor (ER) status [5,7,13,16], progesterone receptor (PR) status [5,7], human epidermal growth factor receptor 2 (HER2) status [5,7,10,16], proliferation index Ki67 value [5,7,13], Nottingham histological grade (NHG) [5,7,8,12], histological type [5,7,8,12], and lymphovascular invasion (LVI) [6,7,11].

ER, PR, HER2, and Ki67 showed moderate to very good concordance between core needle biopsy (CNB) and surgical specimens [18]. Therefore, these variables have potential as preoperative predictors of lymph node status. Similarly, NHG and histological type showed concordance rates of >70% [19] and >80% [20], respectively, for the same comparison. However, LVI is challenging to evaluate on preoperative CNB because of the limited amount of tissue sample, and a high failure rate of 30% has been reported [21]. Along with tumor size, LVI status is the most important clinicopathological predictor of N status [22]. Although preoperative evaluation of LVI remains a challenge, an accurate preoperative assessment of LVI is needed to predict the N status.

Imaging of the breast and axilla can be used to assess preoperative tumor size and extract other features related to the N status. Standard imaging modalities in the diagnostic workup of breast cancer are mammography and ultrasound (US) of the breast and axilla; therefore, data from these imaging modalities can be obtained routinely. Several models have been developed using US features [5,10,11,16,17]. However, US is operator dependent; therefore, it is not reproducible, limiting its utility in prediction models. In addition, prediction models using other imaging modalities or combinations, such as US and magnetic resonance imaging (MRI) [9], positron emission tomography combined with US [13], MRI [14], contrast-enhanced spectral mammography (CESM) [15], and US combined with computed tomography [16], lack clinical feasibility.

Nomograms have been developed based on postoperative, nonimaging, and pathological data. Li et al [8] showed an internal validation area under the receiver operating characteristic curve (AUC) of 0.718 (95% CI 0.714-0.723) when predicting lymph node metastasis including tumor size, NHG, and histological type. The discriminatory performance of the Memorial Sloan-Kettering Cancer Center nomogram [22] for the prediction of sentinel lymph node metastasis, developed based on 3786 patients, decreased significantly from an AUC of 0.75 in the internal validation to an AUC of 0.67 (95% CI 0.63-0.72) when externally validated in a Dutch population (n=770) [23]. Furthermore, the Skåne University Hospital nomogram [6], a logistic regression model based on 800 patients in Lund, Sweden, aiming to predict negative sentinel lymph nodes, had an internal validation AUC of 0.74 (95% CI 0.70-0.79). The nomogram was temporally (n=1318) and geographically (n=1621) externally validated with an AUC of 0.75 (95% CI 0.70–0.81) and an AUC of 0.73 (95% CI 0.70–0.76), respectively [24].

In 2019, Dihge et al [7] predicted axillary N status in patients with cN0 breast cancer using a multilayer perceptron (MLP) model for noninvasive lymph node staging (NILS) based on 15 clinical and postoperative pathological predictors. The NILS concept includes logistic regression and machine learning models for noninvasive staging of the axilla, aiming at a web interface implementation to be used in clinical practice. Similar to previous N prediction models, pathological tumor size and LVI were the top-ranked predictors in the original (MLP) NILS model [7]. Training and internal cross-validation were performed on the same 800 patients as in the study by Dihge et al [6] and provided a prediction of the disease-free axilla. In addition, the possible clinical benefit of using the model to identify patients who were least likely to benefit from SLNB was assessed. Surgical axillary lymph node staging could have been avoided in 27% of patients, given a false-negative rate (FNR) of 10%, corresponding to the accepted FNR for SLNB [25]. Although the benefit of replacing logistic regression with machine learning in clinical prediction models is not specified [26], the MLP model outperformed the multivariable logistic regression model, given its discriminatory performance.

This study primarily aimed to externally validate the original NILS model presented in 2019 [7] and develop a new N model in a large population-based cohort of routinely collected data from the Swedish National Quality Registry for Breast Cancer (NKBC). In addition, it secondarily aimed to develop an LVI model and assess how the overall predictive performance of the N model was affected by applying the LVI model for missing values. To the best of our knowledge, this is the first LVI model to be incorporated into an N model. This study was conducted in accordance with the Transparent Reporting of a multivariate prediction model of Individual Prognosis Or Diagnosis (TRIPOD) to develop and validate prediction models [27].

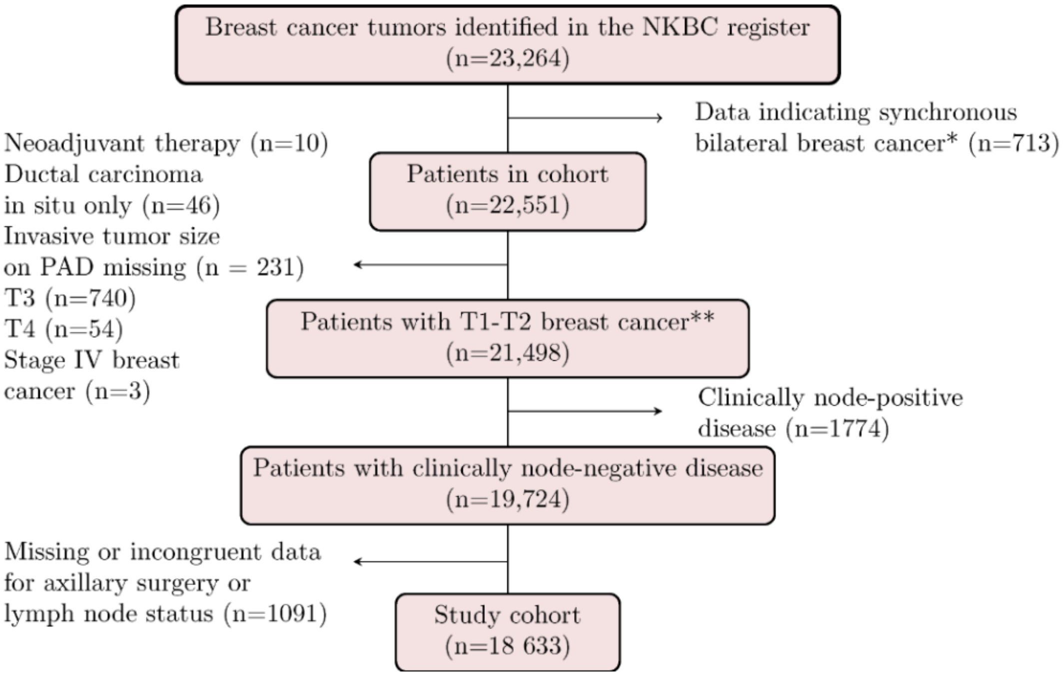
Methods

Study Population

Three data sets with nonoverlapping populations were used for model development and evaluation. The inclusion criteria for all 3 cohorts were female patients with invasive primary breast cancer and cN0 axilla scheduled for primary surgical treatment, with excision of the breast tumor by total mastectomy or partial mastectomy and axillary staging by SLNB. In addition, the exclusion criteria for the 3 cohorts were male sex, previous ipsilateral breast or axillary surgery, bilateral cancer, previous neoadjuvant therapy, ductal carcinoma in situ only, missing pathological-anatomical diagnosis tumor size, tumor size >50 mm, a tumor growing into the chest wall or skin, metastatic disease (stage 4 breast cancer), patients with clinically node-positive disease, and missing or incongruent data for axillary surgery or lymph node status.

The 3 data sets originated from different periods. Data set 1 (n=995) comprised consecutive patients diagnosed with primary breast cancer at Skåne University Hospital Lund, Sweden, between January 2009 and December 2012. Data were extracted from the medical records and pathology reports, with a final cohort size of 761 (Multimedia Appendix 1). For data set 1, a quality assessment scheme was used to ensure accurate histopathological reporting and internal quality control of the retrieved data from the medical records. Data set 2 (n=23,264) was a large population-based cohort of a breast cancer registry for external validation and development of a new N model. It consisted of patients with primary breast cancer from all breast cancer treatment units in Sweden included in the NKBC registry from 2014 to 2017, with a final cohort size of n=18,633 (Figure 1). Löfgren et al [28] examined the data quality of NKBC in 2019 and reported high validity and coverage of 99.9% between 2010 and 2014. Data set 3 (n=598) comprised consecutive patients with primary breast cancer surgically treated in Malmö or Helsingborg, Sweden, between 2019 and 2020, respectively. Data were, similar to those of data set 1, extracted from medical records and pathology reports. The final cohort size was 525 patients (Multimedia Appendix 2). The data extraction for cohort III was validated and monitored by an independent researcher according to a specific quality assurance protocol [29]. The sample size calculation for validating the NILS concept has been published previously [29].

Figure 1. Patient selection for cohort II. *Including records with the same information on age, mode of detection, hospital, and date of diagnosis but with different laterality. **Note that 31 patients were excluded by 2 of the 6 criteria in this step. NKBC: Swedish National Quality Register for Breast Cancer; PAD: pathological-anatomical diagnosis.



Outcomes

The following 2 outcomes were assessed: pathological N status (node-negative [N0] vs node-positive [N+] disease) and pathological LVI status (LVI-positive vs LVI-negative disease). Lymph node involvement was defined as metastatic infiltration of >0.2 mm in the lymph nodes; therefore, patients with only N micrometastasis were included in the study and categorized as N+. LVI positivity was defined as the presence of tumor cells within endothelium-lined lymphatic channels or blood vascular vessels [30]. A board-certified specialist in clinical pathology assessed both outcomes on surgical breast specimens according to the national guidelines for pathology [30].

Data Availability and Preprocessing

The original NILS model [7] included the following variables available preoperatively: age at diagnosis, BMI, tumor laterality, mode of detection (mammographic screening or symptomatic presentation), menopausal status, tumor localization (centrally or 1 to 12 o'clock position), and variables assessed on surgical breast specimens (ie, largest pathological tumor size, tumor multifocality assessed by pathology, histological type, NHG, LVI status, ER status, PR status, HER2 status, and Ki67 labeling index). The inclusion of tumor characteristics and lymph node status in the contralateral breast and axilla violated the assumption of independent samples, and patients with bilateral tumors were excluded (Figure 1). Although the information on LVI status was missing in cohort II, a separate prediction model for LVI status was developed in cohort I because of its importance in predicting N status [7,22]. All variables were defined and preprocessed as described by Dihge et al [7], except for the histological type. In cohorts I and II, the histological type was categorized into the following 3 groups: no special type, lobular, and other or mixed. In cohort III, data on other or mixed histological type were regrouped, and the mixed histological type was set as missing.

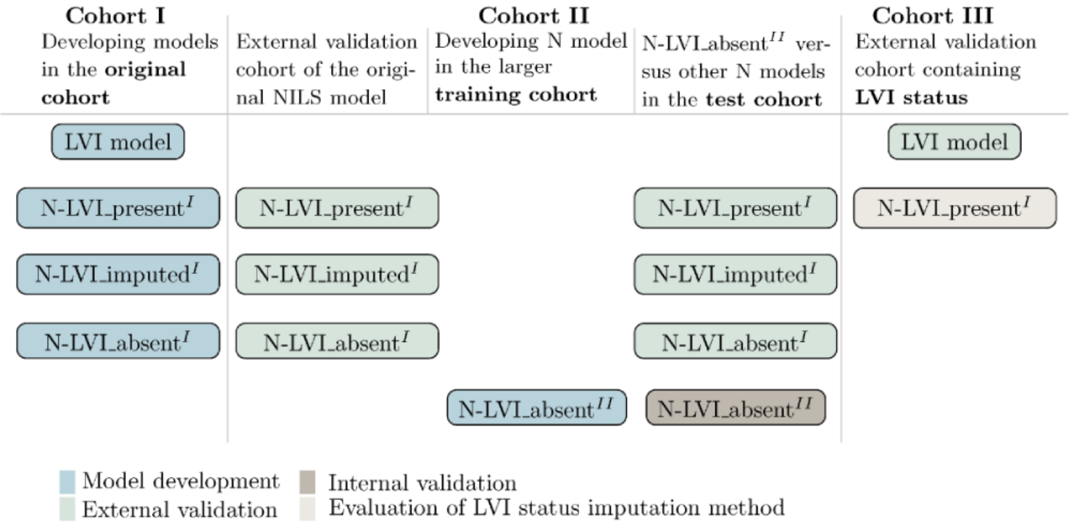
Study Design

This was an observational diagnostic study. Because of the absence of information on LVI status in cohort II, a total of 3 N models trained in cohort I (N-LVI_present^{I}, N-LVI_imputed^{I}, and N-LVI_absent^{I}; Figure 2) were developed to externally validate the original NILS model [7]. Each of the 3 models had different access to values for the LVI status. When applicable, missing data on the LVI status were imputed using an LVI model (LVI model in Figure 2). The model N-LVI_present^{I} was developed using only patients with a documented LVI status (613/761, 80.6% patients in cohort I). For the model N-LVI_imputed^{I}, patients with missing values for LVI status (148/761, 19.4% patients) had these predicted using the LVI model, and the model was trained on all 761 patients in cohort I. The model N-LVI_absent^{I} was developed without access to LVI status in all 761 patients in cohort I. The LVI model was developed based on 613 patients in cohort I with a documented LVI status.

The 3 available cohorts enabled us to externally validate the original NILS model [7] and investigate the effect of imputed LVI status values on N model predictions. Imputations by the LVI model were further evaluated in the model N-LVI_present^{I} (refer to the LVI Model Evaluation section). The considerably larger size of cohort II also enabled the development of a new N model (N-LVI_absent^{II}; Figure 2) in a large population-based cohort.

Cohort II was categorized into a training and a test data set of 80%/20% (14,906/3727) stratified by N status to compare the performance of the model N-LVI_absent^{II} with that of N models N-LVI_present^{I}, N-LVI_imputed^{I}, and N-LVI_absent^{I}. The model N-LVI_absent^{II} was developed using the training data set whereas the test data set was set aside for comparison with the other developed N models.

Figure 2. Models developed and evaluated in the study. Three nodal (N) models were developed to account for the lack of data on lymphovascular invasion (LVI) status in cohort II. The external validation was made in cohort II (Swedish National Quality Register for Breast Cancer; n=18,633). A new N model was developed in the training cohort (n=14,906) of cohort II, and its performance was compared with that of the 3 other N models in the test cohort (n=3727) of cohort II. An LVI model was developed to predict the LVI status for patients without documented LVI status in cohort I, and the LVI model was externally validated in cohort III. In addition, different alternatives for LVI imputation were tested in the model N-LVI_present^{I} in cohort III.



Model Development and Selection

The process of training the LVI model and the 4 N models was similar to that by Dihge et al [7] but with minor modifications owing to different access to data, as presented in the Study Population section, an ensemble MLP was developed for each examined hyperparameter combination, and every network in the ensemble was trained using 5-fold cross-validation, stratified by the outcome distribution. The mean validation AUC of each ensemble was compared to identify the hyperparameter combination that yielded the highest validation AUC value. One difference from the original model development was the use of random search instead of grid search, where each learning algorithm was assigned randomly selected hyperparameters, given a range of values. This hyperparameter optimization method is more efficient than iterating over all possible hyperparameter combinations [31].

Missing Data

The 3 cohorts had between 1% and 2% missing values and 72% to 90% complete-case patients (Multimedia Appendices 3-5). Missing LVI status was assumed to be missing at random conditional on the other predictors, and other values were assumed to be missing completely at random. In the original NILS model, missing data were handled using multiple random imputation. In this study, missing data were imputed either by multiple random imputation or by the LVI model. Although the methodology used to develop the LVI model can be applied to other variables with missing data, it was decided to be relevant only for LVI because of its importance for the N prediction models.

All cases with missing LVI status values were predicted using the LVI model. During the development of the model N-LVI_imputed^{I}, the LVI model was used to predict the LVI status of 148 patients lacking information on LVI status in cohort I at the beginning of each fold in the 5-fold cross-validation. For each training epoch, the LVI status was set to positive or negative, given the probability of the prediction. Missing values among other variables were imputed using multiple random imputation, where a missing value was randomly replaced by a value in the present data distribution for the corresponding variable. This procedure was repeated at the beginning of each training epoch.

LVI Model Evaluation

To evaluate the LVI model developed in cohort I, a total of 3 types of imputations of LVI status were compared with the original values for LVI status in cohort III. The comparison was made using the N status predicted by the N-LVI_present^{I} model. Subsequently, the three types of imputation were (1) the probability predicted using the LVI model; (2) the corresponding category (LVI positive or LVI negative) given the probability of the prediction; and (3) the corresponding category of the prediction given a cutoff of 0.3, matching the distribution of the LVI predictions in the internal cross-validation with that of the development cohort.

The imputation option yielding the highest validation AUC for N status, calculated as the mean of the N-LVI_present^{I} model's predictions over 25 imputed data sets, was chosen for the imputation of the LVI status in cohort II. Calibration curves of the observed versus mean predicted probabilities were used to visualize the LVI model calibration.

N Model Evaluation

The N model validation AUC was calculated as the mean of the AUCs over 25 data sets imputed for missing values, and the LVI status was imputed by the LVI prediction model for each data set when applicable. In addition, a secondary outcome for the N models was the proportion of patients that could be omitted from SLNB while maintaining the FNR at 10% (the generally accepted FNR of SLNB [25]). The successful criteria for developing an N model to identify potential candidates for omitting SLNB in every fifth patient with cN0 breast cancer were established in advance.

Model predictions were recalibrated to the prevalence in the external validation cohort to account for the different N status distributions of cohorts I and II [32]. In addition, calibration curves of the observed versus mean predicted probabilities were used to visualize the model calibration. Finally, decision curves [33] were analyzed to examine the standardized clinical benefit [34] of the N models, where the threshold probabilities were set to the range of the acceptable level for the FNR (0%-10%).

Software and Hardware

All parts of the study were conducted using Python (version 3.9.7; Python Software Foundation) [35] and TensorFlow (version 2.6.0; Google Brain Team) [36], with a computer equipped with an Intel Core i7-8700K CPU at 3.70 GHz and 2 GeForce RTX 2080 GPUs.

Ethical Considerations

The Regional Ethics Committee at Lund University, Sweden, approved cohort I for the study (LU 2013/340), and ethics approval was obtained for the use of an opt-out methodology. Cohorts II and III received approval from the Swedish Ethical Review Authority under reference numbers 2019-02139 and 2021-00174, respectively, for the study. Written informed consent for participation was not required for this noninterventional study in accordance with the national legislation and institutional requirements. All patients included in the study were given the option to opt out. The data sets generated and analyzed from anonymized data were separated from personal identifiers. Data are not publicly available because of privacy and ethical restrictions, and information is not made available or disclosed to unauthorized individuals, entities, or processes.

Results

Study Population and Data Availability

Access to variables differed between the large population-based register (cohort II; Table 1) and the data obtained from medical records in cohorts I and III (Multimedia Appendices 6 and 7, respectively). BMI and tumor localization data were not routinely registered in the NKBC, and these 2 variables were excluded.

Table 1. Patient and tumor characteristics for cohort II (n=18,633).

	All patients	Node negative (n=14,829)	Node positive (n=3804)
Age (years), median (range)	65 (22-95)	65 (22-95)	63 (23-94)
Menopausal status, n (%)			
Premenopausal	3336 (19)	2515 (18.04)	821 (22.9)
Postmenopausal	14,224 (81)	11,457 (81.96)	2767 (77.12)
Missing[a]	1073 (5.76)	857 (5.8)	216 (5.7)
Mode of detection, n (%)			
Mammographic screening	10,816 (58.17)	8992 (60.78)	1824 (48.01)
Symptomatic presentation	7777 (41.83)	5802 (39.22)	1975 (51.99)
Missing	40 (0)	35 (0)	5 (0)
Tumor size (mm), median (range)	15 (1-50)	14 (1-50)	19 (1-50)
Multifocality, n (%)			
Absent	15,537 (83.54)	12,730 (85.98)	2807 (74)
Present	3061 (16.46)	2075 (14.02)	986 (26)
Missing	35 (0)	24 (0)	11 (0)
Histological type, n (%)			
No special type	14,322 (76.86)	11,325 (76.37)	2997 (78.79)
Lobular	2387 (12.81)	1862 (12.56)	525 (13.8)
Other invasive, including mixed types	1924 (10.33)	1642 (11.07)	282 (7.4)
Nottingham histological grade, n (%)			
1	4112 (22.32)	3600 (24.57)	512 (13.6)
2	9672 (52.49)	7595 (51.83)	2077 (55.03)
3	4643 (25.2)	3458 (23.6)	1185 (31.4)
Missing	206 (1.1)	176 (1.2)	30 (1)
Estrogen receptor status, n (%)			
Negative (<1%)	1490 (8.32)	1199 (8.41)	291 (7.9)
Positive (≥1%)	16,423 (91.68)	13,053 (91.59)	3370 (92.05)
Missing	720 (3.9)	577 (3.9)	143 (3.8)
Progesterone receptor status, n (%)			
Negative (<1%)	2672 (15.14)	2182 (15.56)	490 (13.5)
Positive (≥1%)	14,973 (84.86)	11,839 (84.44)	3134 (86.48)
Missing	988 (5.3)	808 (5.4)	180 (4.7)
Human epidermal growth factor receptor 2 status, n (%)			
Negative	16,288 (88.67)	12,989 (88.87)	3299 (87.88)
Positive	2082 (11.33)	1627 (11.13)	455 (12.1)
Missing	263 (1.4)	213 (1.4)	50 (1)
Ki67 (%)			
Values, median (range)	20 (0-100)	20 (0-100)	24 (1-100)
Missing, n (%)	133 (0.7)	123 (0.8)	10 (0)

[a] The number of missing values is shown for noncomplete case variables.

LVI and N Model Evaluation

Training and Validation of the LVI Model

The LVI model was trained on 613 patients in cohort I and evaluated in the validation part of cohort III (n=525; Figure 2; Multimedia Appendix 7). The model had an internal cross-validation AUC of 0.799 (95% CI 0.751-0.846) and an external validation AUC of 0.747 (95% CI 0.694-0.799; Figure 3). In addition, the LVI model showed good calibration in external validation (Multimedia Appendix 8). The final architecture for the LVI and N models can be found in Multimedia Appendix 9.

All alternatives for LVI imputation were evaluated in cohort III using the N model N-LVI_present[I]. The model N-LVI_present[I] imputed with probabilistically drawn categorical values of LVI status performed slightly better than the other options (Table 2); therefore, this type of LVI imputation was subsequently used.

Figure 3. ROC curve for the LVI model. The lymphovascular invasion model had a discriminatory performance area under the receiver operating characteristic curve (AUC) of 0.799 (95% CI 0.751-0.864) in the internal validation and an AUC of 0.747 (95% CI 0.694-0.799) in the external validation. ROC: receiver operating characteristic.

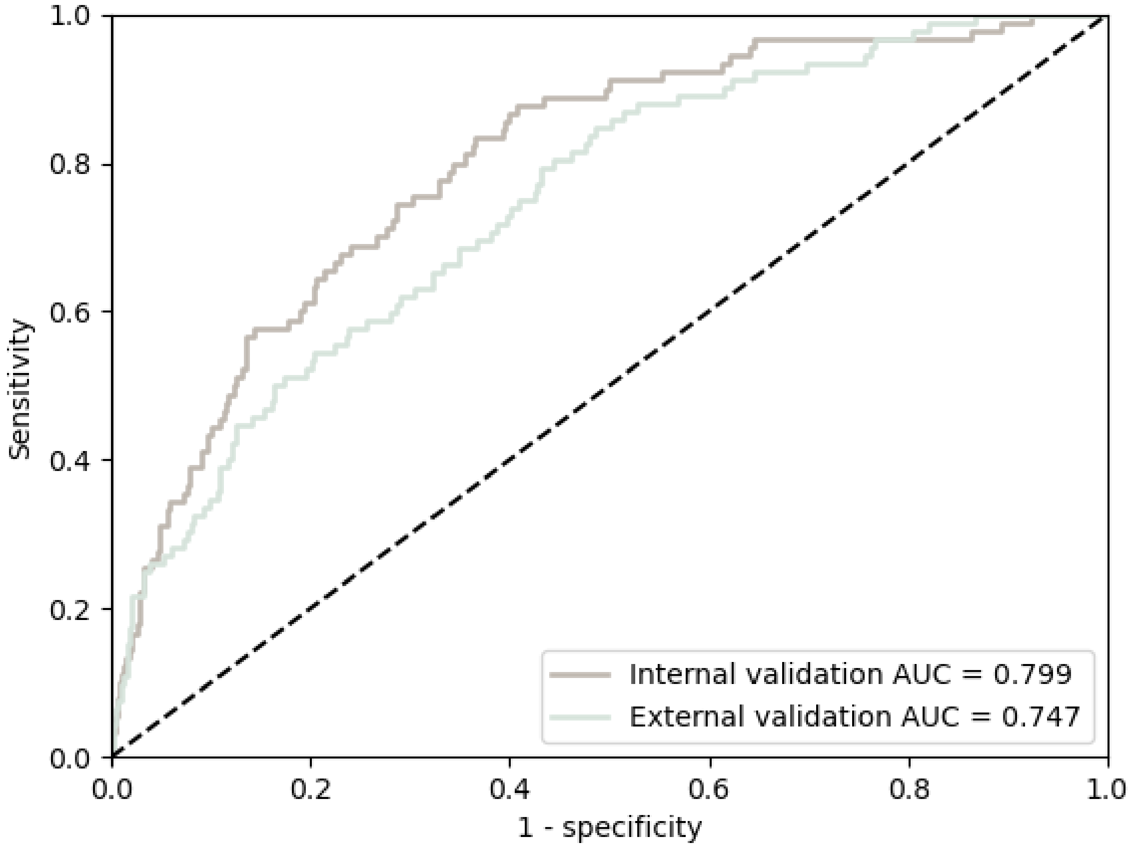


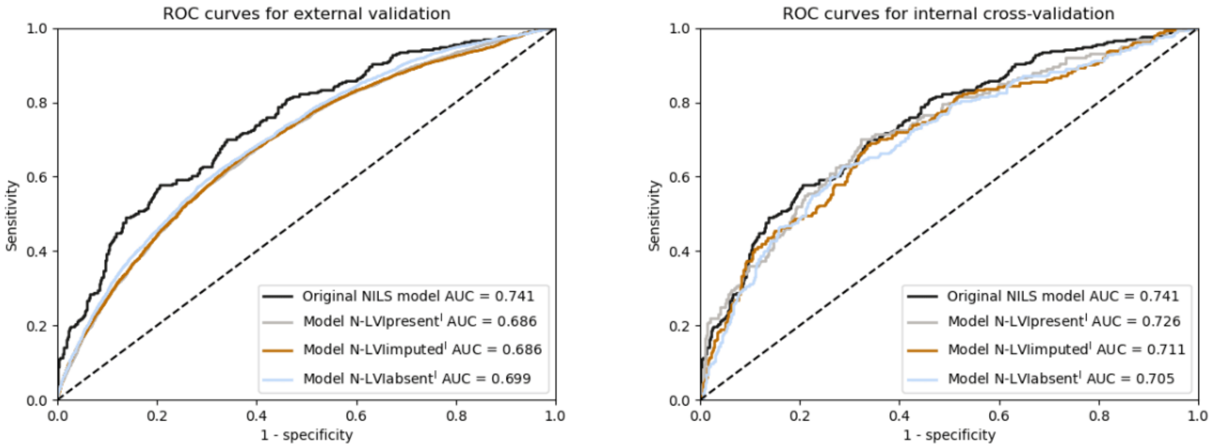
Table 2. Area under the receiver operating characteristic curve (AUC) for the nodal status predictions of the model N-LVI_present[I] for different strategies for imputing values of lymphovascular invasion (LVI) status. The highest AUC, except when using the original LVI values, was obtained when imputing LVI status using the probabilistic imputation, this is why we chose to use this method for LVI imputation in the subsequent analysis.

	Original LVI status	LVI status imputed by the predicted probability	LVI status imputed by probabilistically categorical imputation	LVI status imputed by categorical imputation with threshold 0.3
N-LVI_present[I], AUC (95% CI)	0.750 (0.704-0.795)	0.737 (0.689-0.783)	0.740 (0.693-0.784)	0.738 (0.691-0.783)

External Validation of the Original NILS Model

To externally validate the original NILS model in cohort II without information on the LVI status, 3 N models (N-LVI_present[I], N-LVI_imputed[I], and N-LVI_absent[I]) were developed for cohort I (n=761), as shown in Figure 2. The original NILS model was internally cross-validated, with an AUC of 0.740 (95% CI 0.723-0.758) [7]. In the external validation in cohort II (n=18,633), both the N-LVIpresent[I] and N-LVIimputed[I] models reached an AUC of 0.686 (95% CI 0.677-0.695; Figure 4, left [7]). Furthermore, upon validation, the model N-LVIabsent[I] reached an AUC of 0.699 (95% CI 0.690-0.708). The classification performance of all N models is summarized in Multimedia Appendix 10.

Figure 4. The receiver operating characteristic (ROC) curve for the external validation (left) and the internal validation (right) of the original noninvasive lymph node staging (NILS) model in the study by Dihge et al [7]. The models of this study had access to slightly different variables and a different number of patients in the training cohort than that of the original NILS model. The models N-LVI_present^{I} and N-LVI_imputedI both included LVI status, whereas N-LVI_absentI did not. Note that the original model was cross-validated with area under the receiver operating characteristic curve (AUC) 0.740 in the study by Dihge et al [7], which was an average of 5 runs. The ROC curve of the original NILS model is in this figure represented by the run closest to the mean; AUC 0.741.



The Impact of the LVI Model on the Overall N Status Predictions

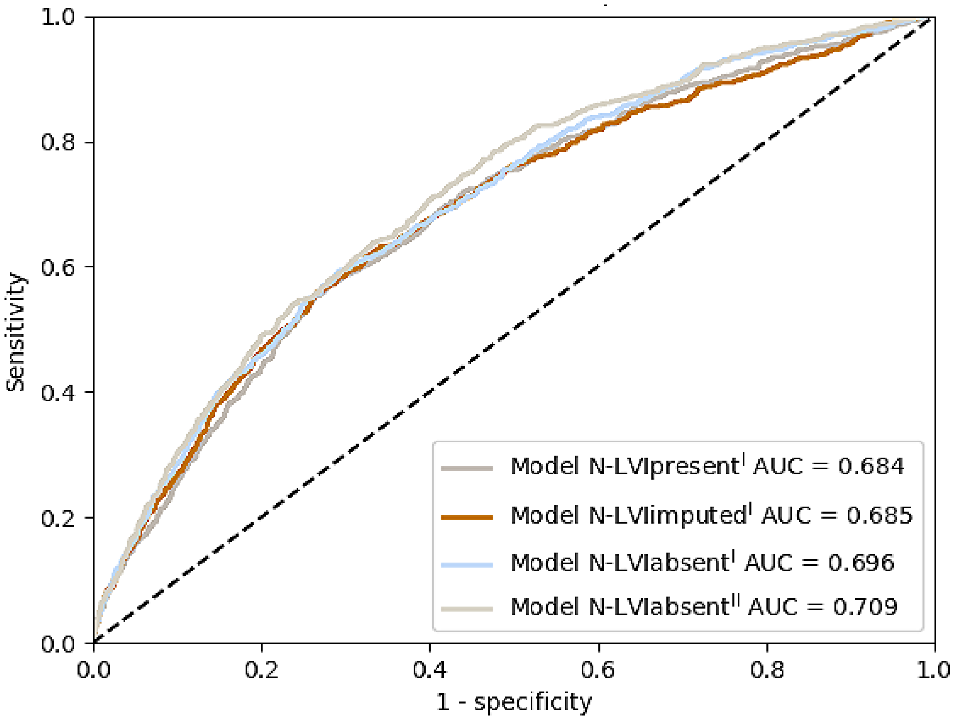
The internal validation of the N models showed a higher performance for models N-LVI_present^{I} and N-LVI_imputed^{I} using LVI status (AUC 0.726, 95% CI 0.681-0.768 and AUC 0.711, 95% CI 0.762-0.750, respectively), compared with that of model N-LVI_absent^{I} not including the LVI status (AUC 0.705, 95% CI 0.665-0.744; Figure 4, right). For external evaluation of the models N-LVI_present^{I} and N-LVI_imputed^{I}, the LVI model was used to predict the LVI status in cohort II.

When externally validated in cohort II (n=18,633), the models N-LVI_present^{I}, N-LVI_imputed^{I}, and N-LVI_absent^{I} showed similar performances (Figure 4, left). Therefore, the rest of the external validation focused on the model developed without access to the LVI status, N-LVI_absent^{I}. In the calibration plot, the model N-LVI_absent^{I} demonstrated slightly lower predictions than the true values in the external validation (Multimedia Appendix 11). However, when transforming the predictions in relation to the prevalence of N0 in the validation cohort, the calibration of the model N-LVI_absent^{I} was satisfactory.

Comparison Between Developed N Models

The fourth N status model, N-LVI_absent^{II}, was developed in NKBC, a large population-based cohort. The cohort was considerably larger (training cohort: 14,906/18,663, 80%) than the development cohort for the other 3 N models and the original NILS model [7] (cohort I). The test cohort of cohort II (3727/18,663, 20%), set aside before the development of model N-LVI_absent^{II}, was used to compare the performance of the developed N models. The models N-LVI_present^{I}, N-LVI_imputed^{I}, and N-LVI_absent^{I} reached AUC of 0.684 (95% CI 0.663-0.705), 0.685 (95% CI 0.663-0.706), and 0.696 (95% CI 0.676-0.717), respectively (Figure 5). The model N-LVI_absent^{II} reached a slightly higher AUC of 0.709 (95% CI 0.688-0.729). The calibration plot for the model N-LVI_absent^{II} is shown in Multimedia Appendix 12.

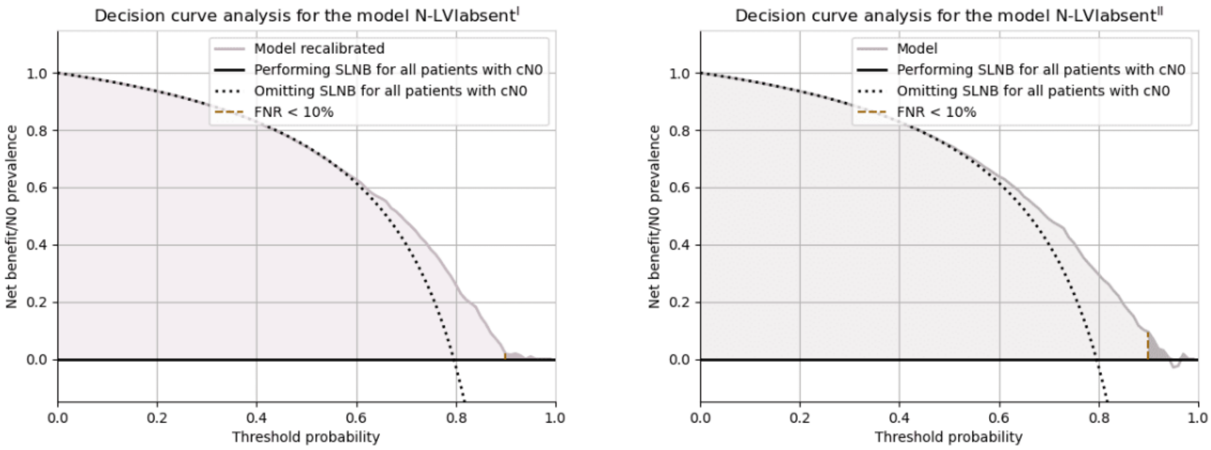
Figure 5. ROC curves for the developed N models. Validation in the test cohort (n=3727) of cohort II for the nodal (N) models N-LVI_present^{I}, N-LVI_imputed^{I}, N-LVI_absent^{I}, and the new N model N-LVI_absent^{II} developed in a larger cohort. AUC: area under the receiver operating characteristic curve; ROC: receiver operating characteristic.



Assessments of Potential Clinical Utility of the N Models

External validation of the N models before recalibration showed potential in sparing approximately 20% of patients with cN0 breast cancer from axillary surgery when using an FNR of <10%. When recalibrating the predictions for the model N-LVI_absent^{I}, the number decreased to approximately 16%). However, the new N model N-LVI_absent^{II} developed in cohort II could potentially spare 24% of the patients with cN0 breast cancer from SLNB. The standardized decision curve analyses (Figure 6) specifically showed the range of predictions where patients could benefit from using the 2 prediction models. The standardized decision curve analysis for the original predictions of N-LVI_absent^{I} before recalibration is presented in Multimedia Appendix 13.

Figure 6. Decision curves showing the standardized net benefit of the model N-LVI_absent^{I} (recalibrated; left) and the model N-LVI_absent^{II} (right). The black horizontal line represents the scenario of all patients being diagnosed as node negative; hence, no sentinel lymph node biopsy (SLNB) is performed. The colored function represents the diagnosis by the model. The golden, vertical (dashed) line at a threshold of approximately 0.9, separating the lighter color from the darker, shows the threshold for false-negative rate (FNR) <10%. When all patients are considered node positive and diagnosed through SLNB, the standardized net benefit is, by definition, 0. Notably, the darker, colored area does not represent the patients spared from surgery. Rather, it displays the standardized net benefit of the model where FNR<10%. cN0: clinically node negative.



Discussion

Principal Findings

The proportion of patients diagnosed with early-stage breast cancer is increasing [4]. Along with improvements in adjuvant therapy, surgical treatment is becoming more conservative. Most patients with early-stage breast cancer have benign lymph nodes and would benefit from preoperative noninvasive staging of the axilla [3,4]. In this study, we externally validated a previously published N model [7] in a national, large, population-based register cohort (n=18,633) without access to the LVI status and developed a new N model within the same cohort. Notably, the discriminatory performance (AUC 0.709, 95% CI 0.688-0.729) of the new N model (N-LVI_absent^{II}) developed in the large population-based cohort demonstrated that routine clinicopathological register data can be used to develop an N model to identify 24% of patients with cN0 for whom surgical axillary staging could be circumvented. The model developed in cohort I without access to data on LVI status (N-LVI_absent^{I}) achieved an AUC of 0.699 (95% CI 0.690-0.708) and the potential to omit 16% of patients Malfrom SLNB. The use of fewer variables and, in some cases, fewer patients was expected to result in a slight decrease in the performance of the models in this study compared with that of the original model. The study is conducted in accordance with the TRIPOD statement as displayed in Multimedia Appendix 14.

Comparison With Prior Studies

Multiple studies have investigated the discriminatory performance of nomograms in predicting the N status using retrospective clinicopathological data alone or in combination with imaging features [6,8-17]. We aimed to externally validate and further develop a diagnostic tool for the noninvasive staging of N status using only routinely available clinicopathological data that can be captured in the preoperative setting to improve the clinical utility of the model. Li et al [8] and Gao et al [12] developed nomograms using solely clinicopathological data that can be obtained preoperatively. However, these studies did not specify whether the data were extracted from the preoperative or postoperative setting. Li et al [8] had the advantage of a very large cohort (n=184,532); unfortunately, combining external validation data with parts of the development cohort resulted in an inaccurate external validation (AUC 0.718). Gao et al [12] developed a nomogram based on 6314 patients with external validation on 503 patients, where the shift from training and internal validation to external validation increased from an AUC of 0.715 and 0.688 to an AUC of 0.876, respectively. This large discriminatory increase in external validation is unexpected and warrants questioning the validity of the model.

One possibility for the transition from postoperative to preoperative variables is the use of imaging features. Mao et al [15] developed a nomogram using CESM-reported lymph node status and a radiomics signature to predict axillary lymph node status. In addition, the nomogram was externally validated on only 62 patients with an AUC of 0.79 (95% CI 0.63-0.94). Using only features that can be obtained preoperatively is an advantage in the study by Mao et al [15]. However, additional larger external validation is required to confirm the results of the study. Furthermore, CESM is not part of the mammography screening program or routine workup for suspected breast malignancies, limiting the clinical feasibility of the study. Bove et al [5] developed a support vector machine (SVM) classifier for clinical data and a SVM for radiomics data to predict N status. They used soft voting, which combines the probabilities of each prediction in the 2 models. They chose the prediction with the highest total probability, which resulted in an AUC of 0.886 on the holdout test set. Combining pre- and postoperative variables is a limitation of the study, and the axillary US is an operator-dependent imaging modality. However, the results show the potential for using imaging features in machine learning models for the noninvasive staging of N status. The SVM classifier had an AUC of 0.739 using only postoperative clinicopathological data, similar to that of the original NILS model [7]. However, both the training (n=114) and test (n=28) data sets were small; therefore, a larger external validation is needed to confirm the results.

In this study, the LVI model, trained using only routine clinicopathological variables and developed to increase the feasibility of the NILS models in the preoperative setting, had an external validation AUC of 0.747 (95% CI 0.694-0.799). To the best of our knowledge, this is the first LVI model to be incorporated into an N model. Preoperative assessment of LVI on CNB is challenging, and several models have been developed to predict the LVI status. For example, Shen et al [37] developed a logistic regression model for the LVI status using clinicopathological variables (n=392). Although the model reached an AUC of 0.670 (95% CI 0.607-0.734) in the training data set, it was not validated further. In addition, others have investigated the importance of radiomics features for predicting LVI status, for example, digital mammography features [38] with LVI prediction specificity of 98.8% in the development cohort and MRI features [39] with an AUC of 0.732 in the test data set. However, while highlighting the potential for predicting LVI status using radiomics, the data used are not part of the diagnostic workup for breast cancer, thus limiting clinical feasibility.

Despite the AUC of 0.747 for the LVI model in this study, the imputation of values for the LVI status did not improve the discriminatory performance of the N models in the large population-based register cohort (NKBC). One problem with developing prediction models for the classification question at hand is the scarcity of larger cohorts including relevant clinicopathological data such as LVI as well as the lack of identified strong predictors of LVI. Those reported in the literature include tumor size, HER2 status, and Ki67 [37] and were included in the LVI model as well as in the N model, which might have hampered the signal to predict N status by imputing LVI. Novel approaches using image analysis seem to capture features with superior discriminatory capacity [38,39]. Moreover, the reliability and distribution of data, such as multifocality, may change in the preoperative setting [40], which could change the prerequisites for predicting LVI status. Given the growing evidence on the significance of LVI status as a predictor of axillary N status [7,11,22,41], further evaluation of the presented LVI model is warranted.

Potential Clinical Utility

Omitting SLNB in subgroups of patients is consistent with the American Society of Clinical Oncology guidelines from 2021 [2], stating that SLNB is optional for all patients aged ≥70 years with cN0, ER+, and HER2− if the patient received adjuvant endocrine therapy. In this study, using only routine clinicopathological data, the models developed without access to LVI status in cohort I (recalibrated) and cohort II presented the potential to spare 16% to 24% of patients with cN0 from SLNB, irrespective of age and tumor subtype. Providing clinicians and patients with a decision support tool enabling the identification of one quarter of patients as eligible for abstaining SLNB could enhance the adoption of the 2021 American Society of Clinical Oncology guidelines [2]. In addition, a health economic study concluded that the NILS model is cost-effective [42]. If lymphedema is considered to negatively affect patients' quality of life, the NILS model also showed a net health gain [42].

Strengths and Limitations

Criticism has been raised against the use of small sample sizes in the development and external validation of machine learning models in oncology as well as the poor handling of missing data [39]. Accordingly, we aimed to externally validate the original NILS model [7] in a nationwide and large population-based register cohort (n=18,633) and to develop a new NILS model within this larger cohort (14,906/18,633, 80%). Using a large population-based register cohort is advantageous in the following two ways: (1) its consecutive nature constitutes a good approximation of the true distributions of the population and (2) it demonstrates the reality of data handling where input data will comprise missing values and occasional mistakes in documentation. The limitations of using quality registry data are the risk of misclassification and missing data, which were handled by meticulous data curation and exclusion of patients without properly defined or missing variables (1091/23,264, 4.69%). Moreover, the register lacks information on race; hence, the generalizability to other populations outside Sweden has to be proven in external data sets. Importantly, our findings demonstrate that register data can be used to create an N model with results just as satisfactory as those obtained from more meticulously curated data, including the LVI status. Our external validation of the original NILS model [7] was performed in a temporally, geographically, and domain-wise different cohort from the original development cohort. We presented calibration and net benefit curves to demonstrate the utility of the models. In addition, the 1091 patients in cohort II with missing or incongruent data for axillary surgery and lymph node status (Figure 1) showed a similar distribution of clinical variables (data not shown) as the final study population of cohort II. Therefore, there was no indication of selection bias.

Another strength of our study is the thorough management of missing data using both the LVI model and multiple random imputation. Our comprehensive handling of missing values may increase the utility of N models in a clinical preoperative setting. It also showed that for the discriminatory performance in N staging, the manner in which the predictions of LVI status were presented to an N model was of minor importance. However, this requires further investigation in the preoperative setting and use of an LVI model with an even higher discriminatory performance to completely rule out the potential advantage of MLP LVI predictions in NILS.

However, this study had some limitations. First, the models were developed using a combination of variables available before and after surgery to externally validate the original NILS model [7], which is based on preoperative and postoperative variables. Further development of the NILS concept is an ongoing validation of the NILS model using exclusively preoperative variables [29]. Second, the generalizability of the LVI and N models developed in cohort I can be affected by the smaller size of the development cohorts, which can be considered a weakness of the study. Therefore, regularization of the networks and 5-fold cross-validation were used to minimize overfitting. The drop in performance from the internal to external validation was small for all models, which is a clear strength of our findings.

Recalibration was performed for the model developed without access to LVI status in cohort I (N-LVI_absent^I) because of the different prevalence of benign lymph nodes in cohorts I and II (497/761, 65.3% pathological benign nodal status [pN0] vs 14,829/18,633, 79.58% pN0). No recalibration was performed for the LVI model because the prevalence of a positive LVI status was similar in cohorts I and III. Notably, when transforming the N status predictions in relation to the new prevalence, the calibration and the overall net benefit of the model N-LVI_absent^I improved, whereas the fraction of patients to be spared from SLNB decreased. Therefore, to potentially increase the number of candidate patients to be omitted from SLNB, an important future development of the model could be to evaluate it using partial AUC [43] or concordant partial AUC [44]. The model selection is then based on the model's performance under specific conditions, for example, FNR of <10%, which could optimize the model performance for patients most likely to benefit from the prediction. Another option is to investigate the modification of the loss function when training the MLP to optimize the algorithm for the largest number of patients to be omitted from SLNB while maintaining the FNR of <10%.

An additional strength of this study was the use of 3 disjoint cohorts for model development and validation. After model development, 2 patients in cohort I were incorrectly classified as N0 instead of N+. However, these 2 patients corresponded to <1% of the cohort and did not affect the overall results. Cohort II demonstrated high validity and a high coverage of key variables [28]. An independent researcher validated and monitored cohort III according to a specific quality assurance protocol to ensure well-characterized data. All variables, except 1, were defined in coherence; the mixed histological type was categorized as missing in cohort III. However, this should have a limited effect on the results because mixed histological type is rare (approximately 5%) [45]. To avoid potential dependency and information leakage between the 2 tumors and N statuses, we excluded patients with bilateral tumors. The exclusion limits the target group to a minor extent, as bilateral cancers are generally diagnosed in <5% of patients [46].

Future Studies

Future steps include a prospective external validation of the NILS concept in a larger cohort and an evaluation of the incorporation of LVI predictions in a NILS model in the preoperative setting. External validation of the LVI model in a Norwegian breast cancer cohort is also planned. The feasibility of using register data for prediction modeling demonstrates the possibility of using larger and less-curated databases in machine learning models for NILS.

Implementing neural network models that are equal to or superior to linear models allows extending the model to more complex data that cannot be handled by logistic regression in end-to-end learning. This enables less human interference, simpler implementation, and models to optimize the entire task. Therefore, to potentially improve the discriminatory performance of noninvasive staging of lymph nodes for future clinical implementation, additional types of data conferring to the knowledge of lymphatic spread should ideally be investigated. Imaging features are both preoperatively available and have shown high discriminatory performance in N prediction models [5,9-11,13-15]. The possibility of incorporating mammography-based radiomics for the preoperative prediction of N status is intriguing. However, there are challenges in techniques to improve segmentation efficiency and reduce subjective inconsistency from manual segmentation for intratumoral and peritumoral feature extraction. In addition, molecular subtypes are associated with the outcome as well as N status, and the difficult-to-treat triple-negative subtype has the lowest risk of N metastasis compared with luminal tumors [6]. Consequently, models based on gene expression analysis have shown potential in correctly identifying patients with N0 status in specific subtypes of breast cancer, such as luminal A [47], ER+/HER2− [48], and triple-negative tumors [49], to capture additional aspects of lymphatic spread, such as immune signatures. Gene expression data have also shown the potential to increase the number of candidate patients to be omitted from SLNB when combined with clinicopathological data compared with predicting N status using clinicopathological data alone [50]. The added cost and effort of gene expression analysis should be considered in relation to avoiding SLNB. In contrast, gene expression–based assays, especially RNA sequencing, also have the potential to provide additional information through prognostic or predictive signatures. Therefore, planned extensions of the NILS model include mammography images and gene expression data, mainly focusing on molecular subtypes and immune signatures.

Conclusions

We externally validated the original NILS model [7] in a large population-based register cohort, with a discriminatory performance of 0.699 (95% CI 0.690-0.708). Prediction of LVI status did not improve the performance of the N model, despite its documented importance in the prediction of axillary stage. A new MLP model for predicting N status was developed in a large population-based register cohort, demonstrating the feasibility of developing a prediction model for noninvasive N staging using register data comprising only variables available in the preoperative setting and, notably, no information on LVI status (AUC 0.709, 95% CI 0.688-0.729). Therefore, future studies should evaluate the LVI model in the preoperative setting, the ongoing preoperative validation of the NILS concept, and extend the NILS model with preoperative and routinely available data such as mammography images and gene expression data.

Acknowledgments

IS and LD received funding from Governmental Funding of Clinical Research within the National Health Service. LR received funding from the Erling Persson Family Foundation (2018 and 2022), the Governmental Funding of Clinical Research within the National Health Service (2018/40304), the Swedish Cancer Society (2019/0388), the Swedish Research Council (2020/01491), and the Swedish Cancer and Allergy Fund. The funding sources had no role in the study design, analyses, data interpretation, writing of the manuscript, or the decision to submit the manuscript.

Data Availability

The raw data sets are available only upon reasonable request because of privacy and ethical restrictions. The data are not publicly available because of these restrictions. The code is available upon reasonable request.

Conflicts of Interest

None declared.

Authors' Contributions

Authors MH (malin.hjartstrom@med.lu.se) and LR (lisa.ryden@med.lu.se) are co-corresponding authors for this article.

Multimedia Appendix 1
Patient selection for cohort I.
[PDF File (Adobe PDF File), 198 KB - cancer_v9i1e46474_app1.pdf]

Multimedia Appendix 2
Patient selection for cohort III.
[PDF File (Adobe PDF File), 196 KB - cancer_v9i1e46474_app2.pdf]

Multimedia Appendix 3
Data characteristics of the development cohorts for nodal status models.
[PDF File (Adobe PDF File), 156 KB - cancer_v9i1e46474_app3.pdf]

Multimedia Appendix 4
Data characteristics of the validation cohorts for nodal status models.
[PDF File (Adobe PDF File), 153 KB - cancer_v9i1e46474_app4.pdf]

Multimedia Appendix 5
Data characteristics of the development and evaluation cohorts for the lymphovascular invasion status model.
[PDF File (Adobe PDF File), 153 KB - cancer_v9i1e46474_app5.pdf]

Multimedia Appendix 6
Patient and tumor characteristics in cohort I.
[PDF File (Adobe PDF File), 194 KB - cancer_v9i1e46474_app6.pdf]

Multimedia Appendix 7
Patient and tumor characteristics in cohort III.
[PDF File (Adobe PDF File), 194 KB - cancer_v9i1e46474_app7.pdf]

Multimedia Appendix 8
Calibration of the lymphovascular invasion model in cohort III.
[PDF File (Adobe PDF File), 167 KB - cancer_v9i1e46474_app8.pdf]

Multimedia Appendix 9
Model architecture of the lymphovascular invasion and nodal models.
[PDF File (Adobe PDF File), 157 KB - cancer_v9i1e46474_app9.pdf]

Multimedia Appendix 10
Sensitivity, specificity, and false-negative rate of nodal models.
[PDF File (Adobe PDF File), 162 KB - cancer_v9i1e46474_app10.pdf]

Multimedia Appendix 11
Calibration and recalibration of the nodal status model N-LVI_absent^{I} in the test cohort of cohort II.
[PDF File (Adobe PDF File), 171 KB - cancer_v9i1e46474_app11.pdf]

Multimedia Appendix 12
Calibration of the N status model N-LVI_absent^{II} in the test cohort of cohort II.
[PDF File (Adobe PDF File), 167 KB - cancer_v9i1e46474_app12.pdf]

Multimedia Appendix 13
Standardized decision curve analysis for the original predictions of the model N-LVI_absent^{I}.
[PDF File (Adobe PDF File), 183 KB - cancer_v9i1e46474_app13.pdf]

Multimedia Appendix 14
Transparent Reporting of a multivariate prediction model of Individual Prognosis Or Diagnosis (TRIPOD) checklist.
[PDF File (Adobe PDF File), 121 KB - cancer_v9i1e46474_app14.pdf]

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Abbreviations

AUC: area under the receiver operating characteristic curve
CESM: contrast-enhanced spectral mammography
cN0: clinically node-negative
CNB: core needle biopsy
ER: estrogen receptor
FNR: false-negative rate
HER2: human epidermal growth factor receptor 2
LVI: lymphovascular invasion
MLP: multilayer perceptron
MRI: magnetic resonance imaging
N: nodal
NHG: Nottingham histological grade
NILS: noninvasive lymph node staging
NKBC: Swedish National Quality Register for Breast Cancer
pN0: pathological benign nodal status
PR: progesterone receptor
SLNB: sentinel lymph node biopsy
SVM: support vector machine
TRIPOD: Transparent Reporting of a multivariate prediction model of Individual Prognosis Or Diagnosis
US: ultrasound

Edited by T de Azevedo Cardoso; submitted 15.02.23; peer-reviewed by D Surian, N Jiwani; comments to author 30.05.23; revised version received 05.09.23; accepted 11.09.23; published 20.11.23.

Please cite as:
Hjärtström M, Dihge L, Bendahl PO, Skarping I, Ellbrant J, Ohlsson M, Rydén L
Noninvasive Staging of Lymph Node Status in Breast Cancer Using Machine Learning: External Validation and Further Model Development
JMIR Cancer 2023;9:e46474
URL: https://cancer.jmir.org/2023/1/e46474
doi:10.2196/46474
PMID:37983068

Original Paper

Using Shopping Data to Improve the Diagnosis of Ovarian Cancer: Computational Analysis of a Web-Based Survey

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Abstract

Background: Shopping data can be analyzed using machine learning techniques to study population health. It is unknown if the use of such methods can successfully investigate prediagnosis purchases linked to self-medication of symptoms of ovarian cancer.

Objective: The aims of this study were to gain new domain knowledge from women's experiences, understand how women's shopping behavior relates to their pathway to the diagnosis of ovarian cancer, and inform research on computational analysis of shopping data for population health.

Methods: A web-based survey on individuals' shopping patterns prior to an ovarian cancer diagnosis was analyzed to identify key knowledge about health care purchases. Logistic regression and random forest models were employed to statistically examine how products linked to potential symptoms related to presentation to health care and timing of diagnosis.

Results: Of the 101 women surveyed with ovarian cancer, 58.4% (59/101) bought nonprescription health care products for up to more than a year prior to diagnosis, including pain relief and abdominal products. General practitioner advice was the primary reason for the purchases (23/59, 39%), with 51% (30/59) occurring due to a participant's doctor believing their health problems were due to a condition other than ovarian cancer. Associations were shown between purchases made because a participant's doctor believing their health problems were due to a condition other than ovarian cancer and the following variables: health problems for longer than a year prior to diagnosis (odds ratio [OR] 7.33, 95% CI 1.58-33.97), buying health care products for more than 6 months to a year (OR 3.82, 95% CI 1.04-13.98) or for more than a year (OR 7.64, 95% CI 1.38-42.33), and the number of health care product types purchased (OR 1.54, 95% CI 1.13-2.11). Purchasing patterns are shown to be potentially predictive of a participant's doctor thinking their health problems were due to some condition other than ovarian cancer, with nested cross-validation of random forest classification models achieving an overall in-sample accuracy score of 89.1% and an out-of-sample score of 70.1%.

Conclusions: Women in the survey were 7 times more likely to have had a duration of more than a year of health problems prior to a diagnosis of ovarian cancer if they were self-medicating based on advice from a doctor rather than having made the decision to self-medicate independently. Predictive modelling indicates that women in such situations, who are self-medicating because their doctor believes their health problems may be due to a condition other than ovarian cancer, exhibit distinct shopping behaviors that may be identifiable within purchasing data. Through exploratory research combining women sharing their behaviors prior to diagnosis and computational analysis of these data, this study demonstrates that women's shopping data could potentially be useful for early ovarian cancer detection.

(JMIR Cancer 2023;9:e37141) doi:10.2196/37141

KEYWORDS

carcinoma; ovarian epithelial; ovarian neoplasms; self-medication; diagnostic errors; symptom assessment; machine learning; nonprescription drugs; over-the-counter; pharmaceutical; symptom; ovary; ovarian cancer; oncology; cancer

Introduction

Ovarian cancer is often diagnosed at an advanced stage, leading to lower 5-year survival rates compared to those for other cancers [1]. When diagnosed at a late stage, 54% of the people survive for a year or more compared to 98% when diagnosed at the earliest stage [1]. Reid et al's [2] survey of 1531 women with ovarian cancer from 44 countries found that the United Kingdom had the lowest percentage of women (30%) and Italy the highest percentage of women (62.3%) diagnosed with ovarian cancer within 1 month of first visiting a doctor [2].

The reasons for late diagnosis are unclear but may partially be due to symptomatic presentation that is nonspecific and not well-defined clinically [3-5]. The assessment of the shopping behavior for products that may be purchased in reaction to these symptoms represents an approach that could improve the evaluation of prediagnostic delay. Two small-scale studies consisting of 26 interviews [6] and examination of prediagnosis loyalty card data for 6 women [7] have previously provided evidence of individuals self-medicating through health purchases in response to early symptoms of gynecological cancers. How prevalent this behavior is among women with ovarian cancer and why women buy products remain undetermined. However, the potential success of this line of investigation is supported by evidence of self-medication linked to an individual's pathway to diagnosis relating to patient self-appraisal and self-management of symptoms in the decision to seek help [8]; the frequency drop of general practitioner (GP) consultations and patient self-misdiagnosis [9]; misdiagnosis and masking of symptoms [10]; and delay in seeking health care for rheumatoid arthritis [11], tuberculosis [12], and gastrointestinal cancers [13].

Loyalty card data collect information on customer purchases, such as item type, spending category, purchase amount, time stamp, and store location. This is an area of growing interest, given that the General Data Protection Regulation [14] now gives people the right to obtain their personal data collected by organizations, thus enabling individuals to donate loyalty card data to medical studies [15-18]. Previous studies have also shown that computational analysis of such shopping data, collected through retailers' loyalty card schemes, in terms of diet and self-medication, are able to produce valuable, new, and previously unavailable insights into population health [19,20]. Set against this background, the objective of this exploratory study was to gain new domain knowledge from women's experiences, better understand how women's shopping behavior relates to their pathway to the diagnosis of ovarian cancer, and inform this growing research imperative.

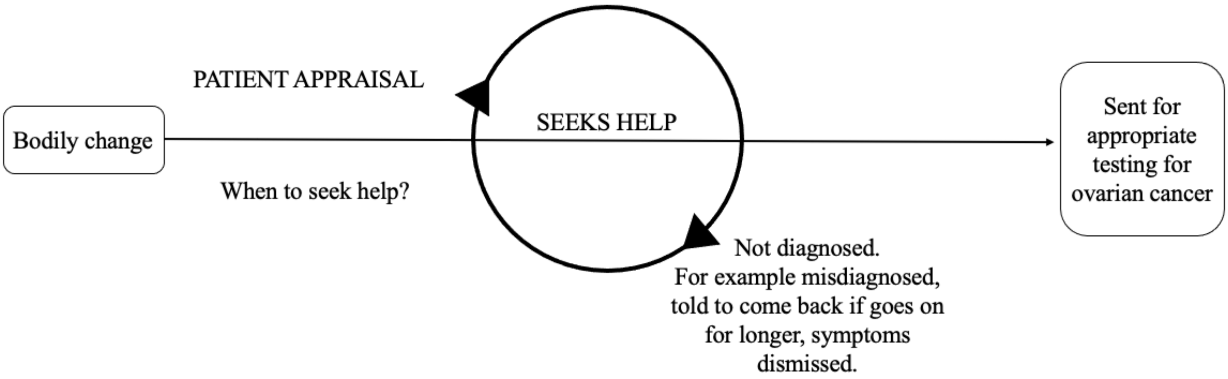
Methods

Survey Design

A web-based survey study was established to investigate health and shopping patterns in relation to ovarian cancer. The survey was developed by the research team in direct collaboration with Ovacome [21], a UK National Charity that supports around 18,000 people a year affected by ovarian cancer. The survey asked women to report their experience of symptoms and shopping habits for nonprescription health care products prior to their diagnosis with ovarian cancer across a series of 53 questions (Multimedia Appendix 1), divided into the following sections: information on diagnosis; health problems and if, what and why you purchased health products related to them; the impact of health care product purchases; donating loyalty card data; and demographics. Administered via the Jisc online survey tool [22], the survey was designed to elicit knowledge on how shopping behavior interacts with a woman's pathway to diagnosis, as illustrated in Figure 1 (adapted from Scott et al's [8] model of pathways to treatment) and with correspondence to the depiction of events prior to a diagnosis of ovarian cancer from Mullins et al [23]. Survey questions were also specifically designed to examine routes to diagnosis (Q11), awareness of symptoms of ovarian cancer (Q12), timings of health problems and health product buying (Q15 and Q22), influence and rationale in the decision-making process to buy health care products (Q17-21), and the impact of buying health care products (Q36-46). Free textboxes also enabled participants to further describe their experience of health care products.

Most questions were optional, and survey data were only stored on completion. Health problems prior to ovarian cancer diagnosis were obtained from Goff et al [24], National Institute for Health and Care Excellence [5], and advised by Ovacome. Health care product types were those that had been identified as likely to be bought in relation to these problems, also advised by Ovacome, with the option to name "Other" types provided to respondents. Products were divided into 12 types, with explanations provided where necessary, and accompanied by photos of example products. Multiple-choice options were decided upon via researcher engagement with women attending Ovacome events and desk research of products available both online and in physical stores.

Figure 1. Pathway to ovarian cancer diagnosis. Adapted from Scott et al [8].



Participant Recruitment

The target population of the study was women with a diagnosis of ovarian cancer. Given the fact that recruitment of women with a diagnosis of ovarian cancer is evidenced as challenging [25-27], a pragmatic target of 100 participants was set to underpin this exploratory work. Participants were recruited through Ovacome via their community, including social media sites and web-based health forums. The web-based survey was open from February 23, 2020, to June 3, 2020 (posts advertising the survey are shown in Multimedia Appendix 2 and Multimedia Appendix 3). The survey was distributed via a link to the survey site, where the only content was the survey itself. The survey was open to all, but participants were automatically directed out of the survey if they answered no to “Have you been diagnosed with ovarian cancer?” The informed consent process was delivered through an integrated web-based participant information sheet, privacy notice, and consent form to which participants had to agree before they could complete the survey (See Multimedia Appendix 1).

Ethics Approval

Ethics approval was obtained from the University of Nottingham (ethics panel reference: CS-2019-R28). Ovacome, the ovarian cancer charity who distributed the survey, agreed to give support to anyone who found the survey upsetting via phone, web chat, or email. The availability of this support was made clear in the participant information.

Data Analysis

A first-stage descriptive analysis of the data set was performed, with visualizations and derivations from the survey responses being aggregated to establish domain summaries of women’s experiences captured within the data, including what health problems (possible symptoms) women presented with and whether women thought they had conditions other than ovarian cancer. After statistical testing, a logistic regression model was fit to the data to assess odds ratios (ORs) and 95% CIs to examine the following:

1. Whether the duration of health problems reported prior to a diagnosis of ovarian cancer was associated with the purchase of health care products.
2. Whether the duration of health problems reported prior to a diagnosis of ovarian cancer was associated with the purchase of health care products because the participant’s doctor thought their health problems were due to a condition but not ovarian cancer.
3. Whether the duration of buying health care products for health problems reported was associated with the purchase of health care products because a participant’s doctor thought their health problems were due to a condition but not ovarian cancer.
4. Whether the number of health care product types purchased was associated with the purchase of health care products because a participant’s doctor thought their health problems were due to a condition but not ovarian cancer.

Each of the 4 logistic regression models, created to investigate the above, tested the effect of a single independent variable on the categorical dependent variable and were not adjusted models. This method was used to identify potential indicators to use in the exploratory predictive modelling. The analysis was undertaken using the Python Stats model module.

Exploratory Predictive Modelling

A second-stage predictive analysis was then implemented to explore nonlinear relationships between independent and dependent variables and to examine the potential of using loyalty card data to support predictive inferences about women’s ovarian cancer diagnoses. A machine learning approach was applied with random forest (RF) classifiers (specifically the RandomForestClassifier() from Python’s *scikit-learn* framework) by using a cross-validated grid search. Independent variables used in the modelling process included those shopping data variables (features) whose β values demonstrated statistical significance as identified by the logistic regression analysis in the previous stage (duration of buying and the total amount of product types bought), alongside the counts for each type of product that women purchased (from the top 10 product types bought). Resulting models were then used to assess if purchasing health care products because a participant’s doctor thought their health problems were due to a condition other than ovarian cancer could be predicted (identified) based upon participant buying patterns. A common challenge in modelling using relatively small samples (n=57) is avoidance of overfitting, which can lead to overoptimistic model performance [28]. To attend to this and to assess the generalizability of models on out-of-sample data sets, a rigorous nested k-fold cross-validation (CV inner k-fold=10, CV outer k-fold=10) was further applied [29], generating alternative test data sets from the original data (See Multimedia Appendix 4 for Python code used). The logistic regression model was used to investigate OR (CIs). RF models were used to determine the predictive potential of the data. For reference predictive results from the logistic regression model for the classification of participants using the same inputs as RF models, the accuracy was 77% (fit to all data).

Results

Participant Characteristics

The survey was completed by 101 women (Table 1) who had been diagnosed with ovarian cancer between 1996 and 2020 from 12 different regions of the United Kingdom. Most women (92/101, 91.1%) were from White ethnic groups, diagnosed via their GP (68/101, 67.3%) and unaware of the symptoms of ovarian cancer before their diagnosis (71/101, 70.3%). There was a 97.2% (1571/1616) completion rate for the 16 questions that applied to all participants and 97.2% (516/531) completion rate for the 9 questions that applied to participants who bought health care products. Other questions only applied to those participants who carried out a particular behavior (eg, purchasing of a pain relief product).

Table 1. Patient demographics and clinical characteristics of the women with a diagnosis of ovarian cancer and their response to health problems and loyalty card use (N=101)[a].

Characteristic	Values
Age (years), mean (SD)	55.5 (10.69)
Current UK resident, n (%)	95 (94.1)
Race/ethnicity, n (%)	
White	92 (91.1)
Asian	5 (5)
Black	2 (2)
Other	1 (1)
Prefer not to say	1 (1)
Routes to diagnosis, n (%)	
Via a general practitioner	68 (67.3)
Other routes	30 (29.7)
General practitioner appointments, mean (SD)	3.66 (3.29)
Unaware of the symptoms of ovarian cancer before their diagnosis, n (%)	
Yes	71 (70.3)
No	27 (26.7)
Stage of cancer at diagnosis, n (%)	
Unknown	6 (5.9)
1	21 (20.8)
2	10 (9.9)
3	45 (44.6)
4	19 (18.8)
Reported symptoms matching those given by the NICE[b] [5] and Goff et al [24] for ovarian cancer, n (%)	
Bloating	66 (65.3)
Fatigue (tiredness)	58 (57.4)
Change in urination habit	55 (54.5)
Abdominal pain (tummy pain)	52 (51.5)
Change in bowel habit	47 (46.5)
Change in appetite	38 (37.6)
Indigestion	31 (30.7)
Irregular bleeding	28 (27.7)
Backache	25 (24.8)
Other	21 (20.8)
Nausea	19 (18.8)
I experienced no health problems	2 (2)
In response to the health problems of ovarian cancer prior to diagnosis, n (%)	
Bought nonprescription health care products	59 (58.4)
Changed their diet	39 (38.6)
Bought new clothes	28 (27.7)
Exercised	18 (17.8)
Other action	13 (12.9)
Had loyalty cards, n (%)	91 (90.1)

Characteristic	Values
Most frequently held loyalty cards, n (%)	
Boots	73 (72.3)
Nectar	66 (65.3)
Tesco	64 (63.4)
Willing to donate their loyalty card data to investigate the diagnosis of ovarian cancer, n (%)	29 (28.7)

[a] Not all values will add up to 101, as there are missing data for some variables.

[b] NICE: National Institute for Health and Care Excellence.

Women's Purchases

Behaviors related to shopping included change of diet, purchase of nonprescription health care products, and purchase of new clothes (Table 1). Figure 2 shows the number of women who undertook more than one of these behaviors. A wide range of health care product types was purchased (Table 2), with women buying a mean of 3.88 different health care product types in response to the health issues caused by ovarian cancer prior to diagnosis. The product category with the highest increase in purchasing levels was abdominal products, with 76% (45/59) of the women never or rarely purchasing prior to their symptoms. The most purchased health care product (32/59, 54%) out of the 5 types of abdominal products was for trapped wind. Prior to symptoms, a lower proportion of women often or always purchased pain relief (16/59, 27%) and vitamins (6/59, 10%) in comparison to those who bought in response to symptoms (pain relief 38/59, 64%; vitamins 19/59, 32%).

Most health care products (71/102, 69.6%) purchased were reported as ineffective in relieving symptoms (Table 3). This ineffectiveness was confirmed within the qualitative descriptions. For example, "Not effective took combination daily was still in a lot of pain;" "Trapped wind products first, then indigestion remedies, then herbal teas, would soothe symptoms for a while but they always came back, so I'd return to the GP."

Figure 2. Number of women with ovarian cancer who reported changing their diet and purchasing health care products and new clothes in response to the health problems due to ovarian cancer prior to their diagnosis.

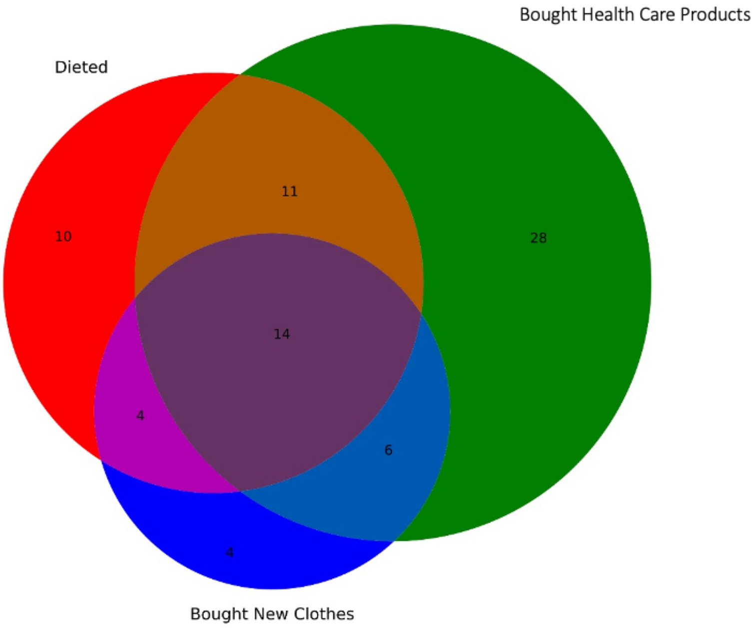


Table 2. Purchasing nonprescription health care products prior to ovarian cancer diagnosis and clinical influences to buy (n=59).

Variable	Values
Health care product types purchased in response to the health problems of ovarian cancer prior to diagnosis, mean (SD)	3.88 (2.13)
Health care product types purchased, n (%)	
Pain relief product	38 (64)
Trapped wind product	32 (54)
Irritable bowel syndrome products	23 (39)
Incontinence or period products	23 (39)
Constipation product	19 (32)
Vitamins	19 (32)
Wheat bags, heat pads, or hot water bottles	17 (29)
Gut health products	16 (27)
Pain relief with codeine	15 (25)
Under eye cream and concealer products	13 (22)
Diarrhea product	9 (15)
Cystitis relief products	5 (8)
Purchasing of health care products before the health problems of ovarian cancer, n (%)	
Pain relief	
Never or rarely	24 (41)
Sometimes	16 (27)
Often or always	16 (27)
Abdominal products	
Never or rarely	45 (76)
Sometimes	6 (10)
Often or always	5 (8)
Vitamins/supplement products	
Never or rarely	38 (64)
Sometimes	11 (19)
Often or always	6 (10)
Purchased health care products because they suspected they had a specific condition that was not ovarian cancer, n (%)	44 (75)
Condition other than ovarian cancer, n (%)	
Diarrhea	25 (42)
Indigestion problems such as stomachache	25 (42)
Constipation	25 (42)
Heartburn	25 (42)
Purchased health care products because their doctor thought their health problems were due to a condition other than ovarian cancer, n (%)	30 (51)
Conditions frequently suspected by doctors, n (%)	
Irritable bowel syndrome	10 (17)
Diverticulitis	4 (7)
Menopause	4 (7)
Constipation	4 (7)

Variable	Values
Prescribed medication because their doctor thought health problems were due to a condition other than ovarian cancer, n (%)	24 (41)
Prescriptions frequently given by doctors, n (%)	
Irritable bowel syndrome medication	5 (8)
Laxatives	5 (8)
Antibiotics	4 (7)
Medication for reflex	4 (7)

Table 3. Nonprescription health care products purchased prior to ovarian cancer diagnosis and the time taken to see if they would work.

	Values, n (%)
Time waited to see if health care products work	
Abdominal products (n=44)	
Two weeks or longer	20 (45)
A month or longer	15 (34)
Vitamins/supplements (n=20)	
A month or longer	17 (85)
Longer than a month	12 (60)
Products did not work or only worked for a few hours	
Pain relief (n=38)	27 (71)
Abdominal products (n=44)	30 (68)
Vitamins/supplements (n=20)	14 (70)

Why Women Purchased Health Care Products

Advice from your GP was the top answer respondents provided when asked what influenced their purchase of nonprescription health care products (23/59, 39%), followed by advice from friends and family (18/59, 31%) and advice found on websites (15/59, 25%). The survey identified that most women (44/59, 75%) were motivated to buy health care products because they suspected they had a specific condition that was not ovarian cancer. Of women who purchased health care products, 51% (30/59) bought nonprescription health care products specifically because their doctor had thought their health problems were due to a condition other than ovarian cancer. Many women (24/59, 41%) who bought health care products were also supplied with prescription medication due to their doctor believing health problems were due to a condition other than ovarian cancer.

Waiting to See If Health Care Products Work

Of participants who bought abdominal health care products prior to diagnosis of ovarian cancer, 45% (20/44) waited 2 weeks or more to see if they worked and 34% (15/44) waited a month or more. Although fewer women bought vitamins or supplements, a larger percentage (17/20, 85%) waited a month or longer to see if they would prove effective.

Loyalty Card Data Donation

The majority of the women (91/101, 90.1%) in the survey had loyalty cards with 72.3% (73/101), 65.3% (66/101), and 63.4% (64/101) having cards from Boots, Nectar, and Tesco, respectively—the 3 top retailers in the United Kingdom—and 28.7% (29/101) of the women gave contact details to share their loyalty card data. Respondents filtered themselves out of giving loyalty card data if they had not used loyalty cards often, their data were old/out-of-date, or they had not made purchases. For example, “I don’t think my loyalty data is relevant becoz I didn’t buy any off the shelf medications. But if you still feel it’s relevant to your research, contact me.”

Relationships Between Health Care Product Purchases and Ovarian Cancer Diagnosis Pathway

Figure 3 illustrates both the number of product types women bought and their duration of buying health care products. Plotting both these variables reveals an observable difference in the purchasing patterns in women who self-medicated because their doctor thought their health problems were due to a condition other than ovarian cancer. Figure 4 illustrates the number of product types women brought and the stage of cancer at diagnosis. It indicates woman are more likely to be shopping as a result of doctor’s advice that their health problems were due to a condition other than ovarian cancer when they have purchased 6 or more health care product types. However, only 23% (12/52) of the women surveyed, who reported the stage of cancer at diagnosis and bought health care products, were in an early enough stage (stage 1 or 2) of cancer at diagnosis to draw reliable results about the relationship between cancer stage and their purchasing patterns.

Figure 3. Categorical scatterplot comparing the duration of buying and number of different health care product types purchased by women with ovarian cancer because their doctor thought their health problems were due to a condition but not ovarian cancer.

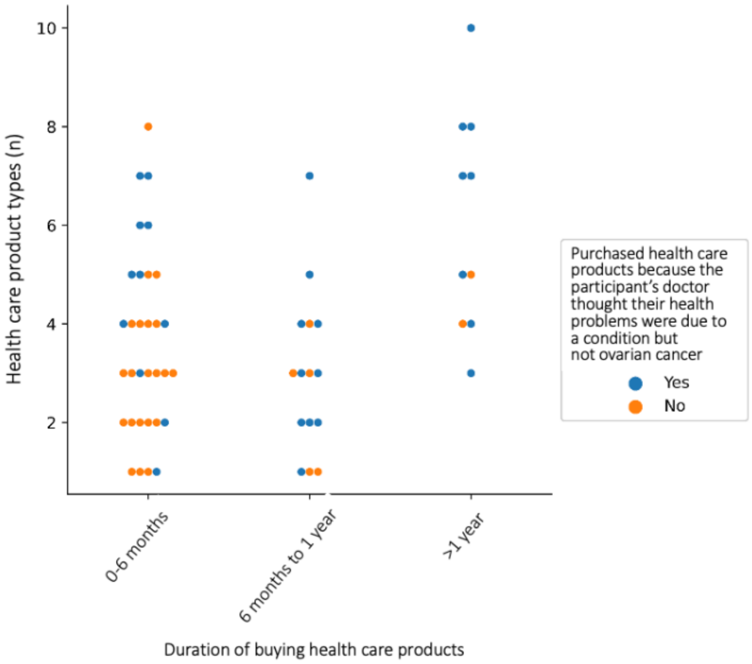
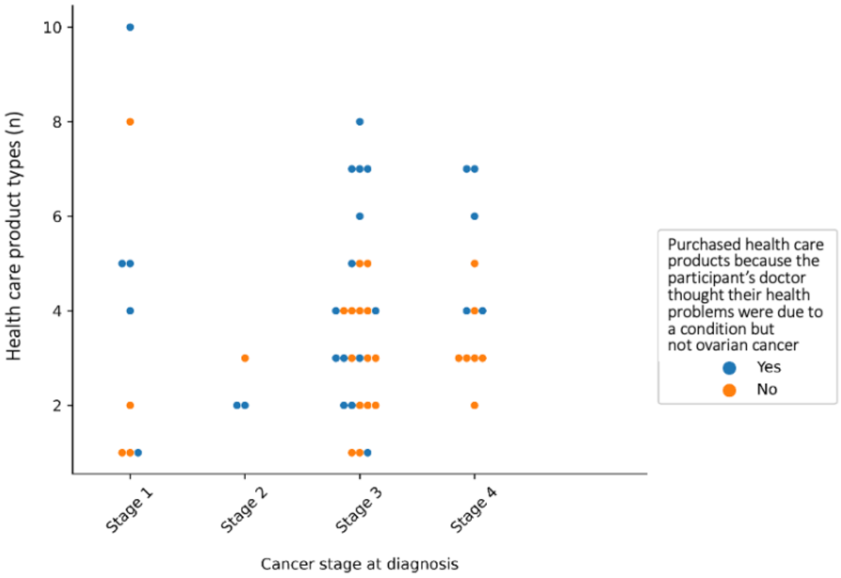


Figure 4. Categorical scatterplot comparing cancer stage at diagnosis and number of different health care product types purchased by women with ovarian cancer because their doctor thought their health problems were due to a condition but not ovarian cancer.



Women who bought health care products were no more likely to have had a longer duration of health problems prior to a diagnosis of ovarian cancer (Table 4). When considering only those participants who purchased health care products, women were 7 times more likely to have had a duration of more than a year of health problems prior to a diagnosis of ovarian cancer (Table 5) if they were self-medicating based on advice from a doctor, rather than having made the decision to self-medicate independently (OR 7.33, 95% CI 1.58-33.97). Women in this situation, who were making purchases due to their doctor believing their health problems may be due to a condition other than ovarian cancer, were more likely to have shopped for 6 months to a year (OR 3.82, 95% CI 1.04-13.98) or more than a year (OR 7.64, 95% CI 1.38-42.33) (Table 6). The likelihood that a participant was shopping because their doctor thought their health problems were due to some condition other than ovarian cancer increased with every extra product type they purchased (OR 1.54, 95% CI 1.13-2.11). Multimedia Appendix 5 shows the distribution of the different product types purchased.

Table 4. Results from the logistic regression model on the relationship between the duration of the health problems prior to the diagnosis of ovarian cancer and participant purchasing of health care products.

Duration of health problems	Participant purchasing of health care products				
	No (n=42), n (%)	Yes (n=59), n (%)	Total (N=101)	Odds ratio (95% CI)	*P* value
<6 months	23 (55)	25 (42)	48	Reference	N/A[a]
6 months-1 year	10 (24)	20 (34)	30	1.84 (0.71-4.74)	.21
>1 year	9 (21)	14 (24)	23	1.43 (0.52-3.93)	.49

[a] N/A: Not applicable.

Table 5. Results from the logistic regression model on the relationship between the duration of health problems prior to the diagnosis of ovarian cancer and participant purchasing of health care products because their doctor thought their health problems were due to a condition but not ovarian cancer.

Duration of health problems	Bought health care products because their doctor thought their health problems were due to a condition but not ovarian cancer				
	No (n=28), n (%)	Yes (n=30), n (%)	Total (n=58)	Odds ratio (95% CI)	*P* value
<6 months	16 (57)	8 (27)	24	Reference	N/A[a]
6 months-1 year	9 (32)	11 (37)	20	2.44 (0.72-8.31)	.15
>1 year	3 (11)	11 (37)	14	7.33 (1.58-33.97)	.01

[a] N/A: Not applicable.

Table 6. Results from the logistic regression model on the relationship between the duration of buying health care products prior to the diagnosis of ovarian cancer and participant purchasing of health care products because their doctor thought their health problems were due to a condition but not ovarian cancer.

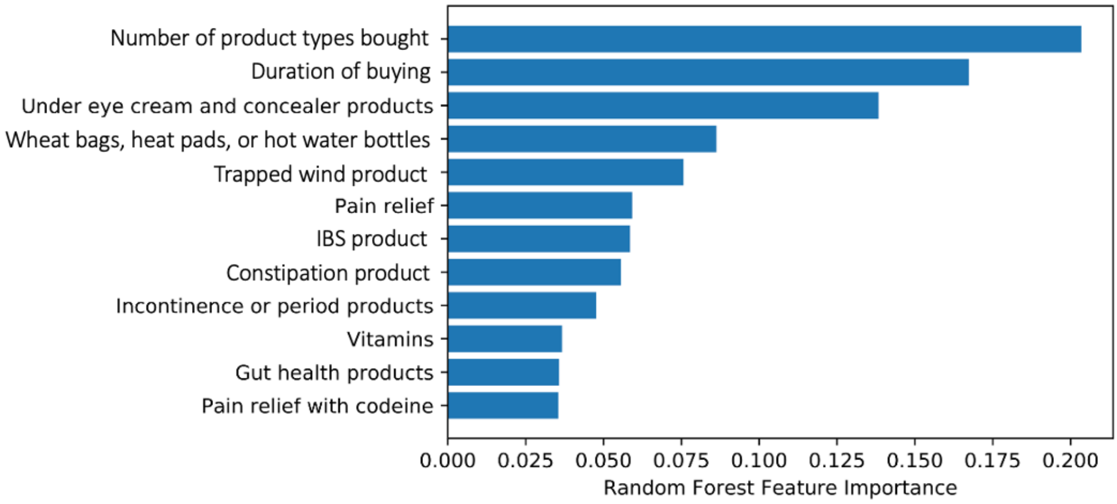
Duration of buying	Bought health care products because their doctor thought their health problems were due to a condition but not ovarian cancer				
	No (n=28), n (%)	Yes (n=29), n (%)	Total (n=57)	Odds ratio (95% CI)	*P* value
<6 months	21 (75)	11 (38)	32	Reference	N/A[a]
6 months-1 year	5 (18)	10 (34)	15	3.82 (1.04-13.98)	.04
>1 year	2 (7)	8 (28)	10	7.64 (1.38-42.33)	.02

[a] N/A: Not applicable.

Exploring Predictive Capabilities of Purchasing Data

Optimized RF models were able to correctly predict the class of 25 out of 29 women who had been shopping because their doctor thought their health problems were due to a condition other than ovarian cancer (with 4 false negatives) and 26 out of the 28 who had chosen to self-medicate independently (with 2 false positives). On average, RF modelling produced classifiers with an accuracy score of 89.1%, a recall score of 89.1%, and a precision score of 89.8% (average scores from 10 RF models). Figure 5 plots the variable (feature) importance revealed by the modelling process. To assess generalizability of the models on out-of-sample data, nested k-fold CV (CV inner k-fold=10, CV outer k-fold=10) was implemented for each of the 3 assessment scores considered (classification accuracy/precision/recall). Due to the stochastic nature of nested CV, 10 experimental runs were implemented using different random seeds each time. The mean scores across all experimental runs returned an average classification accuracy score of 70.1% (SD 20%), an average precision score of 76.4% (SD 26.8%), and an average recall score of 77.9% (SD 23.7%).

Figure 5. Bar chart comparing random forest variable (feature) importance. IBS: irritable bowel syndrome.



Discussion

Principal Findings

Our study is the first to evidence how women change their shopping habits in response to the health problems caused by ovarian cancer prior to a diagnosis. The majority of women (59/101, 58.4%) bought nonprescription health care products in response to symptoms, most being for pain relief (38/59, 64%), followed by abdominal ailments, incontinence, bleeding, and fatigue. Women in the survey were 7 times more likely to have had a duration of more than a year of health problems prior to a diagnosis of ovarian cancer if they were self-medicating based on advice from a doctor, rather than having made the decision to self-medicate independently. Our results also show that women waited for several weeks or longer to see if health care products reduced their symptoms, with advice from the GP being the top influence for purchasing health care products. This study indicates that increased shopping for health care products is associated with cases where women are receiving advice from a doctor who believe their health problems are due to a condition other than ovarian cancer. Further investigation is required to determine if receiving such advice from a doctor might disproportionately increase the time women self-manage symptoms prior to reseeking help, leading to a longer duration to an accurate diagnosis—especially given that the diagnosis of ovarian cancer often occurs at a late stage [1] and doctors in the United Kingdom take longer to refer patients for appropriate investigations compared to doctors in other western countries [2].

Comparison With Prior Work

The study corroborates the findings of previous studies with smaller sample sizes [6,7] by showing the prevalence of self-medication strategies in women with ovarian cancer. The results of our study and the methodologies discussed could be applied to investigate different diseases. Other research reports delay to diagnosis due to self-medication for other conditions [11-13]; however, the reasons for participants self-medicating remained unexplained. Specific buying behaviors reported in these studies varied by disease. For rheumatoid arthritis in the United Kingdom, patients bought tablets from the chemist, but with few speaking to pharmacists [11], and for gastrointestinal cancer in Nepal, patients used alternative medicines and antacids [13]. The increased median time between the onset of symptoms and diagnosis associated with self-medication also varied in these studies from 2.2 weeks for rheumatoid arthritis [11] to over 17 weeks for gastrointestinal cancer [13]. Unlike the results reported in this study, previous studies did not explore in as much granularity the specific health care products that participants bought. A comparison of the buying patterns of women with ovarian cancer examined in this study with those examined in previous research indicates that buying patterns likely vary between different diseases and geographical environments, both in product type and timings of purchases. Finally, almost a third of women surveyed reported that they would be willing to provide access to their loyalty card data to assist a next-stage study. Previous studies have demonstrated that willingness to share loyalty card data varies according to several factors [17,18], and this has been further demonstrated by the qualitative data provided by the women in our survey.

Limitations in This Study

This study did not look at the shopping habits of women without ovarian cancer. It therefore remains an open research question as to whether identifiable differences in shopping behaviors can be found between women who developed ovarian cancer and those who did not [30]. As an exploratory and hypothesis-generating approach, no causality can be inferred from our study. Despite the recruitment process occurring in partnership with Ovacome, due to the use of an open web-based survey, women's ovarian cancer was self-declared rather than clinically confirmed. The shopping data collected were reliant on women's memories and ability to recall correctly, and the study sample is not representative of the population of women diagnosed with ovarian cancer in the United Kingdom. Recruitment exclusively via the Ovacome community may have also led to other sample bias; the average age of the participants was 55.5 (SD 10.69) years, whereas ovarian cancer incidence rates in the United Kingdom are the highest in females aged 75 to 79 years [1]. The terminology "health problems" was used to ask women about symptoms prior to their diagnosis of ovarian cancer, as women may not have realized these were symptoms.

However, it may mean that coincidental health problems have been considered. Although the sample size in our study was notably larger than that in previous studies conducted in this field [6,7], the sample size was still small.

Conclusions

Through exploratory research, our study demonstrates that analysis of information collected on women's shopping data may potentially be useful for early ovarian cancer detection. Future studies using loyalty card data could provide accurate information on patients' behavior and symptoms between consultations where medical data are currently not available. This could be used to investigate what can influence and delay patient help-seeking. Advances in using loyalty card data for health research, made possible due to novel machine learning techniques [19,20], raise the question: Could carefully applied modelling of shopping data be a useful tool in investigating the diagnosis of and expression of symptoms in diseases such as ovarian cancer? This study confirms the importance of consulting with the patient stakeholder to "choose the right problem to address" before considering using machine learning in health care [31]. This study provides evidence that a distinctive pattern in shopping for health care products could be associated with the purchase of health care products because a participant's doctor thought their health problems were due to a condition but not ovarian cancer. The RF models, derived from the knowledge and data obtained from the survey, represent an exploratory modelling approach constructed from a limited sample size. However, with an out-of-sample classification accuracy of 70.1% and recall of 77.9% showing a capability for high sensitivity, they serve to demonstrate the potential to use machine learning to identify women with later diagnosis or a higher risk of a longer duration to an accurate diagnosis of ovarian cancer by using big data sets collected via loyalty cards.

An analysis of loyalty card data could provide evidence to support and enhance women's self-reported narratives. Further studies using loyalty card data could profitably be carried out to establish the precise periods women are waiting to assess the effectiveness of health care products and the exact time delay to diagnosis purchasing health care products can cause. If an analysis of loyalty card data confirmed the findings from this study, it would not only provide probabilistic insight at a national level but also provide evidence to invest in the development of the following 3 initiatives. First, advice on guidelines to doctors and GPs about the recommendation of self-medication when dealing with the following symptoms in women: bloating, feeling full/loss of appetite, pelvic or abdominal pain, increased urinary urgency/frequency, weight loss, fatigue, and change in bowel movements [5]—especially in terms of the ineffectiveness of self-medication for women with ovarian cancer and the critical time delay the recommendation of self-medication can cause. Second, pharmacists in retail settings could observe shoppers whose purchasing appears to follow the discovered pattern from the loyalty card data analysis, and with an individual's permission, assess if they require further investigations for ovarian cancer. Pharmacists could also consider prescription data, as 41% (24/41) of the women with ovarian cancer who bought health care products were also given a prescription because their doctor thought their health problems were related to a condition but not ovarian cancer. Third, a new clinical tool could be developed to identify women with ovarian cancer, which includes asking them about their purchasing habits. This could be implemented by GPs, doctors in accident and emergency departments, and pharmacists.

Acknowledgments

We thank Ovacome for supporting this study and its participants. The first author is supported by the Horizon Centre for Doctoral Training at the University of Nottingham (UKRI grant EP/S023305/1).

Conflicts of Interest

None declared.

Multimedia Appendix 1

Web-based survey.

[PDF File (Adobe PDF File), 1107 KB - cancer_v9i1e37141_app1.pdf]

Multimedia Appendix 2

Web-based post advertising the survey on My Ovacome.

[PNG File , 102 KB - cancer_v9i1e37141_app2.png]

Multimedia Appendix 3

Web-based post advertising the survey on Facebook.

[PNG File , 184 KB - cancer_v9i1e37141_app3.png]

Multimedia Appendix 4

Python code used for the machine learning analysis.

[PDF File (Adobe PDF File), 1594 KB - cancer_v9i1e37141_app4.pdf]

Multimedia Appendix 5
Bar chart comparing the health care product types purchased by women because their doctor thought their health problems were due to a condition but not ovarian cancer.
[PNG File , 47 KB - cancer_v9i1e37141_app5.png]

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Abbreviations

CV: cross-validation
GP: general practitioner
OR: odds ratio
RF: random forest

Edited by A Mavragani; submitted 08.02.22; peer-reviewed by Y Man, J Trevino, W Ceron, SD Boie; comments to author 23.05.22; revised version received 13.06.22; accepted 23.06.22; published 31.03.23.

Please cite as:
Dolan EH, Goulding J, Tata LJ, Lang AR
Using Shopping Data to Improve the Diagnosis of Ovarian Cancer: Computational Analysis of a Web-Based Survey
JMIR Cancer 2023;9:e37141
URL: https://cancer.jmir.org/2023/1/e37141
doi:10.2196/37141
PMID:37000495

Original Paper

Scanxiety Conversations on Twitter: Observational Study

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Abstract

Background: Scan-associated anxiety (or “scanxiety”) is commonly experienced by people having cancer-related scans. Social media platforms such as Twitter provide a novel source of data for observational research.

Objective: We aimed to identify posts on Twitter (or “tweets”) related to scanxiety, describe the volume and content of these tweets, and describe the demographics of users posting about scanxiety.

Methods: We manually searched for “scanxiety” and associated keywords in cancer-related, publicly available, English-language tweets posted between January 2018 and December 2020. We defined “conversations” as a primary tweet (the first tweet about scanxiety) and subsequent tweets (interactions stemming from the primary tweet). User demographics and the volume of primary tweets were assessed. Conversations underwent inductive thematic and content analysis.

Results: A total of 2031 unique Twitter users initiated a conversation about scanxiety from cancer-related scans. Most were patients (n=1306, 64%), female (n=1343, 66%), from North America (n=1130, 56%), and had breast cancer (449/1306, 34%). There were 3623 Twitter conversations, with a mean of 101 per month (range 40-180). Five themes were identified. The first theme was experiences of scanxiety, identified in 60% (2184/3623) of primary tweets, which captured the personal account of scanxiety by patients or their support person. Scanxiety was often described with negative adjectives or similes, despite being experienced differently by users. Scanxiety had psychological, physical, and functional impacts. Contributing factors to scanxiety included the presence and duration of uncertainty, which was exacerbated during the COVID-19 pandemic. The second theme (643/3623, 18%) was the acknowledgment of scanxiety, where users summarized or labeled an experience as scanxiety without providing emotive clarification, and advocacy of scanxiety, where users raised awareness of scanxiety without describing personal experiences. The third theme was messages of support (427/3623, 12%), where users expressed well wishes and encouraged positivity for people experiencing scanxiety. The fourth theme was strategies to reduce scanxiety (319/3623, 9%), which included general and specific strategies for patients and strategies that required improvements in clinical practice by clinicians or health care systems. The final theme was research about scanxiety (50/3623, 1%), which included tweets about the epidemiology, impact, and contributing factors of scanxiety as well as novel strategies to reduce scanxiety.

Conclusions: Scanxiety was often a negative experience described by patients having cancer-related scans. Social media platforms like Twitter enable individuals to share their experiences and offer support while providing researchers with unique data to improve their understanding of a problem. Acknowledging scanxiety as a term and increasing awareness of scanxiety is an important first step in reducing scanxiety. Research is needed to guide evidence-based approaches to reduce scanxiety, though some low-cost, low-resource practical strategies identified in this study could be rapidly introduced into clinical care.

(JMIR Cancer 2023;9:e43609) doi:10.2196/43609

KEYWORDS

anxiety; cancer; medical imaging; oncology; psycho-oncology; social media; twitter; tweet; scanxiety; mental health; sentiment analysis; oncology; thematic analysis; screen time; scan; hyperawareness; radiology

Introduction

“Scanxiety,” or scan-associated anxiety, was a term first coined by a patient writing for *Time* magazine to describe the distress before, during, or after a scan [1]. Scans are often routine in cancer care [2] regardless of cancer type or stage. They are performed for screening, diagnosis, surveillance, and monitoring of cancer and may occur on a regular schedule or in response to new symptoms, signs, or other investigation results. Global cancer incidence has increased over time, with over 20 million new cancers diagnosed annually [3,4]. Cancer survival has also increased over time secondary to improved detection of cancer and the efficacy of anticancer treatments [5,6]. Understanding the impact of scans on patient experiences is valuable, especially as improved cancer survival means more people are living with cancer and more scans are being performed over the course of the cancer journey of a patient [7].

Quantitative research on scanxiety was summarized by a scoping review in people having cancer-related scans [8]. The number of studies (n=57) indicated scanxiety was a clinically important problem, though the range of scanxiety prevalence (between 0% and 83%) was affected by methodological heterogeneity in cancer types, scan modality, and the tools and timing of scanxiety measurement [8].

Meanwhile, qualitative research on scanxiety has focused on physical factors [2,9-14]. Participants described discomfort around positioning, claustrophobia, noise, duration, temperature, cannulation, or contrast. Scanxiety was exacerbated by unfamiliarity with scans and by unempathetic or uncommunicative radiology staff [2,9-14]. A minority of studies acknowledged that scanxiety can occur while waiting for scan results [9,10,12,13]. These studies used traditional research methods such as interviews and focus groups and were limited by selection bias and the difficulty of generalizing results. They had modest sample sizes (4 recruited under 20 participants [2,10-12]), recruited participants with an extended time since their cancer diagnosis (1 with a median of nearly 6 years [10]), or recruited participants from uniform demographic groups [13].

A novel approach to data collection to supplement traditional methods is through web-based cancer communities, which can provide important perspectives on health issues, inform research, be used for health interventions, and enable the sharing or dissemination of information and research findings [15-17]. These communities can be hosted on social media platforms like Twitter, which had over 300 million global users at the time of this study’s inception [18]. On Twitter, users post real-time messages limited to 280 characters (“tweets”) [19], with the potential for users to provide a unique perspective on scan experiences and scanxiety in people having cancer-related scans. The transient phenomenon of scanxiety, which often mirrors the periodic nature of cancer-related scans, may be optimally captured on Twitter given the accessibility of Twitter on internet-enabled mobile and computer devices as well as the ease of posting contemporaneous tweets.

This study aimed to identify and describe Twitter activity about scanxiety by determining the demographics of users who posted about it, and the volume and content of these tweets.

Methods

Overview

We conducted a manual search of Twitter to identify relevant tweets published between January 2018 and December 2020. We used the following search terms: “scanxiety,” “scananxiety,” “scan anxiety,” “scan-anxiety,” “scan-related anxiety,” and “scan-associated anxiety.” Tweets were grouped into “conversations,” consisting of primary and subsequent tweets. Primary tweets were the first tweets about scanxiety in a conversation. Subsequent tweets were comments or retweets stemming from the primary tweets.

The search strategy output within their web browsers was independently reviewed by 2 authors (KTB and ZL). Included were primary tweets that were publicly available, in English, and related to cancer. Duplicate tweets or those clearly not related to cancer were excluded. Included tweets were extracted into an Excel (Microsoft Corp) document in chronological order. Uncertainty about whether a tweet met eligibility criteria prompted an additional discussion between the 2 authors and a review of user profiles and other tweets by the same author to provide context about whether the tweets referred to a cancer-related scan. All authors were available for additional review if a consensus was not reached, but this was not required.

Relevant data were manually extracted into a standardized electronic data collection form in the Excel document. Data about the tweet itself was extracted, including the date of the tweet, its classification as a primary or subsequent tweet, the content of the tweet (extracted verbatim), the search term used to identify the tweet, and the use of hyperlinks, media, or emojis within the tweet. Demographic data about users who posted a primary tweet were extracted from the user profile on Twitter, including primary role (patient, family or friend, clinician, organization, researcher, advocate), cancer type, gender (male, female, not specified, not applicable), and location. Gender was not applicable for users representing a group or organization.

Objectives and Assessments

We had 3 main objectives. The first was to describe the population who posted primary tweets about scanxiety.

The second objective was to determine the volume of conversations about scanxiety by quantifying the total number of conversations over the prespecified time period. Changes in the number of conversations over time were graphed.

The final objective was to explore content about scanxiety. Conversations underwent inductive thematic analysis through simultaneous data collection and analysis, allowing familiarization with the data and coding of the data into themes. Themes were iteratively reviewed and updated through concept mapping and active discussion among all authors, which included medical oncologists and a behavioral scientist. Theme names were chosen to be in plain language, unique to one another, and purposefully neutral to reduce interpretation bias. Once final themes were determined, all primary tweets were rereviewed by 1 author (KTB), who assigned a predominant theme to each tweet. All authors were available to resolve coding uncertainties, but this was not required. Content analysis was conducted to capture the number of primary tweets using hyperlinks, media, and emojis. Words and phrases used to describe scanxiety were extracted from the data set by manual review of the data collection form by the authors and then compiled using a digital word art creator [20]. Greater text size reflected both the manual selection of words and phrases with greater emotional impact as well as automatic adjustments made by the program's inbuilt algorithm.

Ethics Approval

This study was approved by the University of Sydney Human Research Ethics Committee (2020/868). Although the research was performed on publicly available Twitter content, a precautionary waiver of consent was granted.

Results

User Demographics

There were 2031 unique Twitter users who initiated conversations about scanxiety (Table 1). Most were patients (n=1306, 64%), female (n=1343, 66%), and from North America (n=1130, 56%). Patients most commonly had breast (449/1306, 34%), bowel (150/1306, 11%), or brain (102/1306, 8%) cancer.

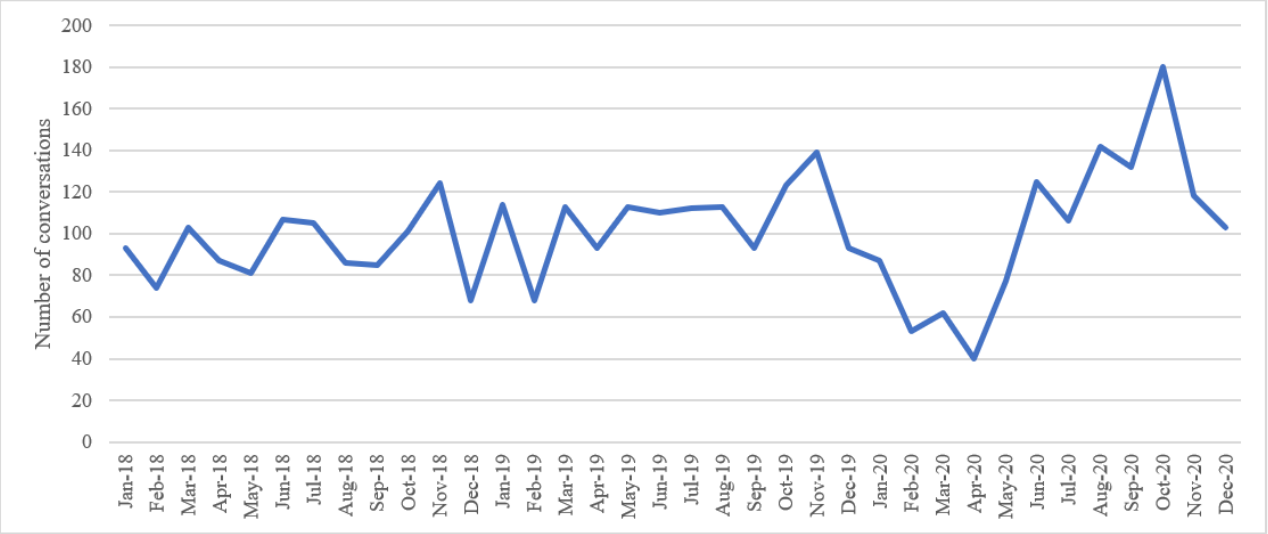
Table 1. Demographics of people who initiated a conversation about scanxiety (N=2031).

	Participants, n (%)
Role	
Patients	1306 (64)
Organizations	254 (13)
Family or friends	251 (12)
Clinicians	128 (6)
Advocates	40 (2)
Researchers	16 (1)
>1 role	19 (1)
Unclear	36 (2)
Gender	
Female	1343 (66)
Male	393 (19)
Not specified	32 (2)
Not applicable	263 (13)
Location	
North America	1130 (56)
United Kingdom	674 (33)
Australasia	76 (4)
Other	66 (4)
Unclear	85 (4)
Most common cancer types	
Breast	514 (25)
Brain	206 (10)
Bowel	170 (8)
Hematological	102 (5)
Lung	88 (4)
Verified account	34 (2)

Volume of Tweets

There were 3623 Twitter conversations about scanxiety over the 3 years, with 56% (n=2031) initiated by a unique user. Most included the search term “scanxiety” (n=3312, 91%; Multimedia Appendix 1). There was a mean of 101 tweets per month (range 40-180; Figure 1).

Figure 1. The number of Twitter conversations about scanxiety by month.



Content of Tweets

Overview

Five themes identified were experiences of scanxiety (2184/3623, 60%), acknowledgment of and advocacy for scanxiety (643/3623, 18%), messages of support relating to scanxiety (427/3623, 12%), strategies to reduce scanxiety (319/3623, 9%), and research about scanxiety (50/3623, 1%).

Primary tweets contained hyperlinks, media, or emojis in 21% (746/3623), 20% (709/3623), and 21% (744/3623), respectively. Twitter users included hyperlinks to their personal blogs (414/746, 55%) or strategies to reduce scanxiety (153/746, 21%). They included photos of themselves (206/709, 29%) or photos related to their scanning experience (90/709, 13%). They used a range of emojis to express a positive, negative, or supportive sentiment or to provide a visual depiction of their words (Multimedia Appendix 2).

Theme 1: Experiences of Scanxiety

Experiences of scanxiety included a personal account of it by patients or their support person. Scanxiety was often described with negative adjectives or similes (Multimedia Appendix 3).

Scanxiety was experienced differently by users. Scanxiety was often episodic, where users lived “scan to scan,” held their breath “for 72 hours every 3 months,” or felt that “every 3 months, cancer makes me feel like a death row prisoner hoping for a stay of execution.” Others felt they were “stuck in constant scanxiety” with scans every 6 weeks. Scanxiety could get “worse every time,” be never-ending (“86 times and I still get scanxiety”), dissipate over time (“I think I’ve finally mastered scanxiety”), or occur for the first time a few years after diagnosis. Around a single scan, users sometimes felt scanxiety for days (“the last month has been lost to scanxiety”) or would notice a peak (“today is results day and our nerves are shattered”). It could occur as a “low simmering bubble” or like “living on a knife edge.” Users expressed the presence of scanxiety through countdowns to their scan results (“It is only 96 hours, 47 minutes, and 34 seconds”). Some users reported minimal scanxiety, believing that “no amount of overthinking will change the result.”

There were psychological, physical, and functional impacts of scanxiety. Users catastrophized (“I plan my funeral during scans”), were hyperaware of symptoms (“the moment I receive my appointment letter, every twine, pain, or ache is suddenly attributed to my cancer”), ruminated (“I wish my brain had an off switch”), found it “hard to stay positive,” or felt mentally frail (“I am barely hold it together”). The psychological burden was sometimes added to “normal” anxiety levels, while others reported that scanxiety occurred despite their usual optimism.

A common physical symptom of scanxiety was insomnia, where users were unable to sleep, woke early or during the night, or had shortened sleep duration. Users reported tremors, anorexia, abdominal pain, nausea, lethargy, and irritability. Some had poor concentration (“my mind is miles away from where I need it to be”). Some were tense and could not “remember how to relax.” Some experienced panic attacks, teeth-grinding, nail-biting (“we’ve entered the ‘rip off all my cuticles’ phase of scanxiety”), and tearfulness.

Functionally, users noted decreased productivity (“I would show you how I handled scanxiety, but no one needs to see the sink filled with dirty dishes that I didn’t do”), stasis in their lives (“I will not be making plans until I know whether I get to have my next 3 months as not-cancer months”), antisocial behaviors (“I disappear for a while to deal with my emotions”), or reported health care consequences where they would delay appointments for scan results.

Users also described factors contributing to scanxiety. A recurring factor was the presence and duration of uncertainty (“the worst part” and “a difficult friend”), especially while waiting for scan results. Some waited weeks to months for scan results, lamented delays due to long weekends or holidays, and described helplessness ("all I can do is wait"). Scanxiety occurred despite the likelihood of cancer recurrence or progression. One person stated, "brain says everything points to a good, stable result. My heart and stomach have their doubts." The duration of uncertainty was extended, and scanxiety was exacerbated, when results were not ready in time or when users were promised a phone call for results that did not eventuate. Users described side effects from scans ("queasy stomach," "taste of metal," and "claustrophobia") or procedural issues ("they can't find a vein...Feel like a pin cushion").

The ongoing COVID-19 pandemic also contributed to scanxiety, as it caused scan delays or cancellations. Policies on visitor limits meant patients had scans and received results alone. Users were worried about getting COVID-19 when coming for appointments for scans or results. Some users likened their experiences with scanxiety to the unease, fear, and anxiety people experienced during the pandemic.

Theme 2: Acknowledgment of, and Advocacy for, Scanxiety.

Acknowledgments of scanxiety included statements without emotive clarification or when users summarized another person's experience using the term scanxiety. Users stated: "scanxiety is real," "scanxiety exists," or simply "Scanxiety." Others stated, "the unofficial term is scanxiety" or "we in the cancer community call it scanxiety." These acknowledgments were often posted by patients as commentary about their own experiences or in response to another patient's experiences.

Advocacy for scanxiety included tweets that raised awareness about scanxiety without mentioning personal experiences and were mostly posted by patients, their families and friends, and organizations. Users stated that scanxiety was "not spoken about often enough" and advocated for the recognition of the term scanxiety. Tweets included hyperlinks to blogs, news articles, podcasts, or videos about scanxiety, as well as invitations to join discussion groups, webinars, or support groups on the topic.

Theme 3: Messages of Support Relating to Scanxiety

Twitter users expressed support for people experiencing scanxiety through well wishes and by encouraging positivity. Messages were often posted by patients or family and friends who were able to empathize with the scanxiety experience. Users provided reassurance to people having scans by stating scanxiety as normal and relatable and by offering assistance (Multimedia Appendix 4).

Theme 4: Strategies to Reduce Scanxiety

Users adopted or recommended strategies to reduce scanxiety (Table 2). These involved general or specific strategies for patients or strategies requiring the involvement of health care professionals or systems. Patients posted about strategies they used or wanted, while organizations posted about strategies to offer advice to patients. Advocates were more likely to post about strategies requiring a change in the practices of health care professionals or the processes of health care systems.

Table 2. Adopted or recommended strategies to reduce scanxiety.

Category	Examples
General patient strategies	
Distraction	• Dietary intake: alcohol, coffee, desserts • Exercise: pilates, walking, running, cycling, swimming • Socializing with friends, family, and pets • Creative outlets: music, art journaling, drawing, writing • Entertainment: games, reading, shopping, movies, television • Mental engagement: mathematics • Productive activities: cleaning, organizing, cooking, making soap
Relaxation	• Physical: yoga, deep breathing, aromatherapy, massage, tai chi, acupuncture • Mental: meditation, spa music, mindfulness
Spiritual practices	• Prayer, reading the bible or Buddhist teachings
Seeking support	• Requesting well wishes • Sharing experiences with family and friends, on forums, in support groups or digitally • Self-education on scanxiety via blogs, websites, workshops, or webinars
Seeking professional support	• Speaking with oncology psychologists or social workers • Cognitive behavioral therapy • Hypnotherapy
Specific patient strategies	
Psychological approach	• Methodological (taking “one day at a time”) • Pragmatic (“no amount of overthinking will change the scan result”) • Optimistic (“I focus on time I’ve already been given – far more than I could have expected”) • Contextualizing by comparing their experiences to others • Problem-solving by recognizing and minimizing personal triggers to scanxiety • Positive self-talk
Practical	• Booking scan and appointment for results close together • Antianxiolytics use • Building relationships with radiology staff
Strategies for health care professionals or health care systems	
Patient education	• Around: scan procedures, results procedures, presence of scanxiety, strategies to reduce scanxiety
Clinician education	• Around: presence of scanxiety, clinician actions to reduce scanxiety
Clinician actions (oncologists)	• Reduce waiting times: immediate or same-day results, being mindful of delays from holidays, results over phone or email • Avoid unnecessary scans • Defer scans until after birthdays or important events • Discuss preferences of scans and result delivery with patients • Assist patient preparedness for scan results by pre-emptively discussing future treatment options • Providing compassionate care
Clinician actions (radiology staff)	• Being mindful of language used in scan reports • Have experienced staff perform intravenous cannulation • Being mindful of music during a scan (eg, do not play depressing music)
Health care delivery	• Direct patient access to scan results • Providing assistance to patients around navigation of health care systems • Improved insurance pathways when approval for scans is needed • Providing contact details for medical or nursing staff for questions

General strategies included distraction, physical and mental methods of relaxation, spiritual practices, and seeking support or professional help. Specific strategies included adopting a helpful psychological approach and using practical strategies. Users gained some control over their situations by reducing the time until they received results, taking antianxiolytics, or building relationships with their health care team. Strategies that required involvement by health care professionals or systems included patient and clinician education, actions by oncologists or radiology staff, and considerations around health care delivery.

Theme 5: Research About Scanxiety

This theme included publications, conference presentations, or news discussing research. The research included the prevalence and severity of scanxiety, preferences for expedient results, and the impact of scanxiety on families. Research about fear of recurrence, frequency of scans, and cost-benefit ratios in cancer surveillance was tied back to scanxiety. The research described ways to reduce scanxiety through medical hypnosis, educational patient videos, the use of miniature magnetic resonance imaging (MRIs) scans, Lego MRIs, or open MRIs, the use of virtual reality, and the alternate use of tumor markers. Tweets about research were mostly posted by organizations, researchers, and clinicians.

Discussion

Principal Findings

This observational study explored activity on Twitter about scanxiety over the 3-year study period. Conversations about scanxiety were most commonly initiated by women with breast cancer. There were 3623 conversations about scanxiety, averaging 101 conversations per month. Most tweets used the term “scanxiety.” Users often shared their personal experiences about scanxiety (60% of conversations), with one-fifth of primary tweets containing hyperlinks, media, or emojis.

The need to recognize and manage scanxiety was evident. Users shared and labeled experiences as scanxiety when describing their own situations, supporting others, or providing commentary on the research, increasing awareness and acceptance of this term. The relatability of scanxiety appeared to unify members of cancer communities across a range of cancer types, despite diverse descriptions of their experiences. The importance of scanxiety was reflected in the number of organizations initiating scanxiety conversations (n=254), with these users potentially reaching a broader readership than individuals. Further, as increasing cancer incidence and improved cancer survival leads to an increased number of scans for patients, there is likely to be a corresponding increase in the relevance, applicability, and impact of scanxiety.

There are discrepancies between existing research on scanxiety and the priorities that emerged from our work. Existing observational research has focused on the physical aspects of scans [9-12,14]. This was also seen in the scoping review on scanxiety, where all 10 intervention studies to reduce scanxiety focused on the scan itself [8]. In contrast, conversations about scanxiety by Twitter users often related to the presence, duration, and degree of uncertainty arising from scans and scan results, mirroring research in people with cancer where uncertainty about cancer trajectory and prognosis increases psychosocial worries from fear of cancer recurrence or progression [2,21]. Interventions proposed by Twitter users to reduce scanxiety involved systemic changes centered around health care delivery, such as improved processes around scan reporting times, digital access to results, and patient education about scan procedures and scanxiety. Users also advocated for improved patient navigation services to assist with timely scan bookings and results and ensure open communication between clinicians and patients. Notably, some strategies described or proposed by Twitter users, such as being mindful of the timing of scans in relation to appointments or birthdays, could be adapted into standard clinical practice without substantial cost or resource use.

Strengths and Limitations

The strengths of this study include capturing a multicountry perspective on a relatable problem across cancer types and stages and using a novel, resource-considerate approach to data collection using a thorough and systematic search strategy. Data collection from social media platforms can allow the capture of real-time experiences from a diverse range of people who may not otherwise participate in research, providing supplementary data to traditional methodologies.

The primary limitation of this study was an unavoidable selection and reporting bias. Patient demographics in our study do not match global cancer statistics, with disparate proportions observed in sex, age, and cancer type compared with either global or North American populations [22,23]. Compared to the general population, Twitter users are also more likely to be more educated, have higher incomes, and have higher digital literacy [24]. Experiences related to scanxiety could be under- or overrepresented by users who were comfortable publicly sharing their experiences, with additional bias introduced through the inclusion of only English-language tweets and the exclusion of unavailable tweets due to user removal, privacy settings, or deleted user accounts. Further, our included search terms may not have captured all tweets about scanxiety, as different words or phrases may be used by other users to describe this experience. Data available in tweets and on user profiles is also subject to reporting bias, as this data cannot be verified. Given the significant selection and reporting bias, we did not attempt to quantify the prevalence or severity of scanxiety from our data. This research should be used to supplement data collected using other methodologies rather than as a stand-alone information resource.

Other limitations include the manual search, data extraction, and analysis of Twitter data, which are less efficient and more susceptible to human error than automated processes. We were restricted by a lack of resources, though we note that research using social media is a new arena for data collection and analysis. Automated processes are being developed and could be used effectively in future studies. For example, since our data collection concluded, Twitter has upgraded its application programming interface to improve access to publicly available data on Twitter for research [25].

Conclusions

Scanxiety is experienced individually by people having cancer-related scans and is likely to increase in significance as the number of people living with cancer and having cancer-related scans increases over time. This research provides clinicians with a starting point to understand and improve scanxiety. It demonstrates how social media platforms can be used to explore psychosocial health issues in the cancer community, though researchers must allow for bias when interpreting results.

Acknowledging scanxiety as a term and as a “real,” lived experience for people with cancer will improve awareness of how clinicians explain, order, and organize scans and scan results. This study identified low-cost and low-resource practical strategies to reduce scanxiety that could be rapidly introduced into clinical care.

Further scanxiety research priorities include understanding the longitudinal trajectory of scanxiety around and between scans and determining an evidence-based approach to reduce scanxiety. Given the potential breadth of scanxiety across all people having cancer-related scans, this likely requires system-based changes.

Acknowledgments

The ANZAC Research Institute/Concord Hospital Summer Research Scholarship Program funded ZL’s involvement. The scholarship program did not influence the conduct of the research or preparation of the study in any way.

Data Availability

The data sets generated during this study are available at reasonable request from the corresponding author. This includes the complete list of deidentified tweets and demographic information.

Authors' Contributions

KTB, PB, HMD, and BEK contributed to the concept and design of this study. KTB developed and implemented the search strategy. KTB and ZL independently reviewed the search strategy output and independently extracted data from the included content. All authors contributed to the analysis of the data. KTB drafted the initial manuscript, and ZL, PB, HMD, and BEK reviewed and approved the manuscript prior to submission.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Search term included in Twitter conversations about scanxiety.
[DOCX File , 16 KB - cancer_v9i1e43609_app1.docx]

Multimedia Appendix 2
Categories and examples of links, media and emojis.
[DOCX File , 17 KB - cancer_v9i1e43609_app2.docx]

Multimedia Appendix 3
A compilation of words and phrases used to describe scanxiety, as extracted from tweets. Greater text size reflected the manual selection and weighting of words and phrases with greater emotional impact, as well as automatic adjustments made by the inbuilt algorithms of the word art creator.
[PNG File , 553 KB - cancer_v9i1e43609_app3.png]

Multimedia Appendix 4
Expressions of support – examples .
[DOCX File , 16 KB - cancer_v9i1e43609_app4.docx]

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Abbreviations

MRI: magnetic resonance imaging

Edited by A Mavragani; submitted 20.10.22; peer-reviewed by J Constance, N Seeman, JD Bacsu; comments to author 28.02.23; revised version received 19.03.23; accepted 20.03.23; published 19.04.23.

Please cite as:
Bui KT, Li Z, Dhillon HM, Kiely BE, Blinman P
Scanxiety Conversations on Twitter: Observational Study
JMIR Cancer 2023;9:e43609
URL: https://cancer.jmir.org/2023/1/e43609
doi:10.2196/43609
PMID:37074770

Original Paper

Extended Family Outreach in Hereditary Cancer Using Web-Based Genealogy, Direct-to-Consumer Ancestry Genetics, and Social Media: Mixed Methods Process Evaluation of the ConnectMyVariant Intervention

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Abstract

Background: Cascade screening, defined as helping at-risk relatives get targeted genetic testing of familial variants for dominant hereditary cancer syndromes, is a proven component of cancer prevention; however, its uptake is low. We developed and conducted a pilot study of the ConnectMyVariant intervention, in which participants received support to contact at-risk relatives that extended beyond first-degree relatives and encourage relatives to obtain genetic testing and connect with others having the same variant through email and social media. The support that participants received included listening to participants' needs, assisting with documentary genealogy to find common ancestors, facilitating direct-to-consumer DNA testing and interpretation, and assisting with database searches.

Objective: We aimed to assess intervention feasibility, motivations for participating, and engagement among ConnectMyVariant participants and their families.

Methods: We used a mixed methods design including both quantitative and qualitative evaluation methods. First, we considered intervention feasibility by characterizing recruitment and retention using multiple recruitment mechanisms, including web-based advertising, dissemination of invitations with positive test results, provider recruitment, snowball sampling, and recruitment through web-based social networks and research studies. Second, we characterized participants' motivations, concerns, and engagement through project documentation of participant engagement in outreach activities and qualitative analysis of participant communications. We used an inductive qualitative data analysis approach to analyze emails, free-text notes, and other communications generated with participants as part of the ConnectMyVariant intervention.

Results: We identified 84 prospective participants using different recruitment mechanisms; 57 participants were ultimately enrolled in the study for varying lengths of time. With respect to motivations for engaging in the intervention, participants were most interested in activities relating to genealogy and communication with others who had their specific variants. Although there was a desire to find others with the same variant and prevent cancer, more participants expressed an interest in learning about their genealogy and family health history, with prevention in relatives considered a natural side effect of outreach. Concerns about participation included whether relatives would be open to communication, how to go about it, and whether others with a specific variant would be motivated to help find common ancestors. We observed that ConnectMyVariant participants engaged in 6 primary activities to identify and communicate with at-risk relatives: sharing family history, family member testing, direct-to-consumer genealogy genetic testing analysis, contacting (distant) relatives, documentary genealogy, and expanding variant groups or outreach. Participants who connected with others who had the same variant were more likely to engage with several extended family outreach activities.

Conclusions: This study demonstrated that there is an interest in extended family outreach as a mechanism to improve cascade screening for hereditary cancer prevention. Additional research to systematically evaluate the outcomes of such outreach may be challenging but is warranted.

(JMIR Cancer 2023;9:e43126) doi:10.2196/43126

KEYWORDS

familial cancer; hereditary cancer; family history; pedigree building; cascade screening; distant relatives; breast cancer; BRCA1; BRCA2; partner and localizer of BRCA2; PALB2; Facebook; patient advocacy

Introduction

Background

For many hereditary cancer-risk genes, guideline-endorsed screening can effectively identify cancer early and surgery can prevent cancer if a pathogenic variant is known [1]. A current challenge is identifying those who would benefit before they get cancer. One of the best methods is through cascade screening in families [2,3]. Cascade screening involves targeted genetic testing in relatives at risk of having a specific genetic variant. It is called cascade screening because testing can “cascade” from one person who tests positive to first-degree relatives and then to additional relatives of those who test positive [3,4]. This strategy has been shown to be cost-effective for *BRCA1*, *BRCA2*, and Lynch syndrome genes and is endorsed by national and international organizations [5-8]. However, cascade screening uptake in the United States is low, with only 10% to 30% of first- and second-degree relatives receiving genetic testing after hearing about the genetic results of a proband—the initial person identified in a family [3,9,10]. Barriers to cascade prevention relate to the structure of the health care system and the lack of effective patient education [3,7,11-17].

Extending cascade outreach beyond first-degree relatives has been proposed to identify nearly all individuals with hereditary cancer risk [2]. Two individuals with the same variant are likely to have a common ancestor [18]. Identifying this common ancestor can in turn lead to the identification of numerous *n*-degree relatives and opportunities for prevention through cascade testing. Traditionally, relatives who would benefit from cascade testing are identified through 3-generation pedigrees created by genetic professionals, and many studies have used this principle to connect families through rare disease mutations, creating very large multigenerational pedigrees [18-22]. However, there is a missed opportunity.

There are various tools that may be useful for finding distant relatives who share a variant and a common ancestor, and these are increasingly available on the web to the public. The use of direct-to-consumer (DTC) genetic testing in conjunction with social media for family history and relative finding is becoming increasingly common [23,24]. However, there can also be potential concerns with the use of these tools, including the need to ensure that those using these tools have the necessary information, support, and discussion to make informed decisions and process any feelings that may result from tool use [25].

Situations where clinicians have noted 2 patients who share the same rare variant and have identified previously unknown familial relationships have led to the identification of additional at-risk relatives (personal communication). However, this impromptu cancer prevention practice has not been implemented systematically as a public health activity. The potential benefits from applying web-based genealogy tools, DTC genealogy genetics results, and social media networks for cascade testing and hereditary cancer prevention have not been fully explored.

Objectives

In this paper, we present a preliminary study of participant experiences with the ConnectMyVariant intervention, which aims to empower participants to engage in family outreach for cancer prevention. Intervention participants receive access to several services, including a central database of individuals interested in talking with others who had the same variant, guidance to participants on seeking and connecting with others with the same variant through web-based message boards hosted by patient advocacy groups and in social media forums, and assistance in the understanding of documentary genealogy and DTC ancestry testing platforms. In addition, a flexible plan was developed to listen to individual patient needs and respond to requests as they arose.

To characterize how participants identified and communicated with at-risk relatives, we performed a qualitative analysis of communication from the ConnectMyVariant intervention. We explored two main research questions: (1) What actions did ConnectMyVariant participants take to find and communicate risk information with their relatives? and (2) What motivations and concerns did participants have about their involvement in study activities? We concluded with implications and areas of need to improve services to connect individuals with the same variants.

Methods

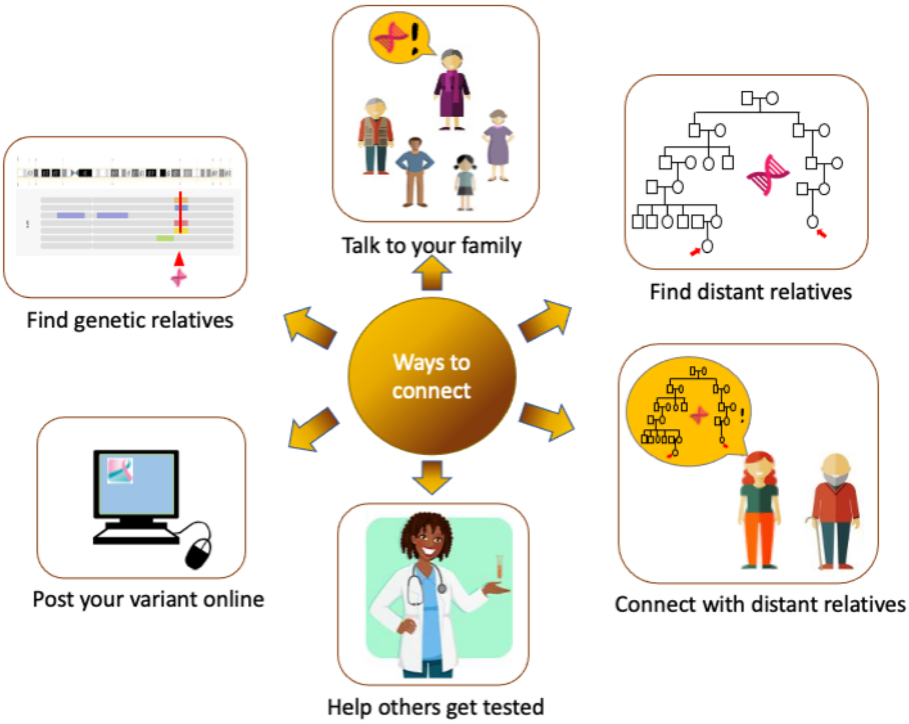
Study Design

In this study, we used a mixed methods design, in which we sought to collect and analyze both quantitative and qualitative data and integrate these 2 forms of data in the analysis and presentation of results [26]. In part 1, we explored intervention feasibility by characterizing recruitment and retention using a combination of descriptive statistics and temporal visualization methods. In part 2, we characterized motivations, concerns, and engagement through project documentation of participant engagement in outreach activities and analysis of participants' communications.

Intervention

The ConnectMyVariant intervention provides educational information on how to spread awareness among families with regard to the risk of inherited diseases. The goal is to empower and assist families in finding others who may have their variant and share information about the disease risk that they might have. This can be done with close family members, distant relatives, relatives found through DNA ancestry testing, or on the web in discussion forums created to help people connect about variants (Figure 1 [27]).

Figure 1. Ways to connect with others [27].



Those who enrolled were sent a message (Multimedia Appendix 1) asking permission for the ConnectMyVariant intervention to share their contact information with others who had the same variant, encouraging them to find others with the same variant on social media, and suggesting that they seek common ancestors with others who share their variants. We created a publicly available website, ConnectMyVariant [28], with educational materials for the participants and their families (Figure 1). All family history and family communication activities were patient initiated and patient driven, with the research study team members making themselves available for guidance and advice whenever requested. All participants were offered their choice of AncestryDNA or MyHeritageDNA kits to help identify others who might be related. For those who used these kits, AncestryDNA or MyHeritageDNA accounts were created and owned by participants. DNA data were shared with the ConnectMyVariant team only if the participants chose to share information for specific genealogy-related purposes. Participants also had access to free, study-related genealogy assistance from the Brigham Young University Center for Family History and Genealogy (BYU CFHG). ConnectMyVariant leaders (BHS, JNC, and JS) worked together before the study to develop genealogy strategies that focus on helping people with hereditary cancer variants determine where in their family tree the variants came from, find common ancestors between ≥2 people with the same variant, and identify other at-risk individuals. This group met with genealogy researchers (HDE, JD, EH, OF, EEL, CO, AP, and KR) in biweekly meetings throughout the study to discuss progress and refine genealogy strategies.

Ethics Approval and Participation

ConnectMyVariant began as an institutional review board–approved research study on August 1, 2019, and ended on January 11, 2021. The study procedures were approved by the University of Washington Institutional Review Board (00007349). Upon completion, the study was replaced with an ongoing public health initiative with the same name, goals, and activities. In mid-December 2020, each participant received an email asking if they would like to opt-in to participate in the public health initiative.

Sample and Recruitment

Individuals could be eligible for the intervention in 2 ways: if they had received clinical testing that identified pathogenic or likely pathogenic hereditary cancer-risk variants or if they were relatives of individuals with hereditary cancer risk who did not have the variant themselves.

We recruited as many participants as possible between August 1, 2019, and January 11, 2021, using multiple recruitment mechanisms: (1) the intervention was featured on the Facing Our Risk of Cancer Empowered (FORCE) website; (2) it was advertised to patients receiving positive results from Ambry Genetics between June 5, 2020, and January 11, 2021; (3) patients found out about the intervention through word of mouth from genetics providers; (4) individuals heard about it in web-based forums from other participants; (5) ConnectMyVariant team members reached out to the providers of patients identified in the University of Washington Laboratory Medicine Database who had variants shared by others and asked them to contact their patients; and (6) ConnectMyVariant team members reached out to researchers who had published about the specific variants identified in other enrolled participants and asked them to contact those patients. If the ConnectMyVariant team communicated with a specific potential participant, the process data regarding contact and communication were included in the analysis. Participants who indicated that they were not interested in the intervention after hearing more about it were asked to describe their reasoning, if possible.

Data Analysis

The first part of our analysis involved assessing intervention feasibility in terms of enrollment and retention. We calculated descriptive statistics for the sample, including representation of genes and variants among prospective participants and those who ultimately enrolled. Then, we characterized the participants' engagement temporally in terms of the duration of study participation.

In the second part of our analysis, we considered motivations and concerns for participating and engagement with the intervention in terms of the activities performed, using both quantitative and qualitative evaluation methods. We performed qualitative data analysis using a general inductive approach, involving the preparation of the data, familiarization with the text, the creation of categories, and category refinement [29]. Our inductive analysis focused on communication between ConnectMyVariant staff and participants, including email and free-text notes. We exported these communications from REDCap (Research Electronic Data Capture; Vanderbilt University), the study database, and aggregated all communications by family. We then imported these data into the Dedoose qualitative data analysis software (SocioCultural Research Consultants) [30] and coded the data based on the actions that these families engaged in. One author (JH), a genetic counselor who is part of the ConnectMyVariant team, performed the initial coding. These codes were verified by a second author (BHS) in conjunction with discussion involving a third author (ATC). In the presentation of quotes illustrating themes, staff notes and participant email text was copy edited for clarity, and we provide information about the variants that participants had, as these variants may have shaped their experience and could potentially be of relevance in interpretation of the quote.

We performed triangulation of this analysis with records of whether participants engaged in the following activities: (1) connecting with the BYU CFHG for genealogy assistance, (2) using an AncestryDNA or MyHeritageDNA kit, and (3) posting information about their variant on the web through the FORCE Share Your Mutation message board, Facebook, or another web-based forum. We compared participation in these 3 activities among individuals who had been introduced to another participant who had the exact same genetic variant and those who did not share a variant with any other study participants using Fisher exact test to evaluate the significance of differences.

Results

Part 1: Recruitment and Retention

Recruitment

We identified 84 potential participants through the recruitment methods described in the *Methods* section. Figure 2 depicts our recruitment process, including the number of participants that we were able to contact, those who consented to participate, and those who ultimately transitioned into the public health initiative.

Table 1 depicts the extent to which we were able to contact and enroll the participants through these mechanisms (Table 1). The staff noted that 32% (27/84) of the participants learned about the study from FORCE and 11% (9/84) learned about it from Facebook. Of those who were identified by the study, 26% (22/84) were contacted through providers and 12% (10/84) were contacted through research studies. For 6% (5/84) of individuals, it was not clear if they found out about the study from FORCE, Facebook, other participants, or another source. Furthermore, 13% (11/84) of the prospective participants learned about the ConnectMyVariant intervention from other participants, suggesting that the snowball method may be a particularly promising form of recruitment.

Figure 2. Diagram of intervention participation.

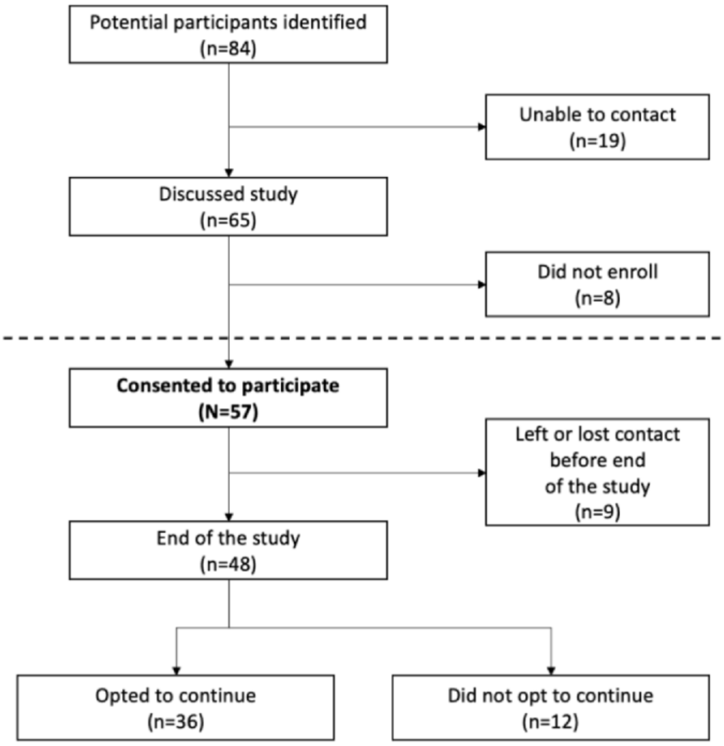


Table 1. Contact and enrollment by recruitment method.

Recruitment method	Recruited (N=84), n (%)	Contacted		Enrolled	
		Participant (n=65), n	Recruited, n/N (%)	Participant (n=57), n	Recruited, n/N (%)
FORCE[a]	27 (32)	27	N/A[b]	26	26/27 (96)
Facebook	9 (11)	9	N/A	8	8/9 (89)
Other participants	11 (13)	10	10/11 (91)	8	8/11 (72)
Through providers	22 (26)	8	8/22 (36)	4	4/22 (18)
Research studies	10 (12)	6	6/10 (60)	6	6/10 (60)
Other or Unknown	5 (6)	5	N/A	5	5/5 (100)

[a] FORCE: Facing Our Risk of Cancer Empowered.

[b] N/A: not applicable. Individuals in these groups contacted the study directly to enroll rather than being contacted by the study.

Overall, 68% (57/84) of the individuals identified joined the study; however, those who self-identified (FORCE or Facebook) joined at a rate of 94% (34/36), whereas those who did not self-identify (found through other participants, medical records, or research studies) joined at a rate of 42% (18/43). There were extended conversations, involving multiple calls or emails over weeks or months between potential participants and the study team before participants decided whether to enroll.

Contacting individuals identified through the health care system was particularly challenging. The study staff members contacted providers and asked them to relay information to 22 patients; providers returned contact information so that staff could introduce the study to 8 (36%) patients and only 4 (18%) patients enrolled. Thus, of the 84 individuals identified as eligible, the study had direct contact with 65, of whom 57 enrolled. Data were not available on how many individuals were in the denominator of seeing the announcement about the ConnectMyVariant initiative on FORCE or Facebook.

Sample

Among the sample (n=57), 36 unique variants in 8 genes were represented. Table 2 lists the number of individuals per gene. The mean age of the participants was 50.5 (SD 14; range 28-76) years and were almost entirely women (54/57, 95%).

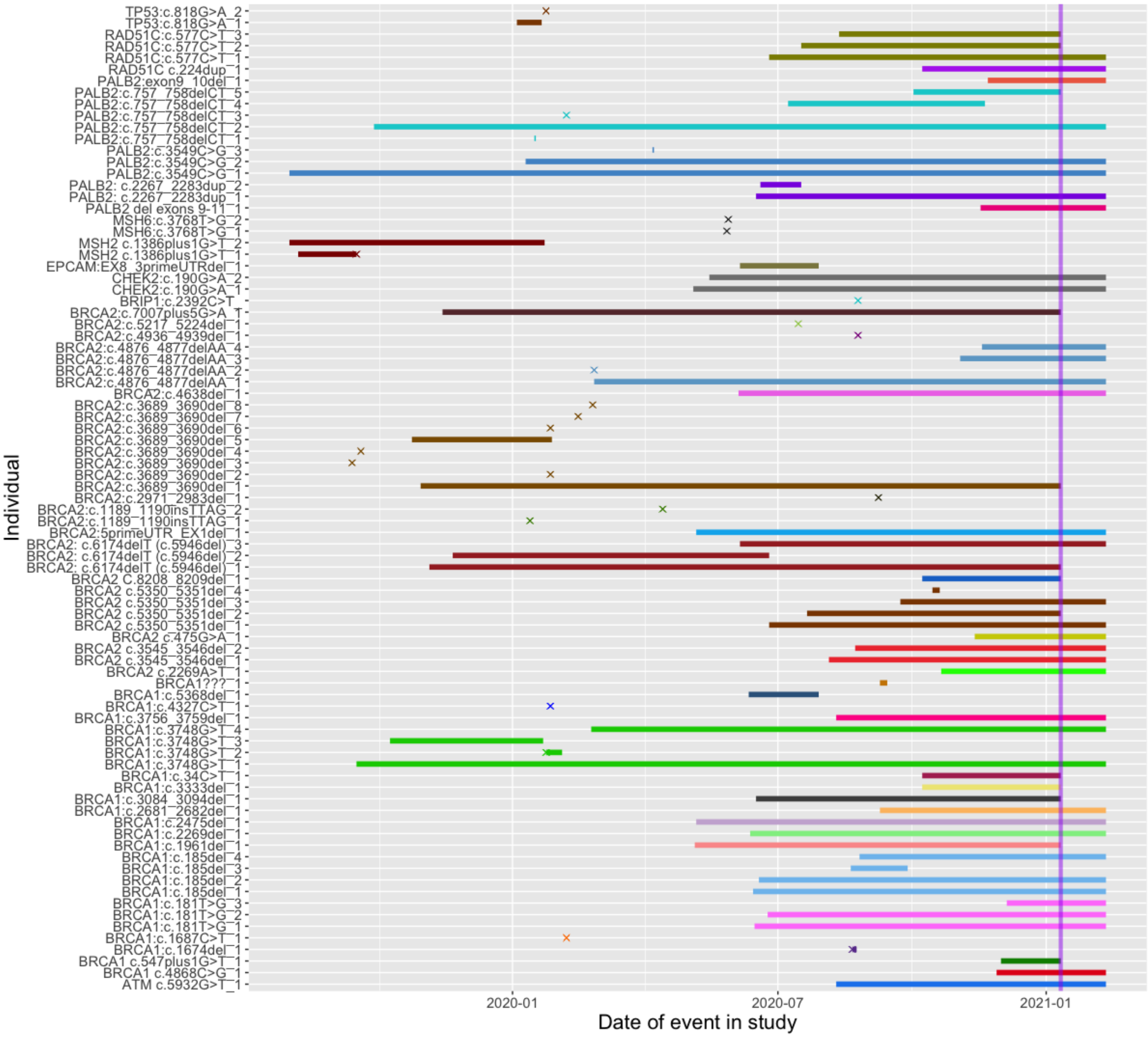
Table 2. Number of individuals by gene reported in the family.

Gene	Identified (N=84), n (%)	Enrolled (n=57), n (%)
ATM	1 (1)	1 (2)
BRCA1	26 (31)	20 (35)
BRCA2	32 (38)	19 (33)
CHEK2	2 (2)	2 (4)
EPCAM	1 (1)	1 (2)
MSH2	2 (2)	1 (2)
MSH6	2 (2)	0 (0)
PALB2	12 (14)	9 (16)
RAD51C	4 (5)	4 (7)
TP53	2 (2)	0 (0)

Participation Duration

The duration of participation in the project varied (Figure 3). When the study ended, 84% (48/57) of the participants were active, and 12% (7/57) of the participants had been active in the study for >1 year. Overall, 63% (36/57) of the participants chose to continue activities under the public health initiative after the study ended, and 21% (12/57) of the participants indicated that they did not want to engage further with the public health initiative. However, several of those who did not want to engage said they were still interested in being contacted by others with their variant, and 1 participant emailed the study team about their successful ongoing efforts to connect with distant relatives and help them get genetic testing.

Figure 3. Duration of time with the connecting variant study after initial outreach. Time is shown along the x-axis starting at August 1, 2019. The end of the study is marked by the vertical line at January 11, 2021. Bars extending beyond the vertical line indicate participants who opted in to continue connecting with others through the ConnectMyVariant public health initiative. Groups of individuals sharing the same variant are plotted adjacent to each other using the same color. Bars for individuals who were identified but unable to be contacted or who did not enroll after one or more conversations are capped with “X” symbols.



Part 2: Motivations, Concerns, and Engagement in ConnectMyVariant

Motivations and Concerns

We evaluated expressed motivations and concerns among the sample of 84 individuals identified as potential participants. Participants chose to enroll for various reasons. Some participants were interested in connecting with others:

> *I’m very interested in finding other distant relatives with the same mutation as me.* [Participant BRCA1c2269del_1]

Some participants wanted to help others or recognize the importance of the knowledge that they held:

> *I am on a sort of mission, to help spare lives from the same disease that has struck my family, because I was fortunate to benefit from genetic knowledge while my sisters were not. This is my way to “pay it forward” to the world.* [Participant PALB2c757758delCT_2]
>
> *But I do carry information that could save someone’s life. It probably saved mine (had all risk reducing surgery), although the decisions were brutal.* [Participant BRCA1c547plus1GT_1]

Some other participants were interested in learning more about the science:

> *I am very interested in learning as much as I can about this gene.* [Participant PALB2c757758delCT_4]

The participants also expressed their concerns. One common concern was whether family members would be open to the communication and how to go about it:

> *I think I would be okay with the conversation, although I'm not really sure how to just throw news like that out there either!* [Participant BRCA1c2682del_1]

> *I don't want to make her feel I am being pushy.* [Participant BRCA1c1961del_1]

The intervention also raised questions and challenged us to find ways to help families in ways that suited them:

> *I am interested, however I find your study to be somewhat disorganized. That is concerning as I don't want my information spread freely, but as I choose to find family members with my variant.* [Participant BRCA1c3748GT_1]

> *If she's hesitant about fully participating in the project, but is interested in the genealogy side and trying to find a familial link with you, then we are happy to just connect her and you to the group of genealogists we're partnering with at the BYU Center for Family History and Genealogy (CFHG).* [ConnectMyVariant team members to participant BRCA1c3748GT_1]

Activities

Through our qualitative data analysis, we observed that participants engaged in 6 main activities and how ConnectMyVariant team members supported those activities. These included sharing family history, family member testing, DTC genealogy genetic testing analysis, contacting (distant) relatives, documentary genealogy, and expanding variant groups or outreach.

Sharing Family History With ConnectMyVariant Staff

Participants shared quite a bit of information with ConnectMyVariant team members about their family history. For example, the following participant shared both genetic information and a health history that she was aware for her family members as they understood it:

> *I do know who the carrier of my mutation was-my paternal grandmother. It's unclear whether it came from her father or mother, but her father died young, possibly of cancer, so it may have been him. I do have a detailed history of my father's mother's siblings, who had any cancer (breast, ovarian, colon) and who their children were.* [Participant BRCA1c547plus1GT_1]

The ConnectMyVariant team would consider what had been shared with them and help participants decide on the next steps. For example, in the notes, the ConnectMyVariant team members noted having discussed:

> *We talked about the following: 1. Connecting with [participant] and seeing if the BYU group can help expand the family tree on both sides. Interested to see if there may be a connection between her maternal side with [participant's] family simply due to the Russia tie...but I know that's still a slim chance due to how common this mutation is. 2. Pursuing AncestryDNA data for her and her son (who has the same mutation). However, I did tell her that since this variant is so common, AncestryDNA may not be a super useful way to identify distant DNA relatives for the purposes of this study.* [Participant BRCA2c6174delTc5946del_3]

Family Member Testing

One theme focused on family members getting tested. Participants reached out to at-risk relatives and encouraged them to get tested, and the ConnectMyVariant team offered assistance with how and what to communicate. One example of such communication is the following, in which a genetic counselor provides a template for a participant to reach out to a relative: "Attached is a Template for a 'Family Letter' that we hope is a very simple & neutral way to share information about your ATM variant with your biological relative. Hope this could help if you choose to reach out to him" (ConnectMyVariant team member, to participant ATMc5932GT_1). This theme appeared in the email communications of 30% (17/57) of families.

In some cases, participants were successful in their efforts to encourage relatives to get tested, and in other cases, they could not encourage them to get tested: "My three female cousins are trying to test since their dad won't do it" (Participant PALB2c22672283dup_1). There are various reasons people might not get tested. For example, sometimes it was a matter of time:

> *Thank you for stepping in and getting things done for all of us. I am very interested but right now I am working 7 days a week...In December I will be off work and in [US state] visiting my Dad. I will be trying to get him to do the DNA test for me.* [Participant BRCA2c48764877delAA_3]

In one situation, a relative brought it up to their health care provider, who told her that it was unnecessary:

> *She said she did bring it up with her doctor after seeing the Facebook posts back during the span we were discussing her mom's memorial services. Her doctor told her she doesn't need to be tested and he wasn't going to worry about it. I felt like with her risk be 50% of having it and she has six children, now grandchildren who are getting older, too, maybe she got bad information?* [Participant BRCA1c1961del_1]

The ConnectMyVariant team suggested that she talk to her relative and recommend seeking a genetic counselor for additional information. Team members also explained to participants that they understand it can be difficult to discuss these topics with their relatives, and they also suggested alternatives of how to communicate this information:

> *It can be uncomfortable to try to contact a relative (even a close relative) about a genetic test result that may impact their health. Even for those who regularly talk to their relatives, not everyone discusses the in-depth details of their medical care. To try to address this issue, we have drafted a letter that you can send to a relative as a good starting place for contact.* [Participant BRCA1c1961del_1]

DTC Genetic Genealogy Testing Analysis

A substantial portion of families (38/57, 67%) mentioned the use of DTC genetic testing services such as AncestryDNA and MyHeritage to find their relatives. Participants sometimes sought relatives via GEDMatch, a third-party genealogy service that allows people to upload data from DTC genetic testing to find matches, and ConnectMyVariant team not only provided instruction to participants on how to perform searches but often also performed searches, shared the results with participants, and provided suggestions on what to do next:

> *I have attached an excel spreadsheet which includes individuals on GEDMatch that have segment matches with you at the location of your BRCA1 variant...it is unclear from which side of the family these individuals are related and it is also unclear if they have the BRCA1 variant. Thus, we encourage caution if you choose to reach out to them. I have attached a document which has some suggestions on how to make connections with individuals on ancestry testing sites who may be related.* [ConnectMyVariant staff to participant BRCA1c185del_2]

Participants also asked questions about how to interpret information that they find:

> *I've been emailing a woman who matched me on my BRCA1 variant, whom I found on GEDmatch using the search terms you gave me. Using the triangulation tool she looks to be an ancestor on my mother's side...My query to you is what are the possible reasons that this woman matched me on the mutated section of my BRCA1 gene and has had ovarian cancer, yet doesn't seem to have my variant.* [Participant BRCA1c2269del_1]

At times, the use of DTC genetic testing services could lead to potentially troubling knowledge:

> *I found out performing AncestryDNA testing on my great aunt. She was not related to my mother and I, both of whom had the same variant. This led me to dig deeper and reach out To DNAangels to help now search for my mother's biological father. I know it was his side that passed down this gene. This is a complete shock to me. I have NOT told my mother yet and I have not had anyone I test based on finding out these results.* [Participant BRCA2c3546del_1]

Contacting (Distant) Relatives

Participants often learned about people who they were related to by using the tools offered on GEDMatch, MyHeritage, and other databases. The ConnectMyVariant team provided information and guidance about how to contact relatives:

> *Most importantly, remember to respect your relative's right to decide to follow up. Genetic risk can be hard for some people. Sometimes a relative may respond that they are not interested. Sometimes people are interested, but it is not a good time in their life. So just try to meet them where they are.* [Participant BRCA1c2682del_1]

Overall, 30% (17/57) of the families contacted cousins that had been identified as at risk through the intervention. The following excerpt illustrates personal guidance from the ConnectMyVariant team members about how a self-introduction to a distant relative might go:

> *I am contacting you because I believe we are distant cousins...we are probably 4th-5th cousins because we share three segments of DNA. I found you through my shared DNA matches in MyHeritage, looked at your family tree, did some Internet searching...and then through my Truthfinder subscription. I sent you a message on MyHeritage, but I also thought I'd try to reach out through email. There is a lot of breast cancer in my family. We found out that it is because of a specific genetic change in a cancer risk gene. I have been doing family history work to find others that have it.* [Participant PALB2c757758delCT_2]

The email threads showed that there were often multiple communications between the participants and the distant relatives whom they contacted. These communications showed it can take time for people to persuade distant relatives to get tested for various reasons, including having to work up the courage to contact them: "Just trying to still work up to feeling comfortable talking to him or texting" (Participant BRCA1c1961del_1). Sometimes, the participants' inclinations to reach out were related to the probability of sharing a match:

> *Are you able to give me any sense of how likely it is that other people near the top of the list would have the BRCA1 mutation. I'm trying to decide whether I feel comfortable contacting them, and it would be good to know if it's a fairly remote chance, or something that's quite likely.* [Participant BRCA1c185del_2]

People are not always interested in getting tested or pursuing things further, which can lead to tension within the family. Participating reminded people of past experiences and led to recontacting those who had not been tested because of prior conversations:

> *I will probably follow up with my close cousin [name] (his mom has BRCA) and see where he is at with testing, but this will probably be my 4th time contacting him about it. There is a lack of interest for testing probably due to his own mom not pushing them to do it. She is also the one who found out she had the mutation back in 2012 when she was diagnosed with breast cancer for the second time and never told any family members. If she would have, my sister probably would not have gotten cancer, so we are slightly bitter about the lack of empathy and attention on her part.* [Participant BRCA1c3084309del_1]

Documentary Genealogy

In total, 49% (28/57) of families attempted to expand their documented genealogy. Participants sometimes ran into difficulties in terms of the types of information sources that might be available, including challenges finding international records:

> *Would you be able to pass on any information regarding the origins of the mutation? I know it's a Norwegian founding mutation, which makes sense since my descendents came over here from Norway. I read that it was due to a genetic drift after the bubonic plaque. I'm really interested in learning more about it, but haven't found much info online. Do you know if Norway has their own database of BRCA variants?* [Participant BRCA1c3084309del_1]

The ConnectMyVariant team members would assist participants by providing information and introducing them to the genealogists at BYU CFHG:

> *I wanted to connect you with our partner genealogists at the Brigham Young University Center for Family History and Genealogy (BYU CFHG). Their role in the ConnectMyVariant project is to help expand your family tree and try to find connections with people you identify through online forums/message boards as well as through the DNA matches you're searching.* [ConnectMyVariant to participant BRCA1c2269del_1]

Tracing genealogy could also lead to additional questions such as the following:

> *There are a couple cases in the [surname] family where an [surname] male married twice, after a first wife died. [Relative's] line comes from children of the first wives, but if the mutation were found in children of the second wives, that would definitely prove the mutation came through the [surname] men...correct?* [Participant PALB2c757758delCT_2]

Expanding Variant Group and Outreach

Participants also engaged in expanding variant groups and outreach activities. This is similar to the tracked variable of web-based outreach but is more expansive as it could also include outreach through other methods. Sometimes participants connected with one another via social media:

> *I was referred to you by [Person with variant]. We found each other through Facebook and share the same exact PALB2 genetic mutation.* [Participant PALB2c2267228dup_2]

> *I saw that you posted your mutation on FORCE and it looks like one other person has commented that they have your same variant!* [ConnectMyVariant team members to participant BRCA2c4638del_1]

In addition, the ConnectMyVariant team sometimes, but not always, was able to connect people with the same variant:

> *I am sending this email to formally connect you all simultaneously. You all have the same BRCA2c.5350_5351del and all indicated an interest in connecting with others who have your variant.* [ConnectMyVariant team member to participants with BRCA2c.5350_5351del_1, BRCA2c.5350_5351del_2, and BRCA2c.5350_5351del_3]

> *Presently, because we have no other participants with your variant in our project, the CFHG involvement will be limited.* [ConnectMyVariant team member to participant RAD51Xx224dup_1]

Participants were successful to varying degrees:

> *I've now had three relatives confirm they've found the mutation in their raw DNA. I've sent two of them an email to ask them what you suggested below so will wait to hear. I'll also ask the third person. They're all in different countries - UK, USA and Australia.* [Participant BRCA1c2269del_1]

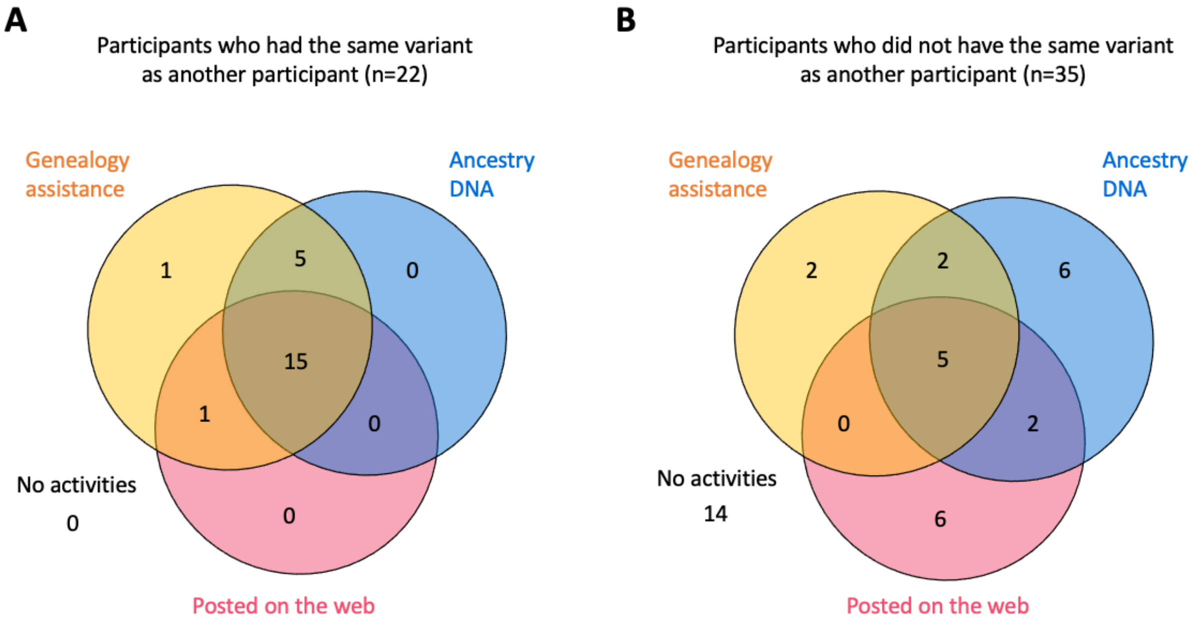
> *[Participant's relative] is the only other person I successfully made any progress with.* [Participant PALB2c3549CG_1]

Connecting With Others With the Same Variant and Engagement

Among the 57 individuals who provided consent to participate in the study, 31 (54%) sought documentary genealogy assistance, 35 (61%) requested or had already undergone genealogy DNA testing, and 29 (51%) posted about their variant on at least 1 web-based forum (Figure 4).

We analyzed the study records to better understand the relationship between participant engagement in study activities and whether they were able to identify others with the same variant. Overall, 39% (22/57) of these participants shared variants with other ConnectMyVariant participants; all of these participants participated in at least 1 of 3 activities, and 26% (15/57) participated in all tracked activities (Figure 4A). Of the 35 participants who did not have the same variant as someone else in the study, only 5 (14%) participated in all 3 activities and 14 (40%) did not participate in any activities (Figure 4B). Connected participants were more likely to use genealogy assistance ($P<.001$), request Ancestry or MyHeritage DNA tests ($P<.001$), and post in web-based forums about their variant ($P=.01$). Individuals may have also been involved in other activities, such as communication with close and distant relatives, which were evaluated through qualitative analysis.

Figure 4. Connecting with others and engagement in study activities. (A) Participants connected with others who do share variants. (B) Participants who do not share variants with other study participants. Study activities: those who sought genealogy assistance from the Brigham Young University Center for Family History and Genealogy; those who requested or had already obtained AncestryDNA or MyHeritageDNA testing; and those who posted information about their variant on the web through the Facing Our Risk of Cancer Empowered Share Your Mutation message board, Facebook, or another web-based forum.



Discussion

Principal Findings

In the first part of our study, we identified potential participants through multiple recruitment mechanisms. Overall, 68% (57/84) of the potential participants enrolled in the study, with 84% (48/57) of the participants remaining engaged for the duration of the study. As enrollment was ongoing, participants engaged for varying lengths of time, but the study findings illustrate that it is possible to enroll and retain participants in cascade family outreach.

It is worth considering how our study recruitment might inform future cascade outreach efforts. In this study, the recruitment methods involving self-identifying mechanisms (eg, Facebook and FORCE) had higher yield. Although this alone might suggest that engaging those who are intrinsically motivated could be an effective strategy to raise awareness, it is also worthwhile to consider the particular dispositions of the sample, including the predominance of particular variants and all being women. In addition to pursuing high-yield avenues, there is also a need to increase efforts to diversify awareness and reduce barriers for persons who may benefit from cascade outreach but may have concerns about participating.

Participants experienced social and emotional challenges related to outreach to relatives or with the logistics related to identifying and communicating with relatives or availability of intervention resources. Some individuals chose not to participate despite knowing that someone with the same variant was interested in communicating with them, indicating that these activities do not appeal to everyone.

The ConnectMyVariant participants engaged in 6 primary cascade outreach activities: sharing family history, family member testing, DTC genealogy genetic testing analysis, contacting (distant) relatives, documentary genealogy, and expanding variant groups or outreach. Different families engaged in different activities and had varying strategies. Although some participants were compelled by a desire to find others and prevent cancer, more participants expressed an interest in finding out more about their family history and medical heritage, with prevention in relatives considered a natural side effect of outreach to distant relatives.

People who connected with others who had their variant were significantly more likely to participate in family history, genealogy DNA testing, and post on web-based forums about their genetic variant than those not connected with others. This observation is perhaps dialogic in the sense. One might expect that the more individuals there are seeking connections of a certain variant, the greater their chances of finding one another. However, there are also other factors, such as the amount of activity pertaining to a given variant on a discussion forum. A greater focus on forum management, communication, and dissemination of information via the web-based forums might increase the likelihood that individuals with the same variant would find one another.

The findings showed that ConnectMyVariant played an important role in facilitating discussion and sharing information. Some discussions were similar to those occurring in genealogy forums that cover technical topics such as shared DNA and how to find information in web-based genealogy databases (eg, Geneanet [31] and Ancestry message boards [32]), whereas others overlapped with those seen on hereditary cancer patient advocacy message boards, with comments on past cancer treatment experience and specific prevention plans (eg, FORCE message boards [33] and the American Cancer Society's Cancer Survivors Network [34]).

However, there was a clear interest in using family history to identify connections among some persons at risk for genetic conditions. Common motivations included the desire to help others prevent cancer because of their own or their relative's experience with cancer, a desire to understand their own personal genetics, or to improve science. Survey research has also shown that people connect with others via social media, particularly Facebook, in the context of rare genetic diagnoses [35]. In addition, research has shown that people use 23andMe results to make sense of their family and health histories, resolve unknowns about their pasts, make changes in day-to-day behaviors, and make sense of broader social and historical contexts [36]. Our study found that a substantial number of individuals with known hereditary cancer risk were interested in using social networking with documentary and genetic genealogy to build their family trees and identify new at-risk relatives. Engagement in these activities was enduring for approximately half of the enrolled participants. A few participants had independently started extended family outreach activities before the intervention began and welcomed ConnectMyVariant as a helpful resource that they had been hoping for. Interestingly, 53% (33/62) of the participants who began working with ConnectMyVariant opted to continue family connection and outreach efforts when the intervention transitioned to a public service (Figure 3). For some relatives, this project was a component of a multiyear, multiparticipant conversation embedded in deeper family communication related to cancer and mortality.

Limitations and Future Directions

This study has various limitations. First, the ConnectMyVariant intervention was not a systematic study to gauge interest in cascade outreach among the general population; therefore, those enrolled are likely to overrepresent the level of interest among those who know about their hereditary cancer risk. In addition, given the complexity of facilitating this type of communication, our sample size was not insignificant, but there is a need to better understand how this approach to facilitate extended outreach might work in a larger and more diverse sample, including an analysis of different cultural groups.

Moreover, this study was not designed to assess the clinical outcomes related to genetic testing or prevention in relatives. Accurately measuring the clinical outcomes of extended family outreach is challenging owing to the heterogeneity of outcomes and the time frame of consequences. Each participant faced different family communication challenges and used different strategies to address these challenges. Moreover, the results of their actions may unfold over a time frame longer than is typically measured in a trial. For example, ConnectMyVariant occasionally receives emails from participants after their involvement with us has ended, informing us of something that they did that ultimately bore fruit, a year or more later. Additional work and new strategies will be required to monitor outcomes of expanding family outreach beyond first- and second-degree relatives and over an extended period.

Conclusions

There is an interest and opportunity among individuals with hereditary cancer risk to extend cascade prevention beyond immediate relatives. In this paper, we presented an approach to facilitate this work. Social networking, documentary genealogy, and DTC genealogy testing can be leveraged to help while addressing limitations and concerns surrounding this use of technology.

Acknowledgments

This study was funded by a gift from the Brotman Baty Institute for Precision Medicine and benefited from additional institutional support from the University of Washington, Department of Laboratory Medicine and Pathology, and the Brigham Young University, Department of History.

Data Availability

Deidentified data sets generated and analyzed during this study are available from the corresponding author upon reasonable request.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Coding guide.
[DOCX File , 14 KB - cancer_v9i1e43126_app1.docx]

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Abbreviations

BYU CFHG: Brigham Young University Center for Family History and Genealogy
DTC: direct-to-consumer
FORCE: Facing Our Risk of Cancer Empowered
REDCap: Research Electronic Data Capture

Edited by A Mavragani; submitted 30.09.22; peer-reviewed by H Thorne, M Kapsetaki; comments to author 19.10.22; revised version received 25.10.22; accepted 28.02.23; published 20.04.23.

Please cite as:
Chen AT, Huey J, Coe S, Kaganovsky J, Malouf EA, Evans HD, Daker J, Harper E, Fordiani O, Lowe EE, Oldroyd CM, Price A, Roth K, Stoddard J, Crandell JN, Shirts BH
Extended Family Outreach in Hereditary Cancer Using Web-Based Genealogy, Direct-to-Consumer Ancestry Genetics, and Social Media: Mixed Methods Process Evaluation of the ConnectMyVariant Intervention
JMIR Cancer 2023;9:e43126
URL: https://cancer.jmir.org/2023/1/e43126
doi:10.2196/43126
PMID:37079361

Original Paper

Impact of COVID-19 on Public Interest in Breast Cancer Screening and Related Symptoms: Google Trends Analysis

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Abstract

Background: The COVID-19 pandemic has led to a decrease in cancer screening due to the redeployment of health care resources and public avoidance of health care facilities. Breast cancer is the most common cancer diagnosed in female individuals, with improved survival rates from early detection. An avoidance of screening, resulting in late detection, greatly affects survival and increases health care resource burden and costs.

Objective: This study aimed to evaluate if a sustained decrease in public interest in screening occurred and to evaluate other search terms, and hence interest, associated with that.

Methods: This study used Google Trends to analyze public interest in breast cancer screening and symptoms. We queried search data for 4 keyword terms ("mammogram," "breast pain," "breast lump," and "nipple discharge") from January 1, 2019, to January 1, 2022. The relative search frequency metric was used to assess interest in these terms, and related queries were retrieved for each keyword to evaluate trends in search patterns.

Results: Despite an initial drastic drop in interest in mammography from March to April 2020, this quickly recovered by July 2020. After this period, alongside the recovery of interest in screening, there was a rapid increase in interest for arranging for mammography. Relative search frequencies of perceived breast cancer–related symptoms such as breast lump, nipple discharge, and breast pain remained stable. There was increase public interest in natural and alternative therapy of breast lumps despite the recovery of interest in mammography and breast biopsy. There was a significant correlation between search activity and Breast Cancer Awareness Month in October.

Conclusions: Online search interest in breast cancer screening experienced a sharp decline at the beginning of the COVID-19 pandemic, with a subsequent return to baseline interest in arranging for mammography followed this short period of decreased interest.

(JMIR Cancer 2023;9:e39105) doi:10.2196/39105

KEYWORDS

breast cancer screening; breast cancer symptoms; COVID-19; public interest; Google Trends; screening; breast cancer; symptoms; cancer; trend; mammography; monitoring

Introduction

The COVID-19 pandemic has led to a decrease in cancer screening due to the prioritization of health care resources toward COVID-19–related efforts and changes in health care–seeking patterns [1]. This may have resulted in delays in diagnosis and treatment [2,3], possibly adversely impacting oncologic outcomes.

This is particularly important in breast cancer as it is the world's most prevalent cancer and the leading cause of cancer death in female individuals [4]. An important measure to reduce breast cancer mortality is the use of population screening by mammography, which aims to diagnose breast cancer at an earlier stage [5]. Female individuals diagnosed with breast cancer at an early stage have 5-year survival rates in excess of 90%, dropping to 85% after locoregional spread and 29% with distant disease [6]. With the World Health Organization (WHO) declaration of a global health emergency in January 2020, followed by the subsequent declaration of the COVID-19 pandemic in March 2020, there was a 74.3% reduction in public interest in mammograms compared to the prepandemic period [7].

In today's technological era, it is common to seek health information on the internet to fill the gap between information one already has and what one seeks to know [8]: 72% of US adults reported seeking health information online, and 77% started with an internet search engine [9]. Google is the primary search engine and accounts for more than 90% of internet searches [10]. Online search interests for COVID-19–related issues peaked with increasing COVID-19 case numbers, which corresponds to the known phenomena of redirected health care resources [11]. The Google Trends [12] tool has been used to measure public interest in various oncological topics [13].

Google Trends has been shown to be a viable tool to understand, monitor, and even forecast information-seeking trends and public interest. It is an increasingly popular method for assessing population preferences in health research [14-16]. Google Trends provides a quick and easy way to access public interest in any topic across time and geographical location. It uses publicly available data, which allow studies to be transparent and easily reproducible. In addition, as data are available in real time, it solves issues with traditional and time-consuming survey methods [13].

Most existing literature on the effect of COVID-19 on cancer screening focused primarily on the medical implications, such as delays in diagnosis and treatment [7,17]. This study instead focused on public perception by analyzing search engine queries to assess if there had been a decrease in interest for breast cancer screening over time since the beginning of the pandemic and whether this has recovered to prepandemic levels. Additionally, this study aimed to observe the other terms that are searched alongside breast cancer screening. These may indicate new areas that need attention with regard to public health initiatives or education campaigns during such periods.

To achieve these objectives, trends in Google search volume were analyzed for mammography, breast self-examination, breast lumps, nipple discharge, and breast pain before and during the COVID-19 pandemic. In comparing these trends, we aimed to illustrate the pandemic's effect on public interest in breast cancer screening and related symptoms.

Methods

Overview

A retrospective study of a publicly available query tool that aggregates data on Google search trends was conducted. Google Trends is a useful tool for tracking the frequency of search terms over time. It can be used to analyze changes in public interest or awareness of certain topics, including breast cancer screening. With these data, researchers and health professionals gain insight into how people are searching for information about breast cancer screening and where the gaps in their knowledge may be.

Using Google Trends, different search terms related to breast cancer screening may be compared. This allows users to understand the search term that has garnered more interest from the public over a period of time. In addition, comparisons can also be made between different geographic regions, time frames, and categories.

The data for any search term are normalized to the time and location of a query by the division of the total searches of the geography and time range it represented, to compare relative popularity. The relative popularity for any term is reported as a relative search frequency (RSF) from 0 to 100, with 100 representing the peak popularity of a term.

A search for a single term gathers results that include the specific word queried. Next, a search of multiple terms includes each word in any order. A search for a term in quotes obtains results that include the specific order of words queried. An alternative search strategy uses *topics*, a group of predefined terms that share the same concept in any language. For example, the topic "breast cancer" will include results for topics such as "brustkrebs," which is "breast cancer" in German. Finally multiple queries can be searched concurrently to compare RSF across the terms (comparison) or individually to reflect the RSF of each individual term (individual search), which is more useful when comparing trends across terms in comparison to relative frequency.

Google Trends can also be used to evaluate related queries, which report on related search terms that users also search for alongside the index search terms. "Top" terms represent the most popular search terms scaled to the most commonly searched query as 100, and "rising" terms represent the queries with the biggest increase in search frequency during the requested time period.

On February 6, 2022, Google Trends was queried with keyword terms representing interest in breast cancer screening ("mammogram") or breast cancer symptoms ("breast pain," "breast lump," and "nipple discharge") as a comparison. "Mammogram" was selected to represent breast cancer screening as this is the standard modality for breast cancer screening. Breast cancer symptoms are common symptoms that patients with breast cancer may experience, or alternatively, patients with otherwise benign conditions may experience and thus require further investigation to rule out a breast malignancy. The 3 most common symptoms were included as search terms. In contrast to "mammogram," the query "breast self-examination" does not require a medical provider visit and so may be less affected by COVID-19; thus, this was included separately as a search term to be analyzed. A worldwide search from January 1, 2019, to January 1, 2022, using the "all-categories" query category was conducted. January 1, 2019, was chosen as the start date to capture baseline interest, the "worldwide" setting was selected to capture search information worldwide, and the "all-categories" query category was chosen to assess interest in any context and to avoid any bias in filtering search results. Related queries were also retrieved for each of the key terms for the same time period. Further searches to compare peaks of terms were conducted as individual searches based on the results retrieved. Since searches included "how to cure breast lump naturally," this was compared to the terms "lumpectomy" and "breast biopsy" as possible routine next steps in the management of a breast lump in contrast to natural treatment.

To assess whether a change in search volumes for "mammogram" was significant, we conducted time series forecasting using an autoregressive integrated moving average (ARIMA) model variant model allowing for seasonal variability (seasonal ARIMA). Expected search interest for "mammogram" from January 1, 2019, to January 1, 2022, was estimated using the seasonal ARIMA model based on the searches for "mammogram" during the 5 years prior to COVID-19 (from January 1, 2014, to January 1, 2019)

Ethical Considerations

This study involved cross-sectional analysis of publicly available search engine metadata and does not use data on or involve individual human subjects; thus, it fulfills the criteria for institutional review board exemption.

Results

In the period from 2019 to 2022, a significant drop in searches for "mammogram" was found from March to April 2020 (Figure 1). This drop is significant compared to the expected search interest based on previous 5 years' worth of search data ($P<.001$; Figure 2). This coincided with the start of the COVID-19 pandemic, announced at the WHO media briefing on March 11, 2020 [18], and the subsequent deferment of nonurgent elective cases and outpatient clinic appointments in response to this in many countries [19,20]. Searches for "mammogram" recovered to a pre–COVID-19 baseline by July 2020.

Notwithstanding the drop in searches for mammogram, interest in breast self-examination did not show any drop in comparison to baseline annual values for the same time period (Figure 3). Also seen in Figure 2 are the October peaks in interest for both mammogram and breast self-examination when the search frequency rises to 1.6-2 times of baseline, coinciding with the internationally designated *Breast Cancer Awareness Month* (BCAM) [21]. This is in contrast to searches for breast cancer symptoms that did not show any increased search volume coinciding with the October BCAM (Figure 1).

Figure 1. Online search interest in "mammogram" and breast cancer related symptoms ("breast pain," "breast lump," and "nipple discharge") during the time period from January 1, 2019, to January 1, 2022. Google Trends relative search frequency (RSF) is reported as a value from 0 to 100, with 100 representing peak popularity of the term over the time period.

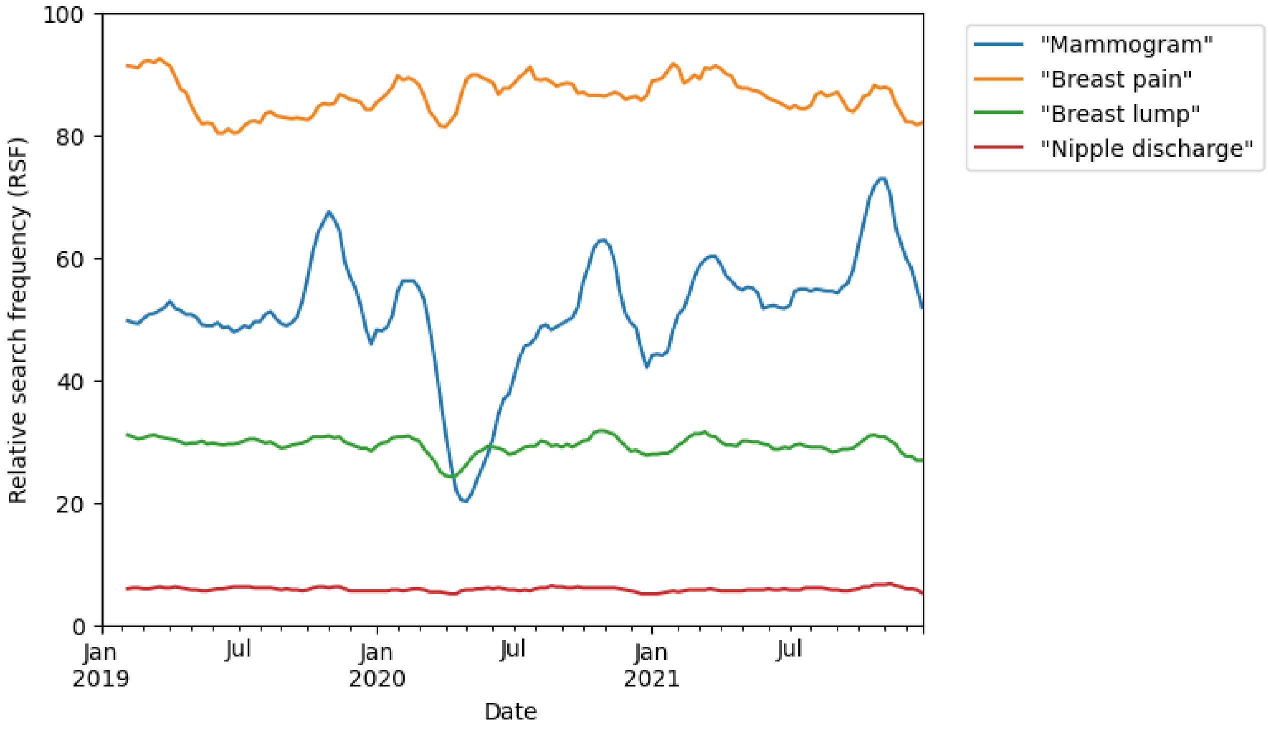


Figure 2. Online search interest in "mammogram" during the time period from January 1, 2014, to January 1, 2019 (pre–COVID-19 mammogram); actual search interest during the time period from January 1, 2019, to January 1, 2022 (actual mammogram); and expected search volume during the latter period predicted from the previous 5 years' worth of data (expected mammogram). Google Trends relative search frequency (RSF) is reported as a value from 0 to 100, with 100 representing peak popularity of the term over the time period as individual search. Shaded area represents 95% CI.

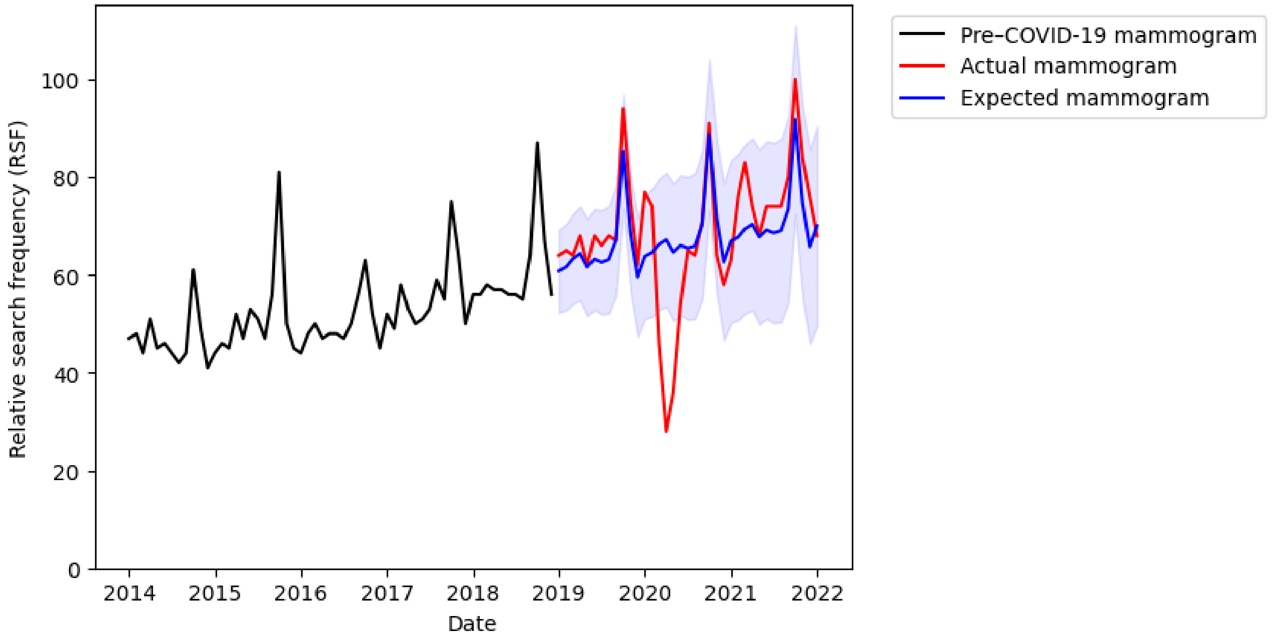
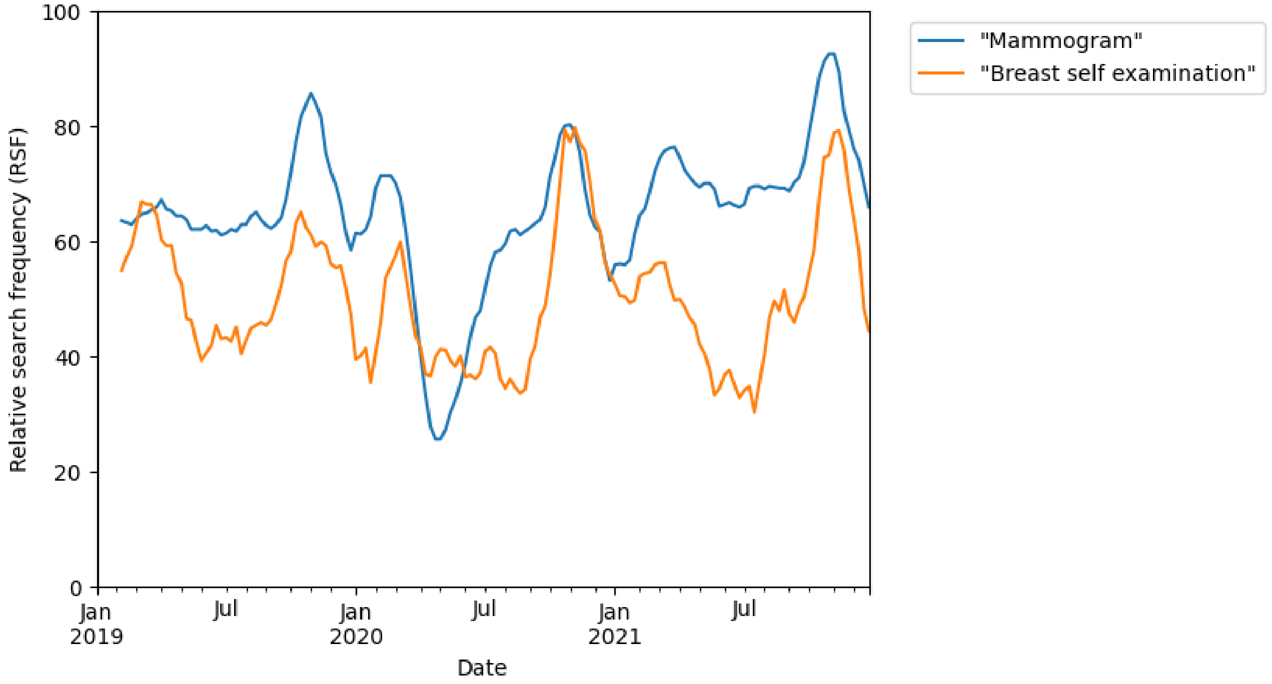


Figure 3. Online search interest in "mammogram" and "breast self examination" during the time period from January 1, 2019 to January 1, 2022. Google Trends relative search frequency (RSF) is reported as a value from 0 to 100, with 100 representing peak popularity of the term over the time period.



To further elucidate the type of information that is searched for in relation to mammogram or breast cancer symptoms, related search terms were assessed. The top and rising terms reported by Google Trends represent search terms that users also searched for alongside the index search terms, thereby giving an unbiased expanded and related search landscape.

The most common related search for mammogram was for basic information: "breast mammogram" and "mammogram screening" (100 and 54 RSF, respectively). This could be a result of individuals seeking information prior to consulting a health care professional for reasons such as obtaining information about disease symptoms, diagnosis, and treatment [22].

During the period from 2019 to 2022, there was an increased interest in the relationship of the COVID-19 vaccine and mammography, the timing of mammogram after COVID-19 vaccination (“covid vaccine mammogram” and “mammogram after covid vaccine”), as well as an increased interest in arranging for mammograms (“mammogram screening near me”; Table 1). When interest in arranging for mammography (“mammogram near me”) was analyzed, we saw that not only did this recover after the initial dip from March to June 2020, but it also exceeded pre–COVID-19 levels. An increased peak size coinciding with the October BRAM (Figure 4) was also seen. Although a relationship between COVID-19 vaccination and mammogram emerged during this time period, after an initial peak at the start of 2021, this quickly diminished in frequency as a search term (Figure 4). An increase in searches for natural and nonsurgical treatment of breast lumps (+170% and +120%, respectively; Table 2) was also observed, which coincided with the start of the COVID-19 pandemic and a drop in interest in lumpectomy and breast biopsy from March to June 2020 (Figure 5).

Table 1. Search terms associated with “mammogram” from January 1, 2019, to January 1, 2022. Relative search frequency (RSF) for “top” terms is reported as a value from 0 to 100, with 100 representing peak popularity of the term over the time period. “Change over time” for rising terms represents the largest increase in search frequency over the aggregated time period.

Term	Value
Top, RSF	
breast mammogram	100
mammogram screening	54
mammogram cancer	53
mammogram near me	41
breast cancer	39
breast cancer mammogram	39
what is mammogram	32
mammogram age	32
ultrasound	29
ultrasound mammogram	29
diagnostic mammogram	24
3d mammogram	24
mammogram icd 10	23
what is a mammogram	18
mammogram cost	16
Rising, change over time	
covid vaccine mammogram	173,100
covid vaccine and mammogram	53,800
mammogram after covid vaccine	53,550
mammogram screening near me	450
focal asymmetry on 3d mammogram	350
breast mammogram near me	250
mammogram near me	180
mammogram screening icd-10	160
free mammogram near me	150
lenox hill radiology	150
schedule a mammogram near me	150
mammogram test near me	130
mobile mammogram near me	120
obgyn near me	120
private mammogram	120

Figure 4. Online search interest in "covid vaccine mammogram" and "mammogram near me" during the time period from January 1, 2019 to January 1, 2022. Google Trends relative search frequency (RSF) is reported as a value from 0 to 100, with 100 representing peak popularity of the term over the time period.

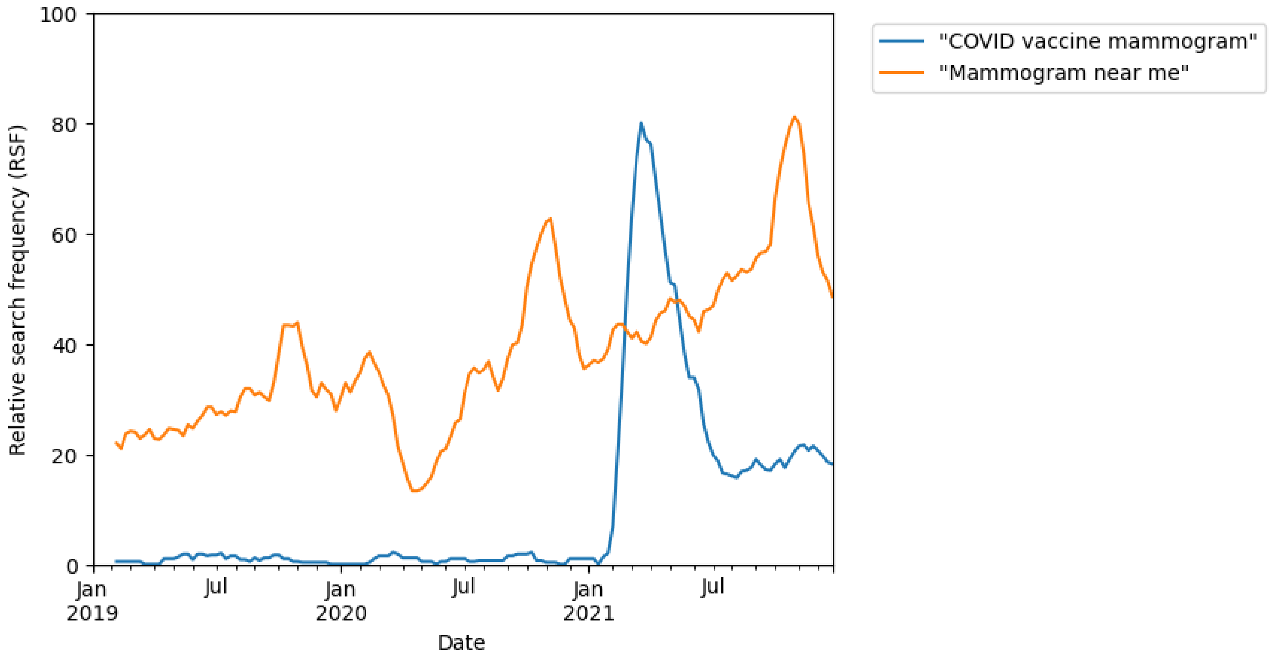
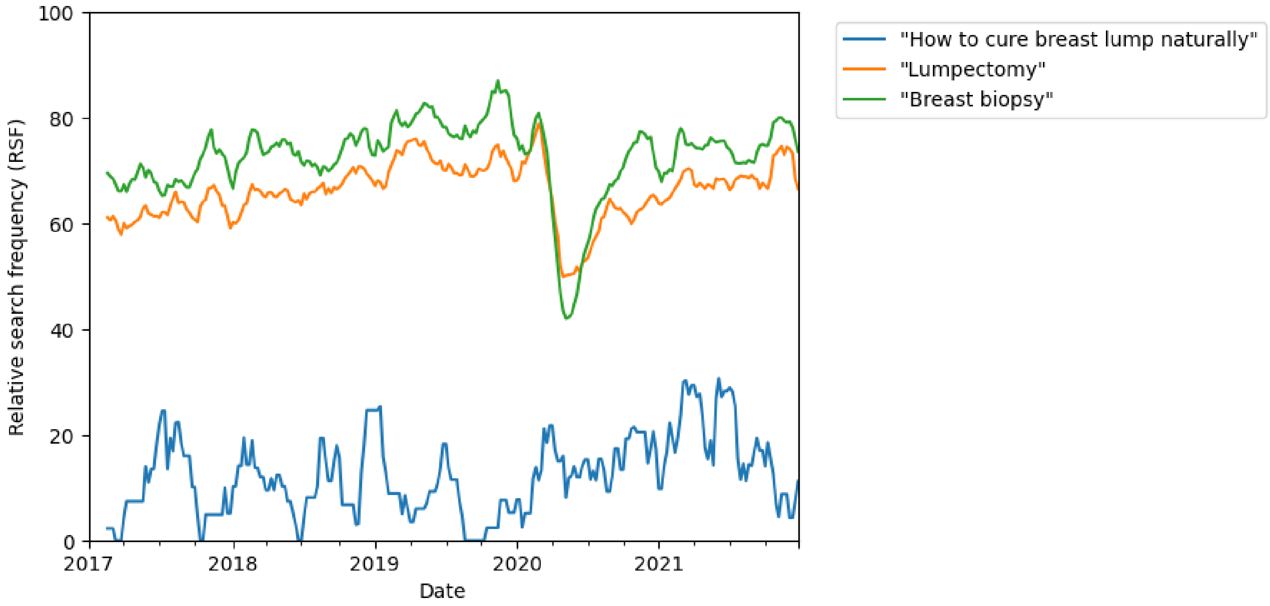


Table 2. Search terms associated with “breast lump” from January 1, 2019, to January 1, 2022. Relative search frequency (RSF0 for “top” terms is reported as a value from 0 to 100, with 100 representing peak popularity of the term over the time period. “Change over time” for rising terms represents the largest increase in search frequency over the aggregated time period.

Term	Value
Top, RSF	
lump in breast	100
cancer breast lump	42
breast cancer	42
lump on breast	35
breast lump pain	21
breast pain	21
painful lump breast	19
painful breast	19
lump in the breast	14
lump under breast	14
Rising, change over time	
breast lump when to worry	400
lump under breast near ribs	350
how to cure breast lump naturally	170
lump on breast bone pictures	160
lump in breast meaning	120
ache in breast no lump	120
how to cure breast lump without surgery	120
which doctor to consult for breast lump	100
left breast lump icd 10	100
pain in left breast	90

Figure 5. Online search interest for "how to cure breast lump naturally," "lumpectomy," and "breast biopsy" between January 1, 2017, and January 1, 2022. Google Trends relative search frequency (RSF) is reported as a value from 0 to 100, with 100 representing peak popularity of the term over the time period.



Discussion

Principal Findings

The purpose of this study was to evaluate the impact of the COVID-19 pandemic on public interest in breast cancer screening and its subsequent recovery. Despite an initial drop in interest in mammography from March to April 2020, it quickly recovered by July 2020. After this period, alongside the recovery of interest in screening, there was a rapid increase in interest for arranging for mammography as indicated by searches for “mammogram near me.”

Previous studies have documented a decrease in cancer screening and diagnosis during the COVID-19 pandemic but not individual’s interest in screening during the crisis [23-25]. The initial dip in search volume could be explained by the postponement of elective visits during the first wave of the pandemic, as searches are usually prompted by upcoming visits and discussions with providers [23,24], or a reluctance in seeking medical attention due to the fear of contracting COVID-19 in the health care setting. As a result of reduced health care contact, newly diagnosed cancer rates declined by 46.4% after the start of the pandemic [26].

Despite the drop in screening, we demonstrated consistent levels of interest in breast cancer–related symptoms and breast self-examination during this period. During times of reduced health care contact, patients continued to use the internet to search for their symptoms. This is concerning given that the use of “Dr. Google” has been linked to increased self-medication and the decision not to see a medical professional [27]. This is reflected in our results showing increased interest in natural treatment of breast lumps, which remains sustained despite the recovery of interest in mammography and breast biopsy.

Our study shows a correlation between health campaign (BCAM) and search behaviors. This result supports previous studies that suggest that infoveillance can measure the success of a campaign in driving information-seeking behaviors in a population [28,29].

Limitations

There are a few limitations to our research. First, there is a potential overrepresentation of younger, more technologically savvy internet users actively searching for health-related terms. Second, data from Google Trends may not represent a portion of the public who do not have internet access, for example, in countries lacking the infrastructure and technology or with lower socioeconomic status. Third, there may be an overrepresentation of English-speaking users who tend to use Google as a primary search engine. For example, instead of Google, Baidu is the top search engine in China with an 83.46% market share [30]. Lastly, even though results indicate general trends, it does not highlight specific subgroups or give information about the demographics of users who could have a higher share in search volumes.

Comparison With Prior Work

Similar prior studies have previously documented a decrease in individuals’ interest in screening during the first peak of the COVID-19 pandemic [7]. We have demonstrated that there does not seem to be lasting adverse effects on public interest in breast cancer screening as interest in mammography and arranging for mammograms returned to or exceeded the pre–COVID-19 level. This recovery may have been aided by BCAM. There are similar levels of peak interest in mammography and breast self-examination during the October BCAM despite the ongoing pandemic.

Conclusions

In conclusion, online search interest in breast cancer screening experienced a sharp decline at the beginning of the COVID-19 pandemic with a subsequent return to baseline interest in arranging for mammography following this short period of decreased interest.

Our study shows that despite concerns about the impact of the COVID-19 pandemic on breast cancer screening, interest in mammography quickly recovered. This has implications for health care providers leveraging this recovery to encourage more individuals to get screened, especially among those who may have delayed their mammogram due to the pandemic and for health service resource allocation to respond to this rapid recovery in interest.

Additionally, the study highlights the importance of monitoring changes in search behaviors related to health care during a crisis, as it may reflect changes in health care–seeking behaviors in the general public.

Future work could investigate whether the pandemic had a differential impact on cancer screening rates and outcomes among different populations, including racial and ethnic minority groups, rural populations, and low-income individuals. It would also be important to assess if the COVID-19 pandemic had a long-term impact on cancer outcomes including delayed diagnoses and increased morbidity and mortality.

Acknowledgments

This study has received no financial support.

Data Availability

Google Trends data are available to all users free of charge [12].

Authors' Contributions

SYT and NBS contributed to conceptualization, data analysis, and manuscript writing. MSST contributed to conceptualization and manuscript writing. C-AJO and VKMT contributed to manuscript review.

Conflicts of Interest

None declared.

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Abbreviations

ARIMA: autoregressive integrated moving average
BCAM: Breast Cancer Awareness Month
RSF: relative search frequency
WHO: World Health Organization

Edited by A Mavragani; submitted 28.04.22; peer-reviewed by DW Han, ER Khalilian, J Lee; comments to author 17.01.23; revised version received 06.05.23; accepted 09.05.23; published 06.06.23.

Please cite as:
Tan SY, Tang MSS, Ong CAJ, Tan VKM, Shannon NB
Impact of COVID-19 on Public Interest in Breast Cancer Screening and Related Symptoms: Google Trends Analysis
JMIR Cancer 2023;9:e39105
URL: https://cancer.jmir.org/2023/1/e39105
doi:10.2196/39105
PMID:37163461

Original Paper

Exposure and Reactions to Cancer Treatment Misinformation and Advice: Survey Study

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Abstract

Background: Cancer treatment misinformation, or false claims about alternative cures, often spreads faster and farther than true information on social media. Cancer treatment misinformation can harm the psychosocial and physical health of individuals with cancer and their cancer care networks by causing distress and encouraging people to abandon support, potentially leading to deviations from evidence-based care. There is a pressing need to understand how cancer treatment misinformation is shared and uncover ways to reduce misinformation.

Objective: We aimed to better understand exposure and reactions to cancer treatment misinformation, including the willingness of study participants to prosocially intervene and their intentions to share Instagram posts with cancer treatment misinformation.

Methods: We conducted a survey on cancer treatment misinformation among US adults in December 2021. Participants reported their exposure and reactions to cancer treatment misinformation generally (saw or heard, source, type of advice, and curiosity) and specifically on social media (platform, believability). Participants were then randomly assigned to view 1 of 3 cancer treatment misinformation posts or an information post and asked to report their willingness to prosocially intervene and their intentions to share.

Results: Among US adult participants (N=603; mean age 46, SD 18.83 years), including those with cancer and cancer caregivers, almost 1 in 4 (142/603, 23.5%) received advice about alternative ways to treat or cure cancer. Advice was primarily shared through family (39.4%) and friends (37.3%) for digestive (30.3%) and natural (14.1%) alternative cancer treatments, which generated curiosity among most recipients (106/142, 74.6%). More than half of participants (337/603, 55.9%) saw any cancer treatment misinformation on social media, with significantly higher exposure for those with cancer (53/109, 70.6%) than for those without cancer (89/494, 52.6%; $P<.001$). Participants saw cancer misinformation on Facebook (39.8%), YouTube (27%), Instagram (22.1%), and TikTok (14.1%), among other platforms. Participants (429/603, 71.1%) thought cancer treatment misinformation was true, at least sometimes, on social media. More than half (357/603, 59.2%) were likely to share any cancer misinformation posts shown. Many participants (412/603, 68.3%) were willing to prosocially intervene for any cancer misinformation posts, including flagging the cancer treatment misinformation posts as false (49.7%-51.4%) or reporting them to the platform (48.1%-51.4%). Among the participants, individuals with cancer and those who identified as Black or Hispanic reported greater willingness to intervene to reduce cancer misinformation but also higher intentions to share misinformation.

Conclusions: Cancer treatment misinformation reaches US adults through social media, including on widely used platforms for support. Many believe that social media posts about alternative cancer treatment are true at least some of the time. The willingness of US adults, including those with cancer and members of susceptible populations, to prosocially intervene could initiate the necessary community action to reduce cancer treatment misinformation if coupled with strategies to help individuals discern false claims.

(JMIR Cancer 2023;9:e43749) doi:10.2196/43749

KEYWORDS

cancer; misinformation; social media; prosocial intervening; treatment; false information; alternative medicine; information spread; dissemination; infodemiology; mobile phone

Introduction

Background

Cancer misinformation shared through word of mouth and on social media is harmful to individuals with cancer, as well as cancer care networks made of friends, family, and individuals who support them [1,2]. Cancer misinformation comprises claims that are not supported by current scientific consensus [2,3]. Specifically, cancer treatment misinformation includes false, exaggerated, or misleading claims about cancer treatments and cures. Individuals with cancer and their care networks receive unwanted advice through cancer misinformation directly from individuals they know and on social media [4,5]. Social media posts with cancer information have been found to contain 30% to 80% misinformation, generally, with treatment-related posts containing more misinformation than other types of cancer support [6-9].

Cancer treatment misinformation harms the psychological health of individuals with cancer and their care networks by increasing distress, self-doubt, or decisional regret [4,10]. Social support can also be disrupted if individuals feel pressured to abandon relationships and resources to avoid exposure to cancer treatment misinformation [4,5]. Cancer misinformation is also potentially harmful to physical health if one acts on treatment misinformation by deviating from evidence-based care plans or using untested supplements, diets, or therapies commonly found on social media [11-14]. Emerging evidence suggests that patients may have over a 2-fold increased risk of death if they abandon evidence-based clinical care for false cures [13,15] and that addressing misinformation for treatment decisions could increase survival by more than 5 times among some cancers [9,13,15]. Moreover, the physical and mental health of individuals with cancer is strained when people in their care networks are distressed by cancer misinformation and care burdens [10].

Cancer misinformation spreads farther and faster than accurate information on social media through public posts and private messages in the United States [6]. Most US adults own or have access to a smartphone (85%) [16], use the web daily (85%) [17], and use visual-based social media (81%) [18]. Individuals use social media to seek cancer-related information and immediate answers for themselves or to support their loved ones in treatment or survivorship [4,19-21]. After diagnosis, individuals with cancer and their care networks receive more web-based cancer misinformation at higher frequencies [4,22] and are particularly susceptible when experiencing stress and despair when cancer advances or recurs or is not responsive to the treatment. Unfortunately, many in cancer care networks amplify harmful cancer misinformation with good intentions [20,23,24]; this misguided altruism should be redirected to support community action to prosocially intervene, including removing or refuting false claims, to reduce cancer misinformation.

Objectives

Understanding exposure and reactions to cancer misinformation is critical for developing responsive social media designs to encourage prosocial intervention, instead of sharing, to reduce misinformation. In this study, we asked US adults about cancer misinformation exposure to better understand where this information comes from and the types of unwanted advice to answer the following research questions: (1) Are people receiving advice for cancer treatment misinformation? If yes, from whom and what is the advice? (2) Are individuals who receive cancer treatment misinformation curious about these alternative treatments or cures? and (3) Are people exposed to cancer treatment misinformation on social media platforms, on what platforms, and do they believe this misinformation to be true? We then explored the reactions to cancer misinformation posts on visual-based social media. US adult participants, including those with cancer and cancer caregivers, viewed 1 of 4 posts about cancer treatments and cures adapted from Instagram and reported their willingness to intervene (intended reaction) and sharing intentions (unintended reaction) to address the remaining research questions: (4) Are individuals willing to prosocially intervene with cancer treatment misinformation? What actions would people take? and (5) Do individuals intend to share cancer treatment misinformation? What are the channels?

Methods

Participants

We recruited a convenience sample of US adults through the Qualtrics Online Panel platform (Qualtrics LLC) from December 7, 2021, to December 10, 2021, as part of a study on health behaviors and beliefs. To be eligible for the study, individuals had to be aged ≥18 years and live in the United States (as determined via “GeoIP Estimation” on the Qualtrics platform) at the time of completing the survey. There were no additional exclusion criteria.

Ethics Approval, Informed Consent, and Participation

The University of North Carolina Institutional Review Board approved all study procedures (#20-2338). After accessing the survey link, the participants provided informed consent by reading the approved consent form. Participants then clicked to move forward with the survey after viewing this statement: “By continuing with the survey below, you acknowledge that you have read the information on this page and agree to be in this research study.” The participants received incentives based on the reward type and amount set by the survey vendor, Qualtrics (eg, cash and reward points). To protect the privacy and confidentiality of participants, all publicly available quantitative data were deidentified, and open-ended responses were not included in those public repositories.

Procedure

The participants provided their consent before beginning the web-based survey. Before responding to our study questions, the participants responded to items about dietary choices, the needs of families with children diagnosed with intellectual or developmental disabilities, trust in health-related information, physical activity and sleep, and access to COVID-19–related information. Participants were then given the following prompt about the focus of our study before answering any items: “We want to ask you about advice for alternative cancer treatments or cures offered by someone outside a clinical care team. Sometimes individuals offer advice about alternative ways to treat or cure cancer (e.g., shrink tumors). You may have experienced this for yourself or for someone you know with cancer. This is different from advice to treat symptoms (e.g., manage pain)” (see Appendix A in Multimedia Appendix 1 for full survey).

After reading this prompt, the participants reported their exposure to advice for alternative treatments or cures for cancer. Participants who reported past exposure to advice were given additional items regarding (1) the source of the advice, (2) a description of what was recommended, and (3) whether they were curious about the treatment or cure.

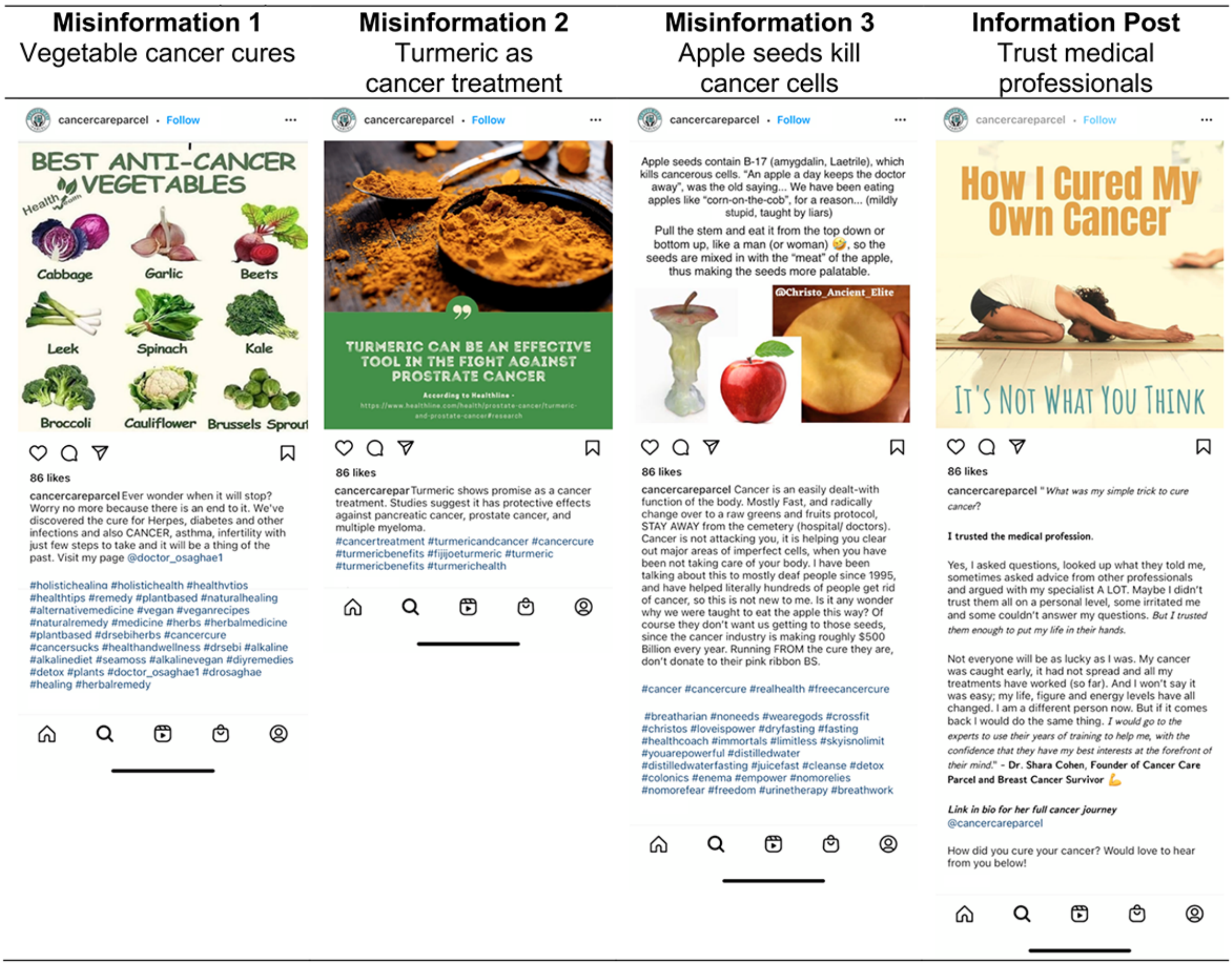
Next, all participants reported whether they had exposure to information about alternative cancer treatments or cures on social media by selecting different platforms, as well as how often they perceived this cancer information to be true. This section began with this prompt: “For these next questions, think about any advice you have been given, information shared with others, or general posts and comments on social media.”

All participants were then randomized to view 1 of 4 Instagram posts with cancer information: 3 misinformation posts (false according to scientific consensus) or 1 information post (accurate according to scientific consensus). With the stimuli shown, participants reported their willingness to prosocially intervene (intended reaction) and intentions to share (unintended reaction), regardless of which of the 4 posts they received (misinformation or information). Finally, the participants reported their demographic information, including their personal experiences with cancer or cancer caregiving. All participants viewed the same survey with 2 exceptions: (1) participants were only asked about the source, description, and curiosity that the cancer treatment advice aroused if they selected “yes” to exposure and (2) the Instagram posts were randomized so that participants only saw 1 of the 4 possible stimuli.

Stimuli

The 4 stimulus posts were adapted from cancer treatment posts found on Instagram (Figure 1). For the misinformation stimuli, we modified 3 Instagram posts that contained misinformation about false cancer treatments and cures. The original posts were all found under the hashtag #cancercure and contained highly prevalent misinformation, encouraging individuals to deviate from their current or evidence-based care by trying untested therapies or experimenting with home remedies, including recommendations for specific supplements or diets [4,6,23,25]. These misinformation stimulus posts were about vegetable cancer cures (misinformation 1), turmeric as a cancer treatment (misinformation 2), and apple seeds killing cancer cells (misinformation 3). For a comparison condition, we selected 1 Instagram post about trusting cancer medical experts for evidence-based care (information post). Screenshots of the Instagram posts were captured to retain the visuals and text as they appeared on social media; only the source and engagement metrics were updated to be consistent across stimuli (ie, the same profile photo, profile name, and number of likes).

Figure 1. Cancer misinformation stimulus posts.



Misinformation 1
Vegetable cancer cures

cancercareparcel • Follow

86 likes

cancercareparcel Ever wonder when it will stop? Worry no more because there is an end to it. We've discovered the cure for Herpes, diabetes and other infections and also CANCER, asthma, infertility with just few steps to take and it will be a thing of the past. Visit my page @doctor_osaghae1

#holistichealing #holistichealth #healthytips #healthtips #remedy #plantbased #naturalhealing #alternativemedicine #vegan #veganrecipes #naturalremedy #medicine #herbs #herbalmedicine #plantbased #drsebiherbs #cancercure #cancersucks #healthandwellness #drsebi #alkaline #alkalinediet #seamoss #alkalinevegan #diyremedies #detox #plants #doctor_osaghae1 #drosaghae #healing #herbalremedy

Misinformation 2
Turmeric as cancer treatment

cancercareparcel • Follow

86 likes

cancercarepar Turmeric shows promise as a cancer treatment. Studies suggest it has protective effects against pancreatic cancer, prostate cancer, and multiple myeloma.
#cancertreatment #turmericandcancer #cancercure #turmericbenefits #fijijoeturmeric #turmeric #turmericbenefits #turmerichealth

Misinformation 3
Apple seeds kill cancer cells

cancercareparcel • Follow

Apple seeds contain B-17 (amygdalin, Laetrile), which kills cancerous cells. "An apple a day keeps the doctor away", was the old saying... We have been eating apples like "corn-on-the-cob", for a reason... (mildly stupid, taught by liars)

Pull the stem and eat it from the top down or bottom up, like a man (or woman) 🤣, so the seeds are mixed in with the "meat" of the apple, thus making the seeds more palatable.

86 likes

cancercareparcel Cancer is an easily dealt-with function of the body. Mostly Fast, and radically change over to a raw greens and fruits protocol, STAY AWAY from the cemetery (hospital/ doctors). Cancer is not attacking you, it is helping you clear out major areas of imperfect cells, when you have been not taking care of your body. I have been talking about this to mostly deaf people since 1995, and have helped literally hundreds of people get rid of cancer, so this is not new to me. Is it any wonder why we were taught to eat the apple this way? Of course they don't want us getting to those seeds, since the cancer industry is making roughly $500 Billion every year. Running FROM the cure they are, don't donate to their pink ribbon BS.

#cancer #cancercure #realhealth #freecancercure

#breatharian #noneeds #wearegods #crossfit #christos #loveispower #dryfasting #fasting #healthcoach #immortals #limitless #skyisnolimit #youarepowerful #distilledwater #distilledwaterfasting #juicefast #cleanse #detox #colonics #enema #empower #nomorelies #nomorefear #freedom #urinetherapy #breathwork

Information Post
Trust medical professionals

cancercareparcel • Follow

86 likes

cancercareparcel "*What was my simple trick to cure cancer?*

I trusted the medical profession.

Yes, I asked questions, looked up what they told me, sometimes asked advice from other professionals and argued with my specialist A LOT. Maybe I didn't trust them all on a personal level, some irritated me and some couldn't answer my questions. *But I trusted them enough to put my life in their hands.*

Not everyone will be as lucky as I was. My cancer was caught early, it had not spread and all my treatments have worked (so far). And I won't say it was easy; my life, figure and energy levels have all changed. I am a different person now. But if it comes back I would do the same thing. *I would go to the experts to use their years of training to help me, with the confidence that they have my best interests at the forefront of their mind.*" - **Dr. Shara Cohen, Founder of Cancer Care Parcel and Breast Cancer Survivor** 💪

Link in bio for her full cancer journey
@cancercareparcel

How did you cure your cancer? Would love to hear from you below!

Measures

Advice for Cancer Treatment and Cures

Exposure to advice about cancer treatment was assessed with the item, "Have you seen or heard anyone offering alternative treatment or cures for cancer?" The response options were "yes," "no," or "not sure"; only individuals who responded "yes" were considered to have prior exposure and were asked about the following items: (1) source, (2) description of the advice, and (3) curiosity. Participants reported the source of advice with the item "Who offered advice about alternative cancer treatment or cures? Check all that apply." The response options included "family," friends," "someone I know but wouldn't consider a friend," "someone I don't know," and "other, please describe." A description of the advice was captured with the open-ended question "What was the advice for treatment of cancer cures?" Curiosity about the advice was captured with "Were you ever curious about using any alternative treatments or cures suggested for yourself or someone you know with cancer?" with the response options "never," "sometimes," "usually," and "always." Higher scores indicated greater curiosity.

Cancer Treatment Misinformation on Social Media

Exposure to information about alternative cancer treatments on social media was assessed with the question "Have you seen any information about alternative cancer treatments or cures on social media? Select all platforms where you have seen advice for alternative treatments and cures." The response options included "Facebook," "Instagram," "Twitter," "YouTube," "TikTok," "Snapchat," "Pinterest," "Reddit," "other," and "I have not seen information about alternative treatments or cures on social media." All the participants then responded how often they perceived the information to be believable or true by replying to the question "To the best of your knowledge, how often is information about alternative cancer treatments and cures shared on social media true?" The response options were "never," "sometimes," "usually," and "always." Higher scores indicated that information was believed to be true more often.

Willingness to Intervene

We assessed whether the individuals would be willing to intervene to reduce cancer misinformation with 5 specific actions. Following the stem of "How likely would you be to...," actions included the following: "flag as misinformation for others to see with system options," "like (endorse) comments that disagree with information in this post," "comment on the post(s) to correct untrue information," "report as misinformation to the platform," and "hide the untrue information so others wouldn't see it, but the poster isn't aware of your action (if available)." The response options were "not at all," "a little," "a moderate amount," "quite a bit," and "a great deal." Higher scores indicated a greater willingness to prosocially intervene.

Sharing Intentions

We assessed whether and how people would share by asking them to follow the stem "How likely would you be to..." with "comment on the post to endorse the information," "share with someone in a direct message," "text it to someone," "show someone in person," or "post on your social media." The response options were "not at all," "a little," "a moderate amount," "quite a bit," and "a great deal." Higher scores indicated greater sharing intentions.

Data Analysis

Before data collection, we preregistered this study on AsPredicted (2WN_3HD). We first analyzed descriptive results for all outcomes (eg, frequencies, means, and SDs), by cancer status (had a previous diagnosis vs no diagnosis) and assigned stimuli (1 of 3 misinformation posts or the information post), to assess the willingness to intervene and sharing intentions. For significance testing, we ran separate 2-tailed *t* tests to compare whether each Instagram misinformation post increased willingness to intervene or sharing intentions compared with the post with information about trusting evidence-based care recommendations. If there were significant differences for a misinformation post versus the information post (ie, $P<.05$), we examined individual actions to better understand how participants would intervene or share the misinformation.

We added to our preregistered analyses in 3 ways: (1) we explored whether there were differences in cancer misinformation exposure (from someone offering advice and social media), curiosity, and believability by cancer status (had a previous diagnosis vs not). We conducted chi-square tests for assessing the categorical outcomes (general exposure and social media exposure) and 2-tailed *t* tests for assessing the continuous outcomes (curiosity and believability); (2) we conducted ANOVAs to examine the main effects and moderation by cancer status (had a previous diagnosis vs not), caregiving status (was or is a caregiver vs not), race (Black vs White participants), and ethnicity (Hispanic vs non-Hispanic) on willingness to intervene or share cancer misinformation. Each subgroup was included as a predictor, along with the participants' assigned stimuli (1 of 3 misinformation posts or the information post), in separate ANOVAs for assessing the willingness to prosocially intervene and sharing intentions; and (3) we coded the open-ended responses for types of cancer treatments and cures that the participants personally received after the data collection was complete.

Cancer treatments and cure responses were coded as "digestive," including food, drinks, dietary supplements, or over-the-counter medication taken orally or inhaled; "natural," including holistic, homeopathic, or natural medicine; "experiential," including positive thinking, knowledge, mediation, yoga, or other physical activity; "location," including traveling to a specific place; "topical," including creams, crystals, clothing, or other items put on the body; and "clinical cancer care," including chemotherapy, radiation, and surgery. Responses were coded for the type of treatment or cure reported (yes=1 and no=0), regardless of the direction of the advice—to use or avoid—or the nature of the advice—accurate or misinformation. Codes for types of alternative treatments and cures were not mutually exclusive except for our last code: if the treatment or cure advice was unclear (eg, lifestyle changes), this was coded as "unspecified" alternative advice only. We double coded all open-ended responses independently with 2 team members (95% agreement). When the initial codes were not in agreement, a third coder independently resolved for the majority or unanimous agreement for all codes in the final data set.

Results

Overview

Participants' (N=603) average age was 46 (SD 18.83) years. See Table 1 for participant demographics and cancer characteristics and Appendix B in Multimedia Appendix 1 for demographics by stimuli exposure group. Participants identified as female (347/603, 57.5%), non-Hispanic (538/603, 89.2%), White (463/603, 76.8%), and Black or African American adults (83/603, 13.8%). Almost 1 in 5 participants (109/603, 18.1%) had a previous cancer diagnosis, and more than a third (211/603, 35%) were cancer caregivers.

Table 1. Participant characteristics (N=603).

Characteristics	Values
Current age (years), mean (SD)	45.74 (18.83)
Gender[a], n (%)	
Woman	347 (57.5)
Man	247 (41.2)
Neither woman nor man	6 (1)
Transgender[a], n (%)	
Yes, transgender	27 (4.5)
No, not transgender	569 (95.5)
Sexual orientation[a], n (%)	
Straight or heterosexual	524 (87.6)
Gay or lesbian	28 (4.7)
Bisexual	46 (7.7)
Race and ethnicity, n (%)	
White	463 (76.8)
Black or African American	83 (13.8)
American Indian or Alaska Native	12 (2)
Asian	21 (3.5)
Native Hawaiian or Other Pacific Islander	2 (0.3)
Some other race	8 (1.3)
Multiracial	14 (2.3)
Hispanic, Latino, or Spanish ethnicity, n (%)	
Yes	65 (10.8)
No	538 (89.2)
Education, n (%)	
Less than high school	37 (6.1)
High school or GED[b]	181 (30)
Some college	162 (26.9)
Associate’s degree	53 (8.8)
Bachelor’s degree	107 (17.7)
Graduate or professional degree	62 (10.3)
Annual household income (US $)[a], n (%)	
0-24,999	227 (37.8)
25,000-49,999	168 (27.9)
50,000-74,999	73 (12.1)
≥75,000	134 (22.3)
Cancer survivor, n (%)	
Yes	109 (18.1)
No	494 (81.9)
Primary diagnosis (n=109)	
Bladder cancer	3 (2.8)
Breast cancer	10 (9.2)

Characteristics	Values
Colon and rectal cancer	11 (10.1)
Endometrial cancer	5 (4.6)
Kidney cancer	8 (7.3)
Leukemia	4 (3.7)
Liver cancer	3 (2.8)
Lung cancer	7 (6.4)
Melanoma	8 (7.3)
Non-Hodgkin lymphoma	4 (3.7)
Nonmelanoma skin cancer	5 (4.6)
Pancreatic cancer	2 (1.8)
Prostate cancer	9 (8.2)
Thyroid cancer	3 (2.8)
Other cancer	22 (20.2)
Cancer caregiver, n (%)	
Yes	211 (35)
No	392 (65)
Relationship to the recipient of cancer care (n=211)	
Spouse or partner	58 (27.5)
Parent	77 (36.5)
Another family member	74 (35.1)
Friend	28 (13.3)
Other	7 (3.3)

[a] Total is <603 participants for demographic characteristics of gender (n=600), transgender people (n=596), sexual orientation (n=598), and annual household income (n=602) because of participants preferring not to report or missing data.

[b] GED: General Educational Development.

Exposure to Misinformation for Cancer Treatments and Cures

When asked about past exposure to advice for alternative cancer treatments and cures generally, about 1 in 4 participants (142/603, 23.5%) reported receiving advice. Exposure to advice about alternative treatments and cures (ie, cancer treatment misinformation) was significantly higher among individuals with a cancer diagnosis (53/109, 48.6%) than those without (89/494, 18%) a cancer diagnosis; $c^{2}_{2}=46.5$, $P<.001$.

Among those exposed to misinformation (n=142), the advice for alternative treatment and cures was primarily from family (39.4%), friends (37.3%), people they did not know (27.5%), and acquaintances (21.1%). In addition, among those exposed to advice, 3 out of 4 individuals (106/142, 74.6%) were curious about these alternative cancer treatments and cures, ranging from being sometimes (43.7%) to usually (18.3%) to always (12.7%) curious. Curiosity did not differ by cancer status (t_{140}=.05; P=.96).

Shared advice for cancer treatment and cures ranged from general to specific advice. Most advice shared was about digestive or dietary treatments (30.3%). Dietary advice included to have a "good diet," "eat more fruits," "vitamins," and use "cannabis" in many forms. Dietary advice also included more problematic and potentially harmful misinformation, which included taking "non-sanctioned," "medication," and "dietary supplements" without US Food and Drug Administration approval; "medication that's meant to treat dogs"; diets with "no solid foods"; and diets to "change the pH of the body." Natural treatments and cures (14.1%), often including recommendations for herbal remedies, were the next most common alternative options. One in 10 participants (14/142, 9.9%) reported receiving some advice for clinical care, including to receive (or not receive) chemotherapy, radiation, or surgery; notably, without patient information, it is impossible to determine whether this advice follows or deviates from scientific consensus for evidence-based care. Fewer participants shared that they received experiential advice for prayer or positive thinking (9.2%), to go to a specific location like "Mexico for treatment" (4.9%), or the use of essential oils as a potential topical treatment (1.4%). About 1 in 10 participants (13/142, 9.2%) did not specify the type of treatment or cure suggested.

Participants reported higher exposure to misinformation on social media; more than half of all participants (55.9%) reported exposure to advice, information shared with others, and general posts or comments about alternative cancer treatment or cures on social media. Exposure to cancer misinformation on social media was significantly higher among those with a cancer diagnosis (70.6%) compared with those without a cancer diagnosis (52.6%; c^2_8=23.0, *P*=.003). Exposure differed by platform, with the greatest exposure on Facebook (39.8%), followed by YouTube (27%), Instagram (22.1%), TikTok (14.1%), Twitter (11.6%), Snapchat (11.6%), Pinterest (6%), and Reddit (3.3%). Although more than a quarter of the participants (28.7%) said this information was "never" true, most thought information on social media about alternative treatments and cures was sometimes (51.4%), usually (14.4%), or always (5.3%) true. Notably, individuals with cancer (mean score 2.17, SD 0.94) believed cancer treatment misinformation on social media to be true more often compared with those without a diagnosis (mean score 1.92, SD 0.76; t_{141}=2.56; *P*=.01).

Willingness to Intervene With Cancer Misinformation on Instagram

Participants were, on average, moderately willing to intervene with any action across the Instagram posts (mean score 2.35, SD 1.08; a=.861). Participants were more likely to intervene (overall) with the misinformation post about vegetable cancer cures when compared with the information post for trusting cancer medical experts (t_{303}=2.03; *P*=.04; Table 2). For specific actions for the vegetable cancer cures misinformation post (vs information post), participants were more willing to flag it as misinformation (t_{302}=2.11; *P*=.04) and endorse (ie, like) comments that disagreed with the post (t_{303}=2.55; *P*=.01). There were no differences in the willingness to comment to correct untrue information (*P*=.88), hide the post so that others would not see (*P*=.07), or report the post as misinformation to the platform (*P*=.11). The act of intervening did not differ for the other 2 misinformation posts (vs information post) about turmeric as a cancer treatment (*P*=.32) and apple seeds killing cancer cells (*P*=.31).

Table 2. Willingness to intervene and sharing intentions.[a]

	All posts (N=603)		Misinformation 1, vegetables (n=148)		Misinformation 2, turmeric (n=156)		Misinformation 3, apple seeds (n=143)		Information post (n=156)	
	Score, mean (SD)	% likely	Score, mean (SD)	% likely	Score, mean (SD)	% likely	Score, mean (SD)	% likely	Score, mean (SD)	% likely
Willingness to intervene										
Overall	2.35 (1.08)	68.3	*2.48 (1.11)*[b]	70.9	2.35 (1.10)	69.9	2.35 (1.06)	69	*2.22 (1.04)*	64.1
Flag as misinformation	2.42 (1.37)	48.3	*2.55 (1.37)*	51.4	2.40 (1.33)	50.0	2.51 (1.45)	50	*2.22 (1.31)*	42.3
Endorse (like) rebuttals	2.29 (1.31)	44.3	*2.54 (1.35)*	53.4	2.36 (1.37)	44.2	2.10 (1.21)	41	*2.15 (1.27)*	39.1
Comment to correct	2.33 (1.33)	45.3	2.39 (1.33)	48.6	2.30 (1.34)	44.2	2.24 (1.29)	43	2.37 (1.36)	45.5
Report to platform	2.43 (1.37)	48.6	2.53 (1.33)	51.4	2.37 (1.34)	48.1	2.56 (1.48)	51	2.28 (1.32)	44.2
Hide post	2.27 (1.35)	42.3	2.37 (1.40)	44.6	2.29 (1.33)	43.6	2.35 (1.42)	45	2.10 (1.26)	35.9
Sharing intentions										
Overall	2.31 (1.23)	59.2	2.50 (1.26)	63.5	2.36 (1.26)	60.9	2.07 (1.15)	51.7	2.29 (1.20)	56.4
Comment to endorse	2.25 (1.31)	43.9	2.40 (1.31)	49.3	2.31 (1.35)	45.5	2.07 (1.27)	39.9	2.22 (1.31)	41
Share in a direct message	2.34 (1.37)	45.6	2.55 (1.42)	53.4	2.41 (1.43)	48.1	2.08 (1.26)	35.7	2.31 (1.32)	44.9
Text to someone	2.32 (1.37)	44.4	2.54 (1.42)	51.4	2.31 (1.38)	44.9	2.05 (1.26)	35	2.37 (1.36)	46.2
Show in person	2.38 (1.36)	47.6	2.58 (1.40)	52.7	2.44 (1.39)	51.9	2.15 (1.34)	39.9	2.33 (1.30)	45.5
Post on social media	2.25 (1.37)	43.1	2.45 (1.42)	50	2.31 (1.37)	43.6	2.01 (1.32)	37.8	2.21 (1.35)	41

[a] Percentage of individuals who reported they were "a moderate amount" (3) to "a great deal" (5) likely to intervene or share on a 1 to 5 scale; participants who selected "not at all" (1) or "a little bit" (2) were excluded from the percentage share. Overall, % likely represents the percentage of participants who were "a moderate amount" to "a great deal" likely to intervene or share via one or more specific actions.

[b] Italicized values indicate that they share a superscript difference by *P*<.05.

Many participants (412/603, 68.3%) reported that they were willing to intervene with the Instagram cancer misinformation posts. Specific to the 3 misinformation posts, participants were willing to "a moderate amount" to "a great deal" (3-5 on a 5-point scale) to intervene by flagging the posts as misinformation for others to see (49.7%-51.4%) and reporting the posts as misinformation to the platform (48.1%-51.4%), followed by liking a comment that disagrees with the post (40.6%-53.4%), commenting to correct untrue information (42.7%-48.6%), and hiding the post from others (43.6%-45.5%).

Being a cancer survivor or a cancer caregiver, as well as race and ethnicity, did not moderate willingness to intervene with the cancer Instagram posts (misinformation vs information). However, there was a main effect of willingness to intervene among cancer survivors; individuals with a cancer diagnosis were significantly more likely to intervene (mean score 2.57, SD 1.08) across any misinformation posts compared with those without diagnoses (mean score 2.30, SD 1.07; F_{1595}=5.12; *P*=.02). There were also main effects of race and ethnicity. Black participants were significantly more willing (mean score 2.81, SD .92) to prosocially intervene across any misinformation posts compared with White participants (mean 2.24, SD 1.08; F_{1539}=19; *P*<.001). Hispanic participants were more willing to intervene (mean score 2.64, SD 1.17) than non-Hispanic participants (mean score 2.31, SD 1.06; F_{1596}=4.01; *P*=.05). Being a caregiver (vs not) did not influence the willingness to intervene overall.

Sharing Cancer Misinformation on Instagram

Participants were, on average, had moderate sharing intentions with any Instagram posts (mean score 2.31, SD 1.23; a=.944). Sharing intentions did not differ across cancer misinformation posts. Participants reported that they would similarly share the information post on trusting cancer medical experts compared with vegetable cancer cures (*P*=.12), turmeric as a cancer treatment (*P*=.63), and apple seeds killing cancer cells (*P*=.12).

More than half of the participants (357/603, 59.2%) reported that they were willing to share the Instagram cancer misinformation posts. Specific to the 3 misinformation posts, participants were most willing to share by showing them to someone in person (39.9%-52.7%) and sending a private, direct message (35.7%-53.4%), followed by sending a text message (35%-51.4%), posting or reposting on social media (37.8%-50%), and commenting on the post to endorse the information (39.9%-49.3%).

The cancer survivor status, cancer caregiver status, race, or ethnicity did not moderate the sharing of cancer posts on Instagram (misinformation vs information). However, there was a main effect among cancer survivors; individuals with a cancer diagnosis were significantly more likely (mean score 2.58, SD 1.28) to share any misinformation posts compared with participants without diagnoses (mean score 3.0, SD 1.21; F_{1595}=6.01; *P*=.02). Again, there were also main effects of race and ethnicity on sharing. Black participants were significantly more likely (mean score 3.05, SD 1.14) to share any misinformation posts than White participants (mean score 2.15, SD 1.20; F_{1539}=37; *P*<.001). Hispanic participants were significantly more likely (mean score 2.78, SD 1.24) to share any misinformation posts than non-Hispanic participants (mean score 2.25, SD 1.21; F_{1596}=10; *P*=.002). Being a caregiver (vs not) did not influence sharing intentions.

Discussion

Principal Findings

Cancer misinformation is shared widely in the United States, especially on social media, where false or misleading claims spread farther and faster than true information. Cancer misinformation is especially problematic when it is about alternative treatments or cures that are not supported by the current scientific consensus and are harmful [3,9]. When people turn to the internet after being diagnosed or when caring for someone, they hope to find information and support [21]. Yet many are exposed to viral, novel, shocking, and personal stories that claim to be true but are not [26]. A good proportion of cancer misinformation (77% in one study) can actually harm individuals with cancer, and too-good-to-be-true treatments and cures can impede treatment decision-making [9,13].

We found that 1 in 2 participants with cancer recalled someone offering them cancer misinformation as advice, while among all participants, about 1 in 4 witnessed or received advice for alternative cancer treatments and cures (in general, not social media specific). The misinformation about cancer treatment was often received from family and friends. Advice on dietary or natural alternative treatments was the most common. Although some pieces of advice may not harm patients unless used in lieu of conventional treatment (eg, following a healthy diet), other pieces of advice reported by participants includes potentially harmful cancer misinformation, including the use of nonsanctioned medicine, treatments developed for animals, or other supplements that are not US Food and Drug Administration approved. Advice about clinical care is a large and potentially problematic issue [1]. Any advice for substandard care could cause harm, and interest in this type of cancer misinformation may be higher among individuals with advanced cancer or individuals seeking advice not received during clinical encounters or novel treatments (eg, data for focal therapy for prostate cancer is weak but patients may want this to be a viable option for them) [27]. Notably, 3 out of 4 participants who received advice were curious about the alternative treatment or cure, indicating high interest among the participants when advice was given.

Exposure to any information or cancer treatment misinformation was more common on social media where more than half of the participants—regardless of cancer or caregiving status—recalled seeing information about alternative cancer treatments and cures. Cancer misinformation on social media platforms mirrored use patterns in the United States; exposure was the greatest on platforms used more by adults, including the most popular sites, YouTube and Facebook, followed by Instagram and other social media platforms [18]. It is not surprising that people see cancer misinformation on platforms that they see often. Our findings support calls for a stronger focus on visual-based social media sharing of cancer misinformation [28].

Problematically, misinformation for alternative cancer treatments and cures on social media is believable; more than two-thirds of the participants thought that these alternative treatments and cures were true at least some of the time. When cancer treatment misinformation is inconsistent with clinical consensus, it puts additional strain on patients and their care networks [9]; these individuals must verify the accuracy and relevance of information with their physicians and clinical care team and must verify other (potentially questionable) information on the internet. As we work to reduce cancer treatment misinformation, strategies that leverage social correction (a form of prosocial intervention) are likely to be more effective if supported with accompanying facts or sources to increase credibility and believability [29].

Stopping the spread of cancer misinformation through prosocial intervention may help reduce the harmful impact of false or misleading treatment claims, but only if people are able to discern false claims. Our findings point to an opportunity, along with a need, to encourage individuals to engage in bystander intervention with cancer misinformation. Although 2 in 3 participants, including those with cancer and caregivers, were willing to prosocially intervene with a variety of digital actions, many appeared to be poor at discerning what is true or trustworthy cancer treatment information on social media. In only one instance did the participants have higher willingness to intervene with false information than they did with true information post, with a recommendation to trust medical professionals. Furthermore, similar sharing intentions for true and false claims suggest that people need more guidance to assess the accuracy of social media posts. Because individuals skim social media posts, they often do not fully vet the accuracy of the content [30]. Thus, in our study, it is possible that the caption for the information post (ie, “How I cured my own cancer. It's not what you think.”) could be perceived as misinformation or people simply may find it difficult to discern trustworthy information.

Notably, individuals with cancer, Black participants, and Hispanic participants were generally more willing to prosocially intervene with and share all cancer posts, not only misinformation. Our findings suggest a greater engagement with cancer misinformation on social media among those directly affected by cancer and racially and ethnically diverse populations. Emerging evidence suggests that Black and Hispanic individuals have more exposure to health misinformation than White individuals [31]. In this context, our findings support that populations who are more susceptible are also more likely to initiate community action and sharing. Individuals who identify as Black or Hispanic or have cancer are likely to have unique motivations for using social media and intervening with misinformation. It is possible that more exposure motivates action to protect one’s community, especially in minoritized populations with health disparities [32]. In other words, Black and Hispanic individuals may be more willing to not only intervene but also share (to alert or support people in their community) health misinformation when their needs are not met by others in power [31,33]. These groups may also be more open to using social media to compensate for poor patient-provider communication or because of medical mistrust—disproportionately experienced by racial and ethnic minoritized populations—and subsequently, are more likely to intervene when informed about false information to counteract or respond to past negative experiences with or perceptions of the medical system [34,35]. Future intervention efforts to reduce cancer misinformation should be tailored and culturally relevant for these individuals, who are most likely to be affected by and are willing to address cancer misinformation on social media.

Prosocial intervention could reduce harmful cancer treatment misinformation from reaching a susceptible audience and quell the overflow of digital cancer-related content to allow for good and helpful information to reach those in need if individuals are better able to identify false claims that warrant action. Social media can be an instrumental resource for finding answers to cancer-related questions, and people can witness others who share their cancer experience and find peer support potentially unavailable with in-person networks [5,36]. Prosocial intervention would likely be most effective if used alongside other strategies, such as low-cost prompts to help people discern false claims and cancer advocacy groups providing true, reliable content on social media or myth-busting accounts (eg, #CancerRealTalk organized by cancer clinicians, patients, and advocates) across platforms [37]. Improving a combination of community efforts to reduce misinformation and encourage helpful support on social media is critical for the health and wellness of individuals with cancer and their care networks.

Individuals are more willing to intervene through simple actions. If the options are available on social media, participants were most often willing to flag posts as misinformation or report to the platform to signal inaccurate claims. Although social media users can refute claims by commenting or supporting (liking) others’ rebuttals [38], our findings indicate that individuals may be less likely to take these direct, and potentially confrontational, actions. People were somewhat less likely to like comments that refuted misinformation or comment to correct untrue claims. Thus, reducing cancer misinformation through unique, indirect platform affordances, such as flagging and reporting, appears to be more promising. These prosocial interventions have been part of effective digital bystander interventions, with increasing evidence of their ability to encourage supportive community action in the face of misinformation that perpetuates injustice, harassment, and harm [39-43]. However, individuals must be able to discern what is misinformation and know how to act; we need prompts and messages to help people question suspicious information and direct community action, as knowing how to intervene is a critical step in the human-computer interaction applications of the bystander intervention model [41]. Thus, we should consider using both prompts to serve as cues to critically assess accuracy (or at least pause to question whether the information is true)—a strategy shown to reduce sharing of false information on social media and misperceptions—and messages to counter misinformation with accurate facts to reduce misperceptions [38,44,45].

The spread of cancer misinformation is amplified by sharing on social media and offline. Sharing about a health issue or behavior interpersonally is associated with people taking the recommended actions highlighted in the message [46]. Unfortunately, more than half of our participants intended to share cancer treatment misinformation posts, causing concern about future engagement with unevidenced behaviors. Most people reported that they would share through untraceable or offline channels, as we have found with cancer prevention messages for adolescents, where most would share in person, via text message, or in ephemeral postings [47]. This could indicate that participants want to share in discreet or less-public ways. People may want to share privately to protect their image or explore curiosities without public scrutiny (eg, someone with clinician’s recommendations for radiation for prostate cancer might want to investigate a cancer treatment misinformation post but not want that to be widely known). Furthermore, these sharing methods do not leave behind trace data that could be investigated using social media data mining and analyses. To assess the implications of cancer misinformation sharing, we need multivariable approaches to ensure valid measures that account for both digital and offline sharing behaviors.

Sharing cancer misinformation may not always be intentional. In general, people share because they believe that they possess information (usually novel information) that can benefit others in their social network (eg, altruism) and not because they want to cause harm [48,49]. This may have been the case among the participants in our study. Although we did not ask for the motivation for sharing the messages in this study, the fact that a relatively high proportion of participants were willing to intervene when exposed to misinformation makes it possible that those who would share the information believed that they were positively impacting their community. Future research should address motivations to share (eg, endorse vs counter), along with sharing intentions, to better understand how misinformation is being shared in cancer networks.

Limitations

This study has limitations. Our study is limited to the responses among a convenience sample of US adults; other populations likely have different rates of exposure to cancer misinformation and may have different reactions to social media posts. Without recruiting specifically for individuals with cancer experience (diagnosis or caregiving), we had many individuals with cancer experience in this study. It is possible that we had more individuals with cancer because of the age of the participants. One-third of the participants (34%) were aged ≥55 years, the age group that accounts for 82% of new cancers in the United States [50]. Participants self-reported caregiving by whether they had “ever cared for someone with cancer” in our survey, which may have been interpreted broadly as contributing to any level of care by some participants. Thus, we do not know whether the individuals were the primary caregivers or part of a cancer care network. In this study, receiving cancer treatment misinformation as advice (general exposure) was reported by fewer individuals than exposure to the same on social media; however, these findings are limited by the wording used in our survey. We asked about general exposure as “anyone offering advice” (potentially interpreted as only direct advice), whereas the social media exposure item was “any information” seen by participants (potentially interpreted as including both passive information and direct advice). More research is needed to determine the best way to ask about cancer misinformation exposure without biasing participants. We asked about our stimulus Instagram posts specifically; prosocial interventions and sharing intentions may differ with other messages or on other social media platforms. We also asked about the willingness for prosocial intervention and sharing intentions but did not assess behavior. In addition, we asked about intervening and sharing a unidirectional item (ie, response options ranged from no action—not at all likely—to increasing likelihood of action), which may have influenced our findings. Future research with a neutral midpoint in the response options should be explored. Future studies should also assess actual, rather than expected, participant intervention with and sharing of cancer misinformation to better understand reactions. Participants were not debriefed in this study; information to help the participants discern the validity of stimuli after participation will be incorporated into future studies. Finally, without patient information, we do not know if all clinical care recommendations align with recommended care (eg, gene therapy is clinical care but may not be recommended if there is no evidence of benefit with particular diagnoses). Additional participant information would be needed to determine whether the clinical advice is misinformation.

Conclusions

In conclusion, cancer treatment misinformation exposure on social media is high in the United States, including visual-based social media and platforms that are widely used for cancer support. We found that many people believe cancer treatment posts on social media to be true at least some of the time, making them susceptible to potential psychosocial or physical harms of false cancer treatments and cures. In this study, 2 in 3 US adults were willing to prosocially intervene with any cancer treatment misinformation, but almost as many were also willing to share this misinformation, and few discerned between false and true claims. With strategies to encourage individuals to identify and prioritize intervening with harmful misinformation posts, there is potential to encourage community action to reduce exposure and negative impact. Susceptible populations—individuals with cancer, Black individuals, and Hispanic individuals—warrant special attention, as they are both more willing to not only prosocially intervene (intended outcome) but also share (unintended outcomes) cancer treatment misinformation.

Acknowledgments

The University of North Carolina’s University Cancer Research Fund provided funding for data collection.

Data Availability

The data sets generated during and analyzed during this study are available in the Carolina Digital Repository [51].

Conflicts of Interest

None declared.

Multimedia Appendix 1
Appendix A: Survey items; Appendix B: Participant characteristics by stimuli exposure group (N=603).

[PDF File (Adobe PDF File), 48 KB - cancer_v9i1e43749_app1.pdf]

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Edited by A Mavragani; submitted 23.10.22; peer-reviewed by M DeVerna, DW Han, C Peters; comments to author 24.01.23; revised version received 28.04.23; accepted 23.05.23; published 28.07.23.

Please cite as:
Lazard AJ, Nicolla S, Vereen RN, Pendleton S, Charlot M, Tan HJ, DiFranzo D, Pulido M, Dasgupta N
Exposure and Reactions to Cancer Treatment Misinformation and Advice: Survey Study
JMIR Cancer 2023;9:e43749
URL: https://cancer.jmir.org/2023/1/e43749
doi:10.2196/43749
PMID:37505790

Original Paper

Perspectives and Experiences of Patients With Thyroid Cancer at a Global Level: Retrospective Descriptive Study of Twitter Data

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Abstract

Background: Twitter has become a popular platform for individuals to broadcast their daily experiences and opinions on a wide range of topics and emotions. Tweets from patients with cancer could offer insights into their needs. However, limited research has been conducted using Twitter data to understand the needs of patients with cancer despite the substantial amount of health-related data posted on the platform daily.

Objective: This study aimed to uncover the potential of using Twitter data to understand the perspectives and experiences of patients with thyroid cancer at a global level.

Methods: This retrospective descriptive study collected tweets relevant to thyroid cancer in 2020 using the Twitter scraping tool. Only English-language tweets were included, and data preprocessing was performed to remove irrelevant tweets, duplicates, and retweets. Both tweets and Twitter users were manually classified into various groups based on the content. Each tweet underwent sentiment analysis and was classified as either positive, neutral, or negative.

Results: A total of 13,135 tweets related to thyroid cancer were analyzed. The authors of the tweets included patients with thyroid cancer (3225 tweets, 24.6%), patient's families and friends (2449 tweets, 18.6%), medical journals and media (1733 tweets, 13.2%), health care professionals (1093 tweets, 8.3%), and medical health organizations (940 tweets, 7.2%), respectively. The most discussed topics related to living with cancer (3650 tweets, 27.8%), treatment (2891 tweets, 22%), diagnosis (1613 tweets, 12.3%), risk factors and prevention (1137 tweets, 8.7%), and research (953 tweets, 7.3%). An average of 36 tweets pertaining to thyroid cancer were posted daily. Notably, the release of a film addressing thyroid cancer and the public disclosure of a news reporter's personal diagnosis of thyroid cancer resulted in a significant escalation in the volume of tweets. From the sentiment analysis, 53.5% (7025/13,135) of tweets were classified as neutral statements and 32.7% (4299/13,135) of tweets expressed negative emotions. Tweets from patients with thyroid cancer had the highest proportion of negative emotion (1385/3225 tweets, 42.9%), particularly when discussing symptoms.

Conclusions: This study provides new insights on using Twitter data as a valuable data source to understand the experiences of patients with thyroid cancer. Twitter may provide an opportunity to improve patient and physician engagement or apply as a potential research data source.

(JMIR Cancer 2023;9:e48786) doi:10.2196/48786

KEYWORDS

data mining; internet; natural language processing; sentiment analysis; social media; thyroid neoplasms; twitter; tweet; tweets; neoplasm; neoplasms; cancer; oncology; thyroid; NLP; perspective; perspectives; sentiment; sentiments; experience; experiences

Introduction

Social media has become an increasingly influential communication tool, enabling individuals to connect and communicate in real time, regardless of geographic location. Furthermore, social media has emerged as a platform for people to share their thoughts, opinions, and ideas with a global audience. Among the various social media platforms, Twitter stands out, enabling users to share short messages called "tweets" with their followers. These tweets can contain text, images, videos, and links and can be up to 280 characters in length. Users can also interact with tweets by liking, retweeting, or replying to them. Since its launch in 2006, Twitter has become a popular platform for communication, news, and information sharing. Users can follow other users to see their tweets in their Twitter feed and can also use hashtags to categorize their tweets and make them more discoverable to other users. Twitter has also become a powerful tool for businesses, organizations, and public figures to engage with their audiences and promote their brand or message. It is commonly used by journalists, politicians, and celebrities to share their thoughts and opinions on current events. Twitter is available as a website and as a mobile app. According to Twitter's second-quarter 2022 shareholder letter, the platform had 237.8 million monetizable daily active users worldwide [1].

Twitter plays an important role in public health for several reasons [2,3]. Twitter allows for the rapid spread of information to a large audience. This is particularly important in public health emergencies, such as disease outbreaks or natural disasters, where timely and accurate information can save lives [4,5]. Twitter can be also used for real-time monitoring of disease outbreaks and other public health events [6]. Public health agencies and organizations can use Twitter to disseminate information on health topics, promote healthy behaviors, and engage with the public [7,8]. Some patients and their relatives may choose to share information about their illness on Twitter as a way of raising awareness, connecting with others who are going through similar experiences, or seeking support from the web-based community [9,10]. Analyzing data from Twitter can help identify trends and patterns in public health [11,12]. This can help public health officials better understand public perceptions and attitudes toward specific health issues, which can inform health messaging and interventions.

Many researchers have used the Twitter platform for both enrollment and intervention [2,13,14]. Twitter is indeed unique in its infrastructure and approach to data sharing. One of the key features of Twitter is the ability for any user to follow another user without requiring permission or approval. Additionally, Twitter provides access to almost all of its data. This allows developers and researchers to access and analyze Twitter data for a variety of purposes, such as sentiment analysis, trend analysis, and social network analysis. Twitter not only provides opportunities for sharing experiences between patients and physicians but also the understanding of patients' perspectives.

Twitter has become a valuable platform for cancer research. Researchers have used Twitter data to study a wide range of topics related to cancer, including public awareness, patient experiences, treatment outcomes, and the use of social media for cancer communication and support. The use of Twitter in cancer research has opened up new possibilities for understanding and addressing the complex challenges associated with cancer and has the potential to improve the lives of patients with cancer and their families. The previous Twitter analysis of patients with cancer found that patients with thyroid cancer had a significantly higher happiness score compared to patients with other types of cancer. This is probably caused by the favorable prognosis and low mortality associated with thyroid cancer, as well as the availability of effective treatment options [10]. Nevertheless, the diagnosis of thyroid cancer frequently triggers intense and immediate emotional responses of shock and fear, evoked by the word "cancer." Comprehending the experiences of patients upon receiving a diagnosis of thyroid cancer is crucial, as their emotional reactions can significantly influence treatment decision-making and overall quality of life [15].

Researchers have extensively studied breast cancer [16,17], cervical cancer [18,19], lung cancer [20,21], colorectal cancer [22-24], and kidney cancer [25] using Twitter as a valuable data source. However, the number of studies dedicated solely to investigating thyroid cancer through Twitter research is comparatively low in comparison to other cancer types. Typically, when studying thyroid cancer on Twitter, the data are frequently incorporated into broader studies that encompass multiple cancer types [26-28]. In an effort to enhance the data concerning thyroid cancer, we aim to conduct the Twitter analysis using advanced Twitter scraping tool to identify tweets related to thyroid cancer. Through this analysis, we aim to examine the content and sentiments expressed in these tweets on a global scale.

Methods

Data Collection and Processing

We searched Twitter for tweets posted between January 1 and December 31, 2020, that included tweets containing the term "thyroid cancer" and collected the data using the Twitter scraping tool Twint. Twint is an advanced Twitter scraping tool written in Python (Python Software Foundation) that allows for scraping tweets from Twitter profiles without using Twitter's application programming interface. Following the accumulation of raw data, the "pandas" and "contractions" packages were used for data manipulation and cleaning during the preprocessing stage. We collected only tweets in the English language and preprocessed the data by removing irrelevant tweets, duplicates, and retweets. The data were cleaned by removing hyperlinks, URLs, websites, emojis, special characters, numbers, digits, symbols, and any identifiable information. Animal-related tweets were also excluded. In terms of excluding irrelevant tweets, this process was conducted manually, with each tweet being meticulously reviewed by 2 independent reviewers with medical backgrounds (SM and CS). This manual intervention ensured the accuracy and relevance of the data for subsequent analysis. The authors reviewed all tweets and categorized them manually. The categorization process was based on mutual agreement between the 2 reviewers, serving as an internal measure to ensure consistency and reliability.

Twitter users were classified into the groups of patients with thyroid cancer (identified by the presence of personal pronouns such as "I," "me," or "my" in their tweets and self-identification as thyroid cancer survivors in their Twitter profiles), patient's family and friends (whose tweets mentioned their family members or individuals known to have thyroid cancer), medical journals and media (indicated by their Twitter profiles showcasing journal publications or involvement in thyroid cancer media), health personnel (identified through designations such as MD, Dr, doctor, RN, nurse, pharmacist, or PhD in their Twitter profiles), medical health organizations (recognized by their Twitter profiles reflecting hospital names, clinics, or medical institutions), patient community (identified by Twitter profiles associated with thyroid patient networks, groups, or forums), companies (corporation, businesses, or enterprises), and life coaches. Twitter contents were further categorized into distinct groups manually based on key messages, including living with thyroid cancer, treatment (including medication, surgery, and radiotherapy), diagnosis (involving physician consultation, biopsy, fine-needle aspiration, and ultrasound), risk factor and prevention, research (journal publications), entertainment (involving the entertainment industry, actors, movies, TV series), symptoms, knowledge, prevalence and incidence, awareness (related to important days such as Thyroid Awareness Month, National Cancer Day, World Thyroid Day), academic (conferences and meetings), prognosis (regarding the natural history of thyroid disease), and advertisement. Descriptive analytic statistics were used for data analysis.

Sentiment Analysis

Sentiment analysis is a powerful tool that can be used to understand the emotions toward thyroid cancer [29]. We applied the Transformers package and used the distilbert-base-uncased-finetuned-sst-2-english model for sentiment analysis, which is a natural language processing (NLP) technique designed to analyze emotions based on text data and initially classified the sentiment as positive or negative [30]. This model was trained on a data set of movie reviews, which, similar to tweets, typically involve concise messages. During analysis, the model generates labels indicating the sentiment as either positive or negative, along with an associated confidence score. The tweets that were difficult to classify as positive or negative (confidence score <0.99) were reclassified as neutral. In order to improve the accuracy of our data set, we calibrated the confidence score based on the consensus of 2 reviewers independently reading and interpreting the tweets, and reaching a consensus. The tweets were finally labeled as positive, negative, or neutral regarding thyroid cancer. The percentages for each of the 3 sentiments were calculated.

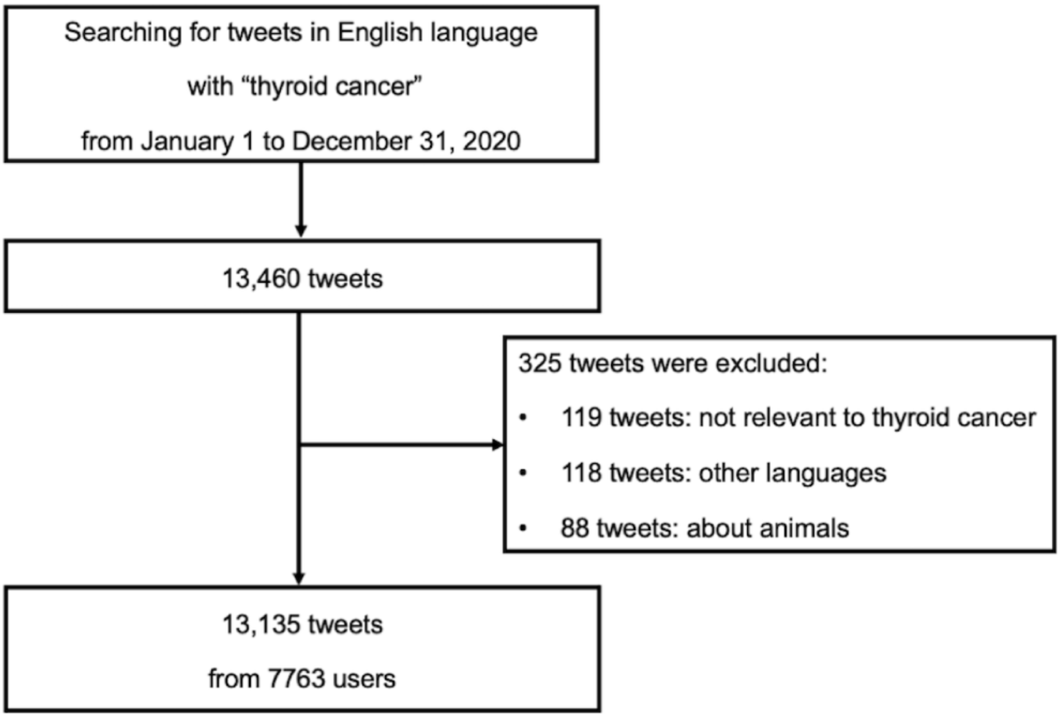
Ethics Approval

Although all retrieved tweets are posted publicly on Twitter, our study was approved by the institutional review board (MURA2021/1039). Any personal identifying information was removed to ensure anonymity and protect the identity of the Twitter users.

Results

Our initial search resulted in a total of 13,460 tweets related to thyroid cancer. We preprocessed the data with the methods previously described. The remaining 13,135 unique tweets from 7763 different users were extracted for analysis (Figure 1).

Figure 1. Study flowchart.



Of the 13,135 total tweets related to thyroid cancer, the highest percentage of tweets were from patients with thyroid cancer (3225 tweets, 24.6%), followed by patient's family and friends (2449 tweets, 18.6%), medical journals and media (1733 tweets, 13.2%), health care professionals (1093 tweets, 8.3%), and medical health organizations (940 tweets, 7.2%), respectively. The remaining 24.2% (3176 tweets) could not be identified because of insufficient evidence on their usernames, Twitter profiles, and tweet context (Table 1). Of the 13,135 total tweets related to thyroid cancer, most conversations relevant to thyroid cancer were related to living with cancer (3650 tweets, 27.8%), treatment (2891 tweets, 22%), diagnosis (1613 tweets, 12.3%), risk factors and prevention (1137 tweets, 8.7%), and research (953 tweets, 7.3%). Examples of these tweet contents are shown in Table 2. Focusing on the users and the content relationship, patients as well as families and friends usually talked about living with thyroid cancer, diagnosis, treatment, and symptoms, while health personnel and medical journal and media mainly posted about treatment, diagnosis, research, and knowledge (Table 3).

Table 1. Definitions of Twitter users and frequency of tweets related to thyroid cancer.

Twitter users	Definitions	Tweets, n (%)
Patients	Thyroid cancer patients (the tweets usually have "I," "me," or "my" in the phrase)	3225 (24.6)
Patient's family and friends	Family members, relatives, friends, and colleagues	2449 (18.6)
Medical journals and media	Medical publications and press	1733 (13.2)
Health care professionals	Physician, nurse, and allied health professionals	1093 (8.3)
Medical health organizations	Hospital, clinic, and medical institution	940 (7.2)
Patient community	Patient network, group, society, and forum	352 (2.7)
Company	Corporation, business, and enterprise	137 (1)
Life coach	Personal coach, wellness coach, and success coach	30 (0)
Inconclusive	Indistinguishable to determine the type of user	3176 (24.2)

Table 2. Twitter contents related to thyroid cancer.

Twitter contents	Examples	Tweets, n (%)
Living with thyroid cancer	• I found a reddit community for thyroid cancer and I’m talking about my rare type on it and giving my WHOLE story like as detailed as I can. It’s like I’m writing a novel lol. • Don't ever tell a person with thyroid cancer that they have the best kind of cancer. I'm in pain almost every day.	3650 (27.8)
Treatment	• Feels like I’ve been training for social distancing for years. I’ve had isolation during treatments of radioactive iodine (thyroid cancer), have physical limitations that make it difficult to get around. So, here’s my advice to the newbies: #COVID2019 • Today marks my 3rd year post operation from my thyroid cancer. Will share some of my before and after photos in my stories. I’m just so happy that I’m alive and healthy from my own perspective.	2891 (22)
Diagnosis	• My throat can hurt and the first thing on Google is throat cancer, thyroid cancer, or swollen lymph nodes from lymphoma or HIV • Real pissed my old endocrinologist never did an ultrasound on my thyroid or even TOLD me that Hashimoto’s makes me way more susceptible to thyroid cancer. My new doc was confused why I’d never had a thyroid ultrasound for that exact reason.	1613 (12.3)
Risk factor and prevention	• Listening to the father-in-law decided to stop his diabetic medication because it may cause thyroid cancer. • Thyroid cancer diagnoses are up to three times more common in 9/11 first responders than the general population. However, the increased cancer rate may be due to over screening, according to a new study in @JAMAInternalMed.	1137 (8.7)
Research	• Lilly Opens Phase 3 Clinical Trial for Selpercatinib (LOXO-292) in RET-Mutant Medullary Thyroid Cancer • Fukushima Nuclear Disaster | Increased Thyroid Cancer in U.S.	953 (7.3)
Entertainment	• I bet this is when Ezekiel tells Carol about his thyroid cancer #TheWalkingDead • Completed watching 'Dil Bechara', Kizie Basu is fighting thyroid cancer when she meets Immanuel Rajkumar Junior or Manny, who has previously suffered from osteosarcoma and is in remission.	582 (4.4)
Symptoms	• I struggle to lose weight. I have an under active thyroid due to thyroid cancer. Some people can't help being overweight. • I've gained a lot of weight because I had thyroid cancer and it caused me to gain almost 75 lbs. I'm a big lady. 250 lbs. My husband says it's just more to love that's all. But I can't bear to look at myself in the mirror.	549 (4.2)
Knowledge	• The Different Types of Thyroid Cancer • Medscape: Review this updated thyroid cancer reference.	531 (4)
Prevalence and incidence	• The number of people diagnosed with #thyroid cancer has more than doubled worldwide since 1990. Much of the increase has been fueled by a rapid rise of #cancer cases in countries in South-East Asia, which accounted for more than 40% of global diagnoses. • Thyroid cancer remains the highest prevailing endocrine malignancy, and its incidence rate has progressively increased in the previous years. #Thyroidcancer	355 (2.7)
Awareness	• Thyroid Awareness Month calls attention to thyroid conditions such as hypothyroidism, hyperthyroidism, Graves’ disease, Hashimoto’ disease, goiter, thyroid nodules, and thyroid cancer. • Thyroid Cancer Awareness Month ends today but the fight against #thyroidcancer is far from over. Help us raise awareness and continue the conversation. #CheckYourNeck #ThyroidCancerAwareness	339 (2.6)
Academic	• Join us to clarify coding misconceptions when collecting cancer data in your role as a cancer registrar. We will be discussing the nuances of abstracting THYROID CANCER. You won't want to miss! #Cancerregistry #Data #Healthcare • Fukushima Thyroid Cancer Symposium live stream 3 February 2020	219 (1.7)
Prognosis	• Papillary and Follicular thyroid is in general excellent. Factors include age, aggressiveness, metastasis. Medullary Thyroid cancer may have a good prognosis too but should be evaluated for other endocrine problems. Anaplastic thyroid cancer may have a poor outcome. • Thyroid cancer has a 99% cure rate. Learn to spot the signs and what to do next if you notice something unusual in your throat or neck: #cancer #cancercare #earlydetection #oncology #Detroit	214 (1.6)
Advertisement	• If you live within 50km of #Pickering nuclear you can order your free KI pills here to help protect against thyroid cancer • Thyroid Cancer: A Guide for Patients 3rd Edition Now Available. For details and ordering information, visit our website: #ThyroidCancer #ThyCa #ThyCa4Life	102 (0.8)

Table 3. Tweet contents related to thyroid cancer classified by various types of Twitter users. The percentage represents the row percentage.

Twitter users	Living with thyroid cancer, n (%)	Treatment, n (%)	Diagnosis, n (%)	Risk factors and prevention, n (%)	Research, n (%)	Entertainment, n (%)	Symptoms, n (%)	Knowledge, n (%)	Prevalence and incidence, n (%)	Awareness, n (%)	Academic, n (%)	Prognosis, n (%)	Advertisement, n (%)
Patients	1501 (47)	729 (23)	503 (16)	72 (2)	11 (0)	79 (2)	251 (8)	8 (0)	4 (0)	41 (1)	2 (0)	19 (1)	5 (0)
Inconclusive	278 (9)	494 (16)	395 (12)	603 (19)	269 (9)	404 (13)	79 (3)	171 (5)	161 (5)	128 (4)	52 (2)	98 (3)	44 (1)
Family and friends	1423 (58)	483 (20)	295 (12)	50 (2)	1 (0)	53 (2)	120 (5)	0 (0)	3 (0)	3 (0)	1 (0)	15 (1)	1 (0)
Medical journals and media	43 (3)	502 (29)	174 (10)	150 (9)	435 (25)	31 (2)	37 (2)	154 (9)	80 (5)	37 (2)	47 (3)	37 (2)	6 (0)
Health care professionals	196 (18)	280 (26)	145 (13)	88 (8)	121 (11)	8 (1)	17 (2)	104 (10)	37 (3)	22 (2)	31 (3)	29 (3)	14 (1)
Medical health organization	72 (8)	294 (31)	64 (7)	151 (16)	81 (9)	3 (0)	32 (3)	62 (7)	57 (6)	53 (6)	48 (5)	15 (2)	8 (1)
Patient community	126 (36)	58 (17)	23 (7)	5 (1)	14 (4)	3 (1)	10 (3)	16 (5)	10 (3)	45 (13)	35 (10)	1 (0)	6 (2)
Company	7 (5)	44 (32)	13 (10)	18 (13)	20 (15)	1 (1)	2 (2)	8 (6)	3 (2)	9 (7)	3 (2)	0 (0)	9 (7)
Life coach	4 (13)	7 (23)	1 (3)	0 (0)	0 (0)	0 (0)	1 (3)	7 (23)	0 (0)	1 (3)	0 (0)	0 (0)	9 (30)

In 2020, an average of 36 thyroid cancer–related tweets were posted each day (Figure 2). The number of tweets posted on July 24, 2020 (357 tweets), was 10 times higher than the average because the United States TV reporter announced that she was diagnosed with thyroid cancer after a viewer spotted a lump on her neck. On the same day, “Dil Bechara,” an Indian movie adapted from “The Fault in Our Stars” the female lead suffered from thyroid cancer, was released on the streaming service. Throughout the year, several other days recorded higher tweet volumes of 80-100 tweets per day. Examples include February 4, 2020 (World Cancer Day), May 8, 2020 (United States Food and Drug Administration approval of Selpercatinib for advanced RET-driven lung and thyroid cancers), and September 1, 2020 (the first day of Thyroid Cancer Awareness Month).

Of the 13,135 total tweets related to thyroid cancer, the sentiment analysis revealed that 7025 (53.5%) tweets were categorized as neutral statements, while 4299 (32.7%) tweets were labeled as negative emotions. Tweets from patients with thyroid cancer had the highest proportion of negative emotion, with 1385 out of 3225 (42.9%) tweets, as shown in Table 4. Notably, tweets discussing symptoms showed the highest prevalence of negative emotions (Table 5). In the year 2020, the COVID-19 outbreak began. There were 427 tweets that relate to thyroid cancer and COVID-19. The highest tweet rate was in March 2020, according to the declaration of COVID-19 as a global pandemic by World Health Organization on March 11, 2020. The predominant topic among COVID-19–related tweets was living with thyroid cancer, accounting for 226 (52.9%) tweets. From sentiment analysis, negative emotions were found in almost half (210/427 tweets, 49.2%) of COVID-19–related tweets compared with 32.2% (4089/12,708) of tweets in non–COVID-19–relevant tweets.

Figure 2. Tweets over the year 2020. US FDA: US Food and Drug Administration.

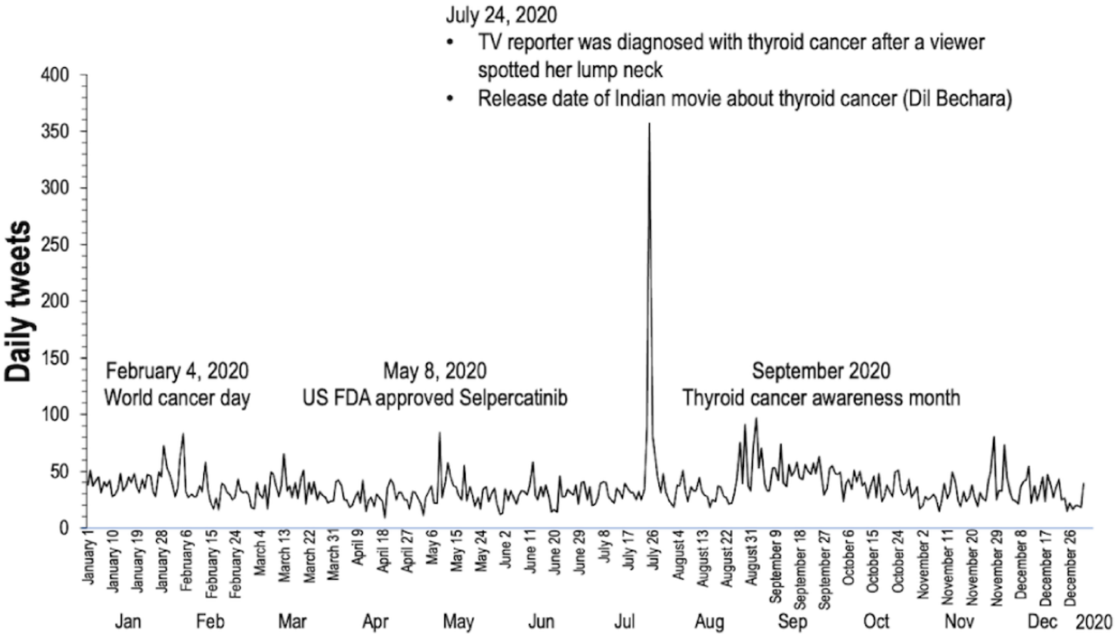


Table 4. Sentiment analysis of tweets related to thyroid cancer according to Twitter users.

Twitter users	Positive, n (%)	Neutral, n (%)	Negative, n (%)
Patients	583 (18.1)	1257 (39)	1385 (42.9%)
Family and friends	525 (21.4)	991 (40.5)	933 (38.1)
Medical journals and media	155 (8.9)	1285 (74.1)	293 (16.9)
Health care professionals	119 (10.9)	737 (67.4)	237 (21.7)
Medical health organization	103 (11.)	596 (63.4)	241 (25.6)
Patient community	84 (24)	197 (56)	71 (20)
Company	11 (8)	108 (78.8)	18 (13)
Life coach	8 (27)	18 (60%)	4 (13)
Inconclusive	223 (7)	1836 (57.8)	1117 (35.2)

Table 5. Sentiment analysis of tweet contents related to thyroid cancer.

Tweet contents	Positive, n (%)	Neutral, n (%)	Negative, n (%)
Living with thyroid cancer	835 (22.9)	1642 (45)	1173 (32.1)
Treatment	376 (13)	1570 (54.3)	945 (32.7)
Diagnosis	160 (9.9)	807 (50)	646 (40)
Risk factors and prevention	33 (3)	635 (55.8)	469 (41.2)
Research	92 (10)	724 (76)	137 (14.4)
Entertainment	66 (11)	273 (46.9)	243 (41.8)
Symptoms	36 (7)	209 (38.1)	304 (55.4)
Knowledge	37 (7)	342 (64.4)	152 (28.6)
Prevalence and incidence	19 (5)	249 (70.1)	87 (24)
Awareness	56 (16)	243 (71.7)	40 (12)
Academic	52 (24)	147 (67.1)	20 (9)
Prognosis	25 (12)	124 (57.9)	65 (30)
Advertisement	24 (23)	60 (59)	18 (18)

Discussion

Principal Findings

In this study, we explored Twitter users and topics of tweet content associated with thyroid cancer in the year 2020. The majority of tweets (5674/13,135, 43.2%) were contributed by individuals who identified as patients or were related to them as family members and friends. A combined contribution of tweets (3766/13,135, 28.7%) was observed from sources such as medical journals and media, health care professionals, and medical health organizations.

The most popular topics of tweet contents pertained to coping with thyroid cancer and its management. According to the sentiment analysis, tweets related to thyroid cancer exhibited a greater prevalence of negative emotions, particularly among individuals diagnosed with thyroid cancer.

Comparison With Prior Work

In comparison to 2014 data [10], there was a significant increase in the proportion of tweets authored by patients, rising from 11.8% to 24.6% of the total tweets. This indicates a growing interest in patient-centered discussions about thyroid cancer on Twitter. However, it is important to acknowledge that the previous study only included geotagged tweets from the United States, which may not provide a representative view at the global level [10]. Nonetheless, this highlights the potential of social media as a valuable tool for thyroid cancer, enabling them to connect, find support, access information, and raise awareness. When used responsibly, social media can substantially enhance the patient experience and contribute to improved outcomes throughout their cancer journey.

Our findings demonstrate the potential of Twitter as a robust medium for individuals with thyroid cancer to share personal experiences, ranging from diagnosis to therapeutic interventions. Through sharing their experience, patients with thyroid cancer can raise awareness about the difficulties associated with cancer and motivate others who may be confronting similar challenges [31,32]. Moreover, health care providers, media outlets, and health care organizations play a pivotal role in disseminating information, articles, and research findings [16,19,33]. By following relevant organizations and individuals on Twitter, patients with thyroid cancer can stay updated on the latest advances in cancer treatment and research, as well as discover resources such as support groups, financial assistance programs, and clinical trials [34-36]. Our results at a worldwide level were consistent with the earlier data reported in the United States [37].

Twitter can also serve as a platform for expressing negative affective states, such as fear, anxiety, anger, frustration, sadness, grief, isolation, and loneliness, which are commonly experienced in the context of cancer diagnosis and treatment. While a previous study found that patients with thyroid cancer had a high average word happiness value [10]; however, this study found that almost half of tweets from patients with thyroid cancer displayed negative sentiments. The negative issues identified in this study were mainly related to symptoms experienced by patients, which caused significant distress. Another significant concern was related to the risk factors associated with thyroid cancer, with many patients expressing uncertainty about the causes of their condition, including the potential impact of nuclear disasters and events like the September 11 attacks. Patients and their families were also greatly impacted by the diagnosis of thyroid cancer, with many expressing shock and disbelief upon receiving the news. While some patients in the prior study reported feeling comfortable with their diagnosis, others felt confused and ignored, particularly in cases where they were told that thyroid cancer was a “good cancer” by multiple sources [38-40]. Based on the previous study conducted on breast cancer, the decline in negative attitudes toward cancer observed across various social media platforms, including Twitter [17], could be indicative of improved efforts by health organizations and agencies to educate the public on cancer, including its prevention, treatment, and management. Social media could serve as a valuable source of information to gain insight into the layperson’s perceptions and attitudes regarding topics related to thyroid cancer. For instance, an examination of tweets has highlighted postoperative weight gain as a significant concern. However, existing evidence indicates that any weight gain among these patients might be linked to the natural process of aging rather than the surgical intervention itself [41]. This knowledge can facilitate informed conversations between health care providers and patients, enabling them to set realistic postoperative expectations and address misconceptions about weight gain after thyroid surgery.

The launch of the movie about thyroid cancer and the news reporter’s announcement of her thyroid cancer diagnosis triggered a surge in the number of tweets. Consistent with previous studies, social media influencers played a significant role in public conversations [42,43]. This study demonstrated the notable involvement of celebrities, public figures, and health care personnel in disseminating health messages through social media.

Our findings support the analysis of Twitter data for implications of public health, clinical practice, and future research. Analyzing Twitter data can provide valuable insights into public perceptions, attitudes, and concerns about health topics, including thyroid cancer. This information aids public health officials in understanding population needs. It can inform the development of targeted health promotion campaigns, interventions, and educational materials to address specific concerns raised by the public on Twitter. In addition, monitoring trends and discussions on Twitter can help identify emerging health issues and facilitate timely public health responses. For clinical practice, studying Twitter data deepens health care providers’ understanding of patient experiences, treatment preferences, and impact on quality of life, enabling more patient-centered care and tailored support resources. Twitter studies also serve as a valuable data source for exploring research questions, uncovered patterns, and generating hypotheses. By examining large volumes of real-time user-generated content, researchers can uncover new patterns, trends, and associations. These data can be used to generate hypotheses, inform study design, and guide the development of research interventions. In addition, the use of social media data can complement traditional research methods, providing a more comprehensive understanding of health issues and allowing for a broader reach and engagement with diverse populations.

Strengths and Limitations of This Study

The main strength of this research was the year-long study period, which reduced the potential for time period bias and allowed for the analysis of different types of tweets at various times. However, there were several limitations to this study, including imperfect data collection. For instance, only public tweets were accessible, and private Twitter accounts were not included. In addition, the use of only a single search term "thyroid cancer" may have resulted in selection bias. We recognize the limitation associated with the absence of geographic data. The origin of the tweets could potentially lead to variations in the data across different regions or countries. Demographic data were not gathered, and some tweets were unclear. It is also important to note that Twitter users tend to be younger, which may not accurately represent the broader population of patients with thyroid cancer. It is essential to acknowledge that while NLP is an exceptionally powerful tool, it also has inherent limitations. For instance, NLP primarily operates on textual data and may encounter difficulties in accurately interpreting ambiguous phrases, slang, and sarcasm. These factors can occasionally result in inaccuracies in sentiment classification. The categorization of tweets was conducted through a meticulous manual assessment process, devoid of a formal codebook. Regrettably, no interrater reliability was evaluated. Nevertheless, the categorization was determined based on mutual agreement between the 2 reviewers, both of whom have medical backgrounds. Furthermore, since the data were collected during the COVID-19 pandemic, negative emotions expressed in the tweets may have been influenced by disruptions in cancer care and the risk of COVID-19 infection and complications [44,45].

Conclusions

Twitter is a valuable social media platform for health research due to the wealth of data available that offers insights into users' perspectives. This study provides essential information to understand the thoughts and emotions of patients with thyroid cancer, which can be helpful in the development of medical services and better patient care. Additionally, this study highlights the potential of Twitter as a platform for health care providers and organizations to disseminate health information and communicate with patients. Collaborating with public figures and social media influencers can enhance the reach and effectiveness of health campaigns and messaging.

Data Availability

The data sets generated and analyzed during this study are available from the corresponding author upon request.

Authors' Contributions

SM and CS designed the study. All authors collected, analyzed, and interpreted the data. SM drafted the manuscript. All authors read, revised, and approved the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

NLP: natural language processing

Edited by T de Azevedo Cardoso; submitted 07.05.23; peer-reviewed by V Patel, S Bonett; comments to author 06.06.23; revised version received 17.06.23; accepted 04.07.23; published 02.08.23.

Please cite as:
Meksawasdichai S, Lerksuthirat T, Ongphiphadhanakul B, Sriphrapradang C
Perspectives and Experiences of Patients With Thyroid Cancer at a Global Level: Retrospective Descriptive Study of Twitter Data
JMIR Cancer 2023;9:e48786
URL: https://cancer.jmir.org/2023/1/e48786
doi:10.2196/48786
PMID:37531163

Original Paper

Positive Design Framework for Carer eSupport: Qualitative Study to Support Informal Caregivers of Patients With Head and Neck Cancer in Sweden

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Abstract

Background: Informal caregivers of patients with head and neck cancer (HNC), such as the patient’s spouse, other close relatives, or friends, can play an important role in home-based treatment and health care. Research shows that informal caregivers are usually unprepared for this responsibility and need support with taking care of patients and other daily life activities. These circumstances place them in a vulnerable position, and their well-being may be compromised. This study is part of our ongoing project Carer eSupport, which aims to develop a web-based intervention to facilitate informal caregivers in the home environment.

Objective: This study aimed to explore the situation and context of informal caregivers of patients with HNC and their needs for designing and developing a web-based intervention (Carer eSupport). In addition, we proposed a novel framework for the development of a web-based intervention aimed at promoting the well-being of informal caregivers.

Methods: Focus groups were conducted with 15 informal caregivers and 13 health care professionals. Both informal caregivers and health care professionals were recruited from 3 university hospitals in Sweden. We adopted a thematic data analysis process to analyze the data.

Results: We investigated informal caregivers’ needs, critical factors for adoption, and desired functionalities of Carer eSupport. A total of 4 major themes, including information, web-based forum, virtual meeting place, and chatbot, emerged and were discussed by informal caregivers and health care professionals for Carer eSupport. However, most study participants did not like the idea of a chatbot for asking questions and retrieving information and expressed their concerns such as a lack of trust in robotic technologies and missing human contact while communicating with chatbots. The results from the focus groups were discussed through the lens of positive design research approaches.

Conclusions: This study provided an in-depth understanding of informal caregivers’ contexts and their preferred functions for a web-based intervention (Carer eSupport). Using the theoretical foundation of designing for well-being and positive design in the informal caregiving context, we proposed a positive design framework to support informal caregivers’ well-being. Our proposed framework might be helpful for human-computer interaction and user experience researchers to design meaningful eHealth interventions with a clear focus on users’ well-being and positive emotions, especially for informal caregivers of patients with HNC.

International Registered Report Identifier (IRRID): RR2-10.1136/bmjopen-2021-057442

(JMIR Cancer 2023;9:e45748) doi:10.2196/45748

KEYWORDS

eHealth; subjective well-being; positive design; adaptability; informal caregivers; head and neck cancer; preparedness to care

Introduction

Background

Head and neck cancer (HNC) cases are increasing globally, and the treatment and rehabilitation process requires many resources from medical caregivers [1]. During treatment, patients with HNC may experience functional impairments, such as problems with speaking, saliva, chewing, and swallowing; they may also experience aesthetic, appearance, and social issues [2]. This may have long-lasting effects on patients and their informal caregivers (hereafter referred to as caregivers). Caregivers are spouses or partners, relatives, friends, or neighbors who have a strong personal relationship with the patient and usually provide care to the patient in the home environment [3]. With some external help, education, and training, caregivers can help patients transition from hospital to home environment [1,4,5]. These patients receive varying degrees of extensive treatments in hospitals and often require support from their caregivers at home. Caregivers need to quickly learn and adopt caregiving skills for these severely impaired patients [6]. Hence, caregivers play an important role in helping such patients with home-based treatments and health care; however, this is a challenging task for them. Caregivers are often not well prepared to take up caregiving activities and help patients adjust to new life realities [6-10]. This can compromise the physical and mental health of caregivers. Several studies have also highlighted that caregivers of patients with cancer might experience emotional, social, and physiological issues [1,6,8].

Recent literature has addressed some aspects of people's subjective well-being when using IT apps [11-15]. However, the needs and situations of caregivers of patients with severe and life-threatening diseases, such as cancer, have not been adequately addressed. Desmet and Pohlmeyer [16] proposed a positive design framework to support human flourishment and users' subjective well-being. In addition, Peters et al [17] adopted positive psychology guidelines and presented another framework with a special focus on the user's psychological well-being, in which they stress users' well-being to be addressed according to their psychological needs, such as autonomy, relatedness, and competence. Gulliksen et al [18] proposed the key principles of user-centered system design, emphasizing the importance of understanding the user's context and environment to provide better usability. However, their work was solely focused on organizational and professional work environments. The studies described earlier provide a general overview of designing for well-being and support the idea of involving users in the early stages of system design and development. Understanding users' contexts and preferences is an important aspect of designing for well-being.

Informal Caregivers' Burden

Many informal caregivers may not feel fully prepared to take on the responsibilities and challenges that come with providing care, especially if they have not received any training or support [7]. Several factors can contribute to the lack of preparedness of caregivers such as a lack of full understanding of the medical condition or care needs of the person they are caring for. They may also not have access to the necessary resources, such as equipment or supplies, to provide care [19]. This is aggravated by caregivers experiencing a caregiving burden. It is the stress experienced by a caregiver caused by the demands of providing care and balancing it with their personal responsibilities, such as managing their time, maintaining their social roles, managing their financial resources, and maintaining their emotional well-being [19]. Studies have shown that caregivers are more likely to have symptoms of poor physical and mental health or anxiety and depression when compared with noncaregivers [12]. Such situations may also lead to insomnia, reduced well-being, and a decreased willingness to care. In addition, they may also struggle with financial burdens because of their caregiving responsibilities while lacking a support system to help them with their caregiving duties, resulting in feelings of isolation and stress [13]. Many caregivers also have other responsibilities, such as work and family obligations, which make it difficult for them to find time to provide care. Hence, it is vital for caregivers to seek out resources and support to help them feel more prepared and equipped to handle their caregiving responsibilities. This may include finding information and education about the medical condition or care needs of the person they are caring for, seeking financial assistance or respite care to alleviate some of the burden, and connecting with other caregivers for support and advice [8]. Hence, it is important to support them to alleviate their caregiving burden and improve their well-being.

Informal Caregivers' Well-being and Positive Design

Human well-being and flourishing are integral elements of any technology [14]. People use and adopt technologies that fulfill their needs to enhance their physical and physiological well-being [15]. Therefore, technology should have a clear impact on users' well-being and enhance their positive emotions. Designers should understand the user group context and their needs and investigate factors that may enhance their well-being [4]. Involving different stakeholders, especially users, is vital in the design of IT apps [20,21]. However, involving users in the design process is insufficient; designers and developers should deliberately focus on the factors that positively impact users' well-being and flourishing [4,14,15,22].

The term "positive design" is used as an umbrella term for design approaches and research in which the main intention of the design is the subjective well-being of people and communities [16]. Positive design principles and concepts are derived from positive psychology [21], which discusses concepts and procedures for enhancing human flourishing and subjective well-being [23]. Desmet and Pohlmeyer [16] used positive psychology guidelines for human flourishment to propose a positive design framework for well-being. They emphasized that designers should have an explicit intention to support individuals' desire to flourish and live pleasurable, enjoyable, and satisfying lives. They established 3 fundamental elements of positive design: design for virtue, design for personal importance, and design for pleasure. They argued that each of these elements should independently stimulate human well-being, whereas the intersection of these elements enables and stimulates human flourishing. Design for virtue refers to the design of products and services that encourage virtuous behavior and support people's values and goals. This refers to designing products that make it easier for people to engage in activities that align with their personal values, such as exercise or volunteering. Design for personal importance involves designing products and services that help people feel a sense of purpose and meaning in their lives. This refers to designing products that allow people to engage in activities that align with their personal goals and values or that allow them to express their identity and personality. Design for pleasure involves designing products and services that provide enjoyment and pleasure to users. This can involve designing products that are esthetically pleasing or that provide a sense of accomplishment or satisfaction to the user. By considering these strategies in the design process, designers can create products and services that not only function well but also have a positive impact on the well-being and happiness of users.

To address basic psychological needs for well-being, Peters et al [17] explicitly translated the concepts of psychology into the human-computer interaction (HCI) context. They suggest that various factors, if used while designing an IT app, will contribute to positive well-being in users. These factors are autonomy (independence in pursuing one's goals and moral values), competence (ability and effectiveness), and relatedness (being connected to other related people).

Zhang [15] investigated the fundamental factors that motivate people to adopt and use a given technology. He stressed that people tend to adopt a given technology when they feel it would support their subjective well-being by fulfilling their basic needs in their daily activities. Therefore, technology-enhanced interventions should focus on the users' quality of life and well-being for better adoption. Zhang [15] highlighted motivational needs such as autonomy, relatedness, competence, and achievement as the basic precursors of successful technology adoption.

The above-described studies give us an overall idea of how positive design concepts can be and should be used to design meaningful technologies that fulfill users' basic needs, simulate their positive emotions, and ultimately enhance subjective well-being. However, there is still a need to understand how these general principles and guidelines can be practically implemented in a specific context such as informal caregiving. Therefore, in this study, we also discuss caregivers' preferences for a web-based intervention from a positive design perspective.

Carer eSupport Project

This project comprises a multidisciplinary research team, including researchers from HCI and software engineers and cancer nursing and medical researchers within the HNC field. The overall goal of Carer eSupport is to prepare caregivers of patients with HNC for caregiving and to decrease their caregiving burden with the help of a web-based intervention called "Carer eSupport." User needs and preferences for Carer eSupport were gathered from caregivers and health care professionals. On the basis of this, the first version of Carer eSupport will be designed and developed. Thereafter, feasibility studies will be conducted to evaluate the effectiveness and acceptability of the first version, the results of which lead to the second version of Carer eSupport. Finally, the effectiveness, usability, relevance, and acceptability of Carer eSupport will be tested in a randomized controlled trial. Further details about the project can be accessed from our study protocol "Internet-based support for informal caregivers of individuals with head and neck cancer (Carer eSupport): a study protocol for the development and feasibility testing of a complex online intervention" [10].

Aim

In this study, we explored the context of caregivers of patients with HNC and their needs for a web-based intervention (Carer eSupport) in Sweden. Critical factors that might influence the adoption of such web-based interventions were also discussed. In addition, the study participants also highlighted the desired functionalities and characteristics of Carer eSupport. The findings of this study assist us in answering the following research questions (RQs):

- RQ1: What are the preferred functions of informal caregivers of patients with HNC in designing a web-based intervention to support their well-being?
    - RQ1.1: What should be the characteristics of different preferred functions in web-based interventions?
- RQ2: What are the facilitators and barriers to adopting the web-based intervention from the perspectives of informal caregivers of patients with HNC and health care professionals?
- RQ3: How can positive design guidelines support informal caregivers' well-being in patients with HNC?

This study contributes to research on caregivers in 3 ways. First, major preferences for a web-based intervention (Carer eSupport) are highlighted from the perspectives of caregivers and health care professionals. Second, facilitators and barriers to the adoption and acceptability of web-based interventions in a specific context are emphasized. Finally, general guidelines for "designing for well-being and positive design" in a particular context of caregivers of patients with HNC are proposed, and eventually, a novel framework "Positive Design Framework for Informal Caregivers" to support caregivers is presented.

Methods

Design

This study adopted a qualitative research approach. Our ongoing project Carer eSupport [10] was used as a case to address the contextual nature of caregivers' well-being. In this study, we conducted focus group discussions with different stakeholders. The focus group method is a qualitative research approach for gathering empirical data on a specific topic with focused and well-organized discussions in small groups of carefully selected people [24]. To understand the context of caregivers and their preferences for Carer eSupport, focus groups were conducted with the caregivers. Thereafter, focus groups were also conducted with health care professionals to make Carer eSupport adaptable and acceptable for clinicians for possible future implementation in routine cancer care. All focus groups were conducted using a web-based videoconferencing tool [25].

Participants and Data Collection

We recruited 15 caregivers from 3 university hospitals in Sweden. A contact person at the oncology and radiotherapy clinics screened individuals with HNC who had an identified caregiver. We enrolled adult participants (aged >18 years) with different stages of HNC who were about to initiate treatment, were undergoing treatment, or had completed treatment within the past 3 months. Thereafter, we contacted each individual with HNC, and if they provided consent, contacted their caregivers to participate in the study. A total of 24 caregivers were invited to participate, and 15 of them consented to participate in the study. Cognitive impairment and inability to understand, speak, or read Swedish were the exclusion criteria for the caregivers.

Thereafter, 25 health care professionals were invited to participate, of which 14 agreed. They were aged approximately 30 years, and the majority of the participants were female. The inclusion criterion for the study was that health care professionals must have prior experience with patients with HNC.

Drawing from the existing literature regarding the needs of caregivers of patients with HNC as well as from health care professionals, 2 interview guides were formulated to conduct focus groups with caregivers and health care professionals (Textboxes 1 and 2). Focus group questions were formulated and developed through a collaborative brainstorming process among the authors UL, YTE, ÅC, and AA. The focus groups addressed questions from the following themes: experiences of being a caregiver, perceptions of IT-based support, support needs of caregivers, and health caregivers' perceptions of internet-based support.

Textbox 1. The interview guide for informal caregivers.

Experiences of being a relative of a person with head and neck cancer

- How did your life change when your relative was diagnosed with head and neck cancer?
- What are or were your needs as a caregiver of the patient with head and neck cancer?
- What support do or did you receive that met your needs?
- What support do or did you lack in your role as a family member?

Informal caregivers' perceptions of an internet-based intervention

- What are your experiences of using the internet for support?
- Describe your experiences with any IT programs or applications you have used in health care and medical care.
- How do you think that internet-based support for relatives should work?
- Follow-up questions:
  - What functions should be available?
  - How to communicate with others?
  - How should the information be presented?
  - How should the application's layout look like?
  - Should it be possible to customize the appearance, and if so, how?
  - Will there be a need for IT support?
  - How do you think a nonphysical person (robot) answers your questions?

Textbox 2. The interview guide for health care professionals.

Support needs of informal caregivers

- What are the support needs of relatives of people being treated for head and neck cancer?
- Which medical professions are needed to support relatives?
- Is there support other than nursing care that the relative may need?

Health caregivers' perceptions of an internet-based intervention

- How do you think that internet-based support for relatives should work to be usable and useful?
- Follow-up questions:
  - What functions should be available?
  - How to communicate with others?
  - How should the information be presented?
  - How should the application's layout look like?
  - Should it be possible to customize the appearance, and if so, how?
  - Have you previously used any technology-enhanced solution (eg, video meetings on Skype) to help or contact patients or their relatives? If yes, what challenges did you face?
- How do you think a nonphysical person (chatbot) answers your questions?
- What would be the key factors that may contribute to the long-term utilization of Carer eSupport for several years?

Data Analysis

To analyze the data, we adopted the 6-step thematic data analysis process by Braun and Clarke [26]. We used both inductive and deductive approaches to analyze the data. Initially, we used an inductive approach to investigate the needs and preferences for Carer eSupport among caregivers of patients with HNC. Subsequently, we used a deductive approach to examine the positive design guidelines in the specific context of caregivers of patient with HNC to support their well-being. The recordings of the focus groups were transcribed and stored in the data analysis software. AA thoroughly and repeatedly read transcripts as the first step of thematic analysis to familiarize himself with the data and inductively explore the initial ideas. The basic ideas related to the study aim were transformed into initial codes in the second step using positive design guidelines for well-being by AA in discussions with ÅC. The third step was to examine the codes and identify broader and more important themes. Study participants' relevant data, such as quotations and observations, were collected for these broader themes. As the focus groups were conducted in the native language (ie, Swedish), the selected quotations were translated into English. These themes were further reviewed and refined in the fourth step. In this step, we also ensured that all themes were directly or indirectly related to answering the RQ. AA and SP performed steps 3 and 4. The fifth step selected and finalized the most relevant and important themes. A workshop was conducted with all the study authors to thoroughly discuss and finalize the themes. Finally, the major themes, linked quotations, and researchers' commentaries are presented in the *Results* section.

Ethics Approval

All research procedures were approved by the Swedish Ethical Review Council (Dnr:2020-04650). Before starting the focus group discussions, the study participants were informed in written form and verbally about their rights and the study's implications. They were also informed of the purpose and procedures of the project. To ensure the security and integrity of the study participants, an end-to-end encrypted videoconferencing tool was used to conduct the focus groups. All gathered data were stored in a safe and secure database at Uppsala University.

Results

Study Participants

A total of 15 caregivers were selected from 3 hospital universities in Sweden. In total, 2 caregivers could not manage the time for the focus group discussions; therefore, they were interviewed individually. The characteristics of the caregivers are presented in Table 1.

Table 1. The characteristics of informal caregivers.

Informants	Sex	Age (years)	Relation with patient	IT literacy	Education
IC.1	Female	64	Partner	Medium	University master’s level
IC.2	Male	58	Spouse	High	University >3 years
IC.3	Male	54	Spouse	High	University bachelor’s level
IC.4	Female	34	Daughter	High	University master’s level
IC.5	Female	58	Spouse	High	University master’s level
IC.6	Male	70	Spouse	Medium	Secondary school
IC.7	Female	34	Daughter	Medium	Secondary school
IC.8	Female	64	Ex-wife	High	University master’s level
IC.9	Female	72	Spouse	Medium	University bachelor’s level
IC.10	Female	75	Spouse	Medium	Secondary school
IC.11	Female	55	Spouse	High	Secondary school
IC.12	Female	63	Spouse	Medium	University bachelor’s level
IC.13	Female	46	Daughter	High	University master’s level
IC.14	Male	66	Son	High	University master’s level
IC.15	Male	55	Spouse	Medium	Secondary school

Focus groups were also conducted with health care professionals to ensure that Carer eSupport is adaptable and acceptable for clinicians and can be implemented in routine cancer care. It also helped us to understand the patients’ disabilities and their needs for care from the health care professionals’ viewpoint. In total, 13 health care professionals were recruited from different hospitals in Sweden. All health care professionals were carefully selected from different fields of caregiving to patients with cancer, including nurses, physicians, dietitians, dentists, and speech therapists. The characteristics of health care professionals are presented in Table 2.

Table 2. The characteristics of health care professionals.

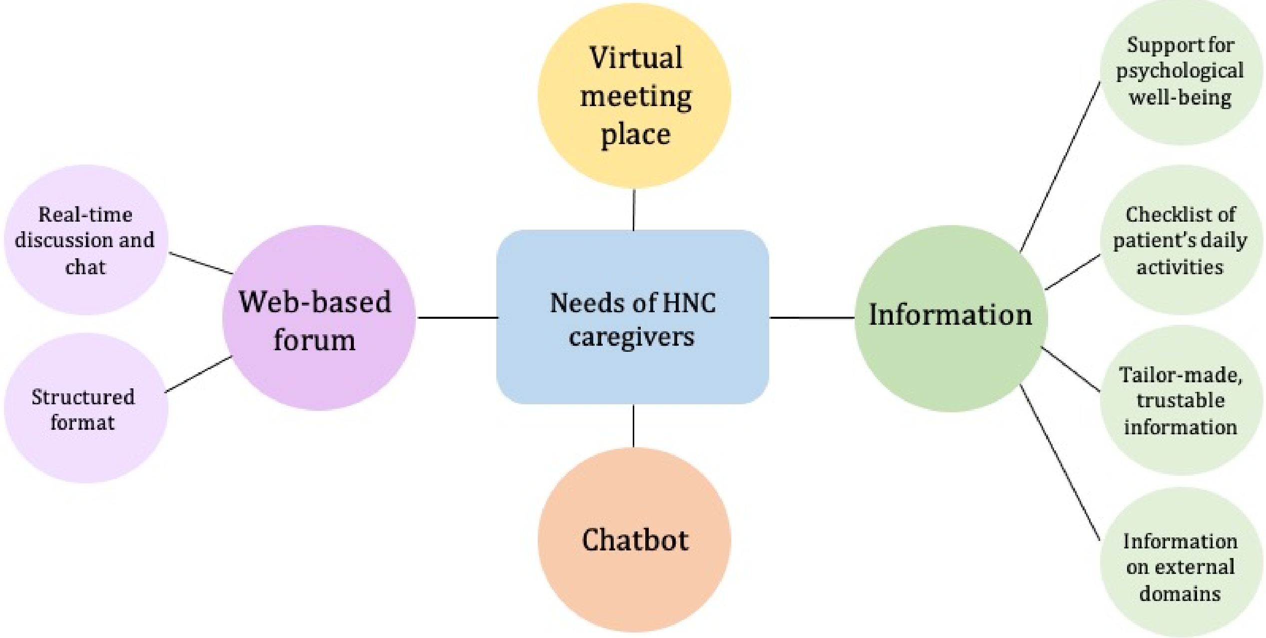
Informants	Professional role	Professional experience (years)
HCP.1	Nurse	5-10
HCP.2	Nurse	>10
HCP.3	Research assistant, nurse	5-10
HCP.4	Dietitian	>10
HCP.5	Physician	5-10
HCP.6	Hospital almoner	3-4
HCP.7	Specialist nurse	<10
HCP.8	Dental hygienist	5-10
HCP.9	Assistant nurse	<10
HCP.10	Speech therapist	5-10
HCP.11	Physician	5-10
HCP.12	Speech therapist	5-10
HCP.13	Speech therapist	<10

Findings

Overview

This section presents the findings of our focus group discussions with caregivers and health care professionals. Figure 1 presents the themes and subthemes identified by the focus groups. To support caregivers’ well-being, study participants highlighted their desired functions on the Carer eSupport platform. The study participants also discuss the facilitators and barriers to successful adoption and the specific characteristics of those functions. The following subsections present the participants’ views and citations.

Figure 1. Themes and subthemes identified. HNC: head and neck cancer.



Information

Most participants emphasized the need for tailored and trustable information for caregiving, their own psychological and mental well-being, and receiving help for their daily life activities. Both caregivers and health care professionals believed that this information should be available digitally and in a format that is easily understandable to caregivers. This information should be presented in a manner that caregivers from nonmedical backgrounds can understand. Health care professionals also stressed that the information about diagnosis and caregiving needs to be provided in an easy-to-access way by structuring them categorically. Most caregivers spent time finding information from external sources and stressed that access to such information in one place would benefit them by reducing their time and effort they spent. Health care professionals felt that most information available on the web or offline could be too general. Most caregivers in the study felt a sense of virtue, acknowledgment, and competence (based on positive design guidelines) through tailor-made and trustable information functionality.

Tailor-made and Trustable Information

Both caregivers and health care professionals suggested that information should be precise according to caregivers' needs and situation-specific and tailored information. They believe that the information currently available is usually generic about diseases and treatments; however, the same disease may have different side effects for different individuals. Hence, they insisted on having access to tailor-made and trustable information. On the basis of this, it can be noted that the generic nature of information can be a barrier to successfully adopting a web-based intervention:

> *I think it is difficult with all written information that it very quickly becomes very general and held for a large group where it is only a small, small part that is related to me. And in such a case, I actually become very selfish. I really don't care how it is for everyone else, but I just want help with something very specific for me.* [IC.3, Table 1]

Although most participants highlighted the importance of tailored information, some health care professionals showed their concern that specific information would not be easy to provide and could create an extra burden for health care professionals, who considered it as a barrier to practical implementation. To avoid this potential barrier of extra workload on health care professionals, they suggested having some general information. In this way, health care professionals do not have to work extra, but caregivers may obtain some important and relevant information:

> *I think it might be best to keep the information general as well. For example, the information about the most common operations...as well as the most common side effects or this is how the radiation treatment works but if you would have something specific for each patient, then there is something extra to be imposed on us.* [HCP.5, Table 2]

Support for Caregivers' Psychological Well-being

Most caregivers highlighted the need for well-being and psychological well-being. They suggested a collection of pages with inspirational and motivational videos and mindfulness exercises to help calm them. They felt that such resources could have a positive effect on their mental health and may help reduce stress. The caregivers also felt that such support could positively affect the quality of care provided to their relatives:

> *It would be quite nice if you had a small collection of pages, not only regular caregiving but something interesting e.g. a movie on the immune system movie. If you have many thoughts and worries, your sleep will probably be affected, maybe it is good with a mindfulness exercise to sort of calm down and get rid of thoughts...even like small video clips, a story or an*

> *interview where you can read about a fictional person who is close relative where he tells about what he has done as a relative. As it can also give inspiration...* [IC.13, Table 1]

Health care professionals also confirmed the need for information and resources related to caregivers' health and well-being. They stated that caregivers would like to have acknowledgment and confirmation about what they are going through in their daily life. They also want to be acknowledged for their work on caregiving:

> *I believe that the need for information and facts also exist to make you feel that you can care for your relative, but then you have your feelings and how I feel as well...When I care for my relative and what needs arise at my side. It feels like two different things, and when you design this support, everything should be included. Therefore, you need to divide it, e.g. these are facts for how I should care for my relative, and then, this is the support for me [as a relative].* [HCP.2, Table 2]

Checklist of Daily Life Activities With a Patient With HNC

All caregivers in our study stressed the need for information regarding their daily life activities. Therefore, a collection of pages containing information about daily life activities as the caregiver of a patient with HNC would be helpful. For example, a checklist for caregivers to take care of relatives at home that includes common items that caregivers may need to consider when providing care at home. It can help caregivers feel more prepared and confident in their role, and it can also make it easier for them to access the support and resources they need:

> *Maybe some checklist. What is common? Now your relative comes home, what is the most common thing you need to think about so that you can get help about what to do? A checklist, only bullet points might be helpful.* [IC.13, Table 1]

Information About Relevant External Domains

Most caregivers felt the need to have information about external domains, such as web pages with information, third-party applications for caregiving or mental health, and videos with exercises for caregivers. Some caregivers described that there were other support groups and information and resource portals for caregivers but not many knew about them. Therefore, it is important to obtain this information from the system:

> *There is a group here in XX [city name] that is only for relatives. And when I talk about it, not many people know about these groups. You as a relative can get there, talk, and participate in activities. Links to such groups where you might be reminded that I need support [as a relative]. I need support to be strong. I will not only be able to be strong by myself.* [IC.13, Table 1]

Most health care professionals stated that information was already available in these external domains and emphasized that this information should be presented in the web-based intervention. Some health care professionals pointed out that although there is information already present on the web, caregivers do not know where and how to access it:

> *I think that there is very good information from other resources, that such a portal could compile, that you provide a lot of links and contact information and, here you as a relative can get support from patient associations and relatives associations and so on, it is a jungle of information in itself, so the patient or relatives should have a place to go to where you can find very different kinds of information.* [HCP.13, Table 2]

Web-Based Forum

Among others, a web-based discussion forum emerged as an important preference for study participants to support caregivers' well-being. Caregivers and health care professionals emphasized the importance of a web-based discussion forum in which stakeholders can share their ideas and experiences. Most caregivers felt that such a space would help them read about other caregivers' situations and learn from their experiences. However, they had reservations about the credibility and accuracy of the information provided by the caregivers. Most caregivers in this study supported the idea of a web-based forum or peer-to-peer support. However, there are some barriers to using a web-based forum. For example, some caregivers use computers at work and do not want to continue using them at home. Some caregivers who have used social media excessively in their daily lives become tired of it and try to avoid any social media or similar activities. However, some caregivers also pointed out that although web-based forums can be useful, they can be generic while having a heterogeneous group of caregivers and hence, expressed a need to have a specific forum for caregivers of patients with HNC. Most caregivers and health care professionals also stressed the risk of spreading incorrect information in such forums during discussions with other caregivers, particularly those directly related to patient caregiving. To this end, health care professionals and caregivers highlighted the need for a moderator that would monitor the discussions and answer caregivers' questions. Most caregivers in this study felt a sense of relatedness, acknowledgment, confirmation and engagement, and competence (based on positive design guidelines) through a web-based forum functionality.

Real-time Discussion and Chat With Other Informal Caregivers

Most caregivers highlighted their positive experiences with other web-based forums, where they could better understand their situation by reading about other caregivers' situations. They also felt that sometimes these posts or texts included best practices that had worked for other caregivers, which they reported as being more trustable. In addition, real-time chats with other caregivers and health care professionals were highlighted as important features for caregivers. It would be helpful to have a real-time chat feature so that caregivers can use it to interact with health care professionals and other caregivers. A major advantage of this approach is its acknowledgment and relatedness. Caregivers should be able to share noncritical information and personal experiences in their daily lives. The caregivers felt that it was important to have a safe space to share their feelings and emotions. Sharing their experiences enables caregivers to obtain a sense of acknowledgment and confirmation. They feel that they are not alone, and there are more people in the same situation:

> *You learn a lot about how everyone feels, what symptoms they have, and what help they have received for the symptoms. It has been very good and very educational because you see others with the same disease.* [IC.15, Table 1]

Health care professionals also confirmed that web-based forums might help overcome social isolation. For example, if caregivers need information in the middle of the night when health care professionals are not available, a web-based forum asking for advice might be helpful. Some health care professionals also stated that if a caregiver is alone and has no friends or family available, they may get exhausted and may need support to overcome tiredness and loneliness. These conversations should be permanent on the forum so that health care professionals can check and comment on them later. This reduces the risk of spreading incorrect information:

> *You can be quite alone as a close relative. It also depends upon your family situation, if I talk about my patients, some of them have a quite large and active network of friends and family, and they all support the patients in different things. However, if you are the only person caring for the patient, you can be exhausted.* [HCP.10, Table 2]

Structured Format of Web-Based Forum

Most caregivers highlighted the need for different dedicated channels in web-based forums for various purposes. The forum could have different channels based on caregivers' needs. For instance, a channel where caregivers can ask questions to health care professionals or a channel that is dedicated to questions related to the daily life problems of caregivers. They described that in daily life, they experienced problems that other caregivers might have encountered and might have some good solutions to. In this way, they could support each other by sharing their experiences and tips:

> *I would like to have a channel where I can really ask any type of question. It can be practical questions, such as: now I go on my knees, I need someone who can clean the home for me. Does anyone have any idea how I can handle this? Or they are doing construction work outside the house so it is not possible to stop with the car outside, how can I do to pick up my wife there.* [IC.3, Table 1]

Health care professionals stressed that they should answer questions related to the patient's treatment, which should be permanently available to everyone. Health care professionals felt that this would ensure that questions were not repeated and that there was a repository of answers created together by caregivers and health care professionals that is available to all:

> *If you enter the questions and the healthcare professionals may answer the questions and the answer should be available for everyone in the forum, so if you post a question everyone can see the question the most suitable person can answer. The answers should also be permanently available so that the others can get benefit from them.* [HCP.9, Table 2]

Virtual Meeting Place

Virtual meeting place emerged as another important function for the web-based intervention. Caregivers would like a place where they can talk to each other and share their experiences and knowledge by being present on a video call. These video meetings can also be used to interact with and receive advice from health care professionals. For example, if caregivers need to discuss their situation with a social worker (curator in a hospital), they should be able to do so using this feature. They suggested that web-based meetings could benefit caregivers for socialization and trust building with other people. Some caregivers provided positive and emotional reflections on the virtual video discussion sessions with other caregivers. They also suggested that such video meetings and discussions might be good for social interaction, engagement, and trust building (based on positive design guidelines) among caregivers with similar circumstances. However, most caregivers highlighted the barriers to these video activities. These web-based video meetings and events are good for easy accessibility, but caregivers might miss human contact in real-life meetings. Some caregivers preferred to meet each other in real life, although they agreed on meeting on the web when they cannot meet in real life. There are also technical issues with these web-based video meetings, and many caregivers and health care professionals did not have good experiences. They were concerned about facing the same problems for web-based video meetings during this intervention:

> *I did not know what this meeting would mean to the others. But a reflection from my side is that God, how nice it has been to meet you all...tears have come out of my eyes, I tried not to burst out completely in tears, it has been very, very nice to share emotions. And as someone said here that we did not know each other before, but still pretty quickly you get a connection with each other, and it is very liberating. Very, very nice so thank you very much, everyone.* [IC.13, Table 1]

Health care professionals also emphasized that there should be a place where caregivers can discuss their problems and feelings with other caregivers in similar situations. They felt that caregivers might not share their feelings with their relatives because of an underlying sense of guilt. In this situation, there should be an outlet for sharing feelings and emotions:

> *Yes, I think you should discuss what you think. If you have such a support function where you could step in as a relative e.g. God, I think this is tough with my husband, he smells bad, we in the family can't eat what we want, but I don't want to say it outright because it's my husband who has this situation, it's not me who should feel pity, although it will be a pity for me, still you should express those feelings, there*

> *should be a forum for me to be able to talk about all this.* [HCP.2, Table 2]

Chatbot

The chatbot was the least desired function by both the caregivers and health care professionals. Only a few caregivers felt positive about it being a good and easy way to access information. However, these caregivers were proficient in using this technology. They felt that they could trust the information from a chatbot, as it works similarly to a search engine, such as Google. According to many caregivers, one of the vital barriers to adopting chatbots was the lack of human contact. They emphasized the need to interact with a person when asking for critical health-related information. Although many acknowledged the relevance of chatbots for general information retrieval, they preferred to communicate with people either verbally or in written form. The lack of trust in robotic technologies has also emerged as a potential barrier to adopting chatbots. Most participants were concerned about the credibility of the information obtained from the chatbots. They were hesitant to retrieve critical information related to their relative's health from chatbots. However, the limited knowledge of the participants regarding chatbots was also seen as a reason for this distrust. Some participants explained that they need to gain a better understanding of the basic mechanisms of chatbots before they could consider using them. Some caregivers who had previously used chatbots felt that they needed more specific answers as opposed to generic responses that they thought chatbots provided. They felt annoyed by the generic answers to their contextual and specific questions:

> *I'm a little hesitant to talk to an artificially intelligent robot in these fragile circumstances. I feel it is not the same as a person with flesh and blood that I have in front of me. So, I'm hesitant there...So, the first thought that comes to the mind when something happens, is you want to talk with someone you know well. Is there anyone who can help me, who can talk, and I think, usually you get much calmer if you talk to a real person rather than a robot...* [IC.10, Table 1]

Similar to caregivers, health care professionals have also suggested the use of chatbots for basic and noncritical information retrieval. For example, tips and suggestions for preparing food for patients might be a good use of such chatbots. Therefore, chatbots might be good for basic information, for example, as nutrition tips. However, they were generally hesitant to interact with robots. Health care professionals have suggested a combination of humans and robots to provide information. Both should complement each other by providing different types of information:

> *I think it can be both like with real people responding to some things and an AI robot responding to some other things. One does not have to exclude the other, you can have both. And both should complement each other and then they can also seek support from each other.* [HCP.9, Table 2]

A summary of the preferred functions, desired characteristics, and facilitators and barriers is presented in Table 3.

Table 3. Carer eSupport's preferred functions, characteristics, and the facilitators and barriers.

Functions	Desired characteristics	Facilitators	Barriers
Information	1. Information about different diagnoses and treatments with easy-to-understand and nonmedical language 2. Psychological help for caregivers' well-being 3. Checklist of daily life activities with the patient 4. Digitalization of paper-and-pen–based information 5. Links to already available information from external resources 6. Links to other groups and portals for the relatives of the patients 7. Inspirational and motivational videos	1. Tailor-made and trustable information 2. Collected information in one place 3. Help for caregiving the patient 4. Help in daily life activities 5. Help for caregivers' well-being and mental health 6. Enhances positive emotions such as virtue, acknowledgment, confirmation, and competence	1. Much information is already available and provided by health care professionals 2. Very general information
Web-based forum	1. The forum should be moderated by the health care professionals 2. Real-time discussion and chat with caregivers 3. Possibility to send private messages to the forum members 4. Permanently available conversations 5. Dedicated channels for different types of discussions, for example, daily life problems of the caregivers, patients' health-related issues, caregivers' health and physiological well-being, and asking questions about head and neck cancer treatments	1. Easy availability and accessibility of information 2. Helpful to combat loneliness, depression, and anxiety 3. Share personal feelings 4. Enhances positive emotions such as relatedness, acknowledgment, confirmation, engagement, and competence	1. Risk to spread wrong information 2. Availability of other web-based forums and groups 3. Antisocial media people
Virtual meeting place	1. Possibility for video meetings with the health care professionals 2. Real-time chat and discussions with health care professionals 3. Possibilities for seminars and group discussions 4. Possibility for video meetings with health care professionals	1. Enhances positive emotions such as social trust, relatedness, acknowledgment, confirmation, engagement, and competence	1. Technical issues 2. Human contact is missing
Chatbots	1. A combination of human and robot 2. Only for noncritical information	1. Easy availability and accessibility of information	1. Human contact is missing 1. Lack of trust in robots 2. Lack of knowledge about chatbots 3. Standard answers

Discussion

Principal Findings

This study explored HNC caregivers' main preferences and desired functionalities for Carer eSupport. These needs of caregivers were also explored and discussed with highly experienced and qualified health care professionals in different areas of HNC treatment. Our main focus was on understanding caregivers' situation and highlighting their preferred functions that may enhance their subjective well-being. Through focus groups with caregivers and health care professionals, we discussed 4 major functions: information, a web-based forum, a virtual meeting place, and a chatbot. The detailed characteristics and content of these functions were also discussed with the study participants according to the caregivers' situation and context. Moreover, we highlighted the facilitators and barriers to the successful implementation of Carer eSupport. The potential barriers also guided the study participants to discuss the characteristics of their preferred functions, which might help them avoid those barriers. We now discuss our findings with previous studies on users' needs, well-being, and adoption of eHealth applications.

Previous literature has highlighted tailored information and peer-to-peer support as the primary needs of caregivers

[7,8,27,28]. This study extends this knowledge by providing functions to address those needs and an in-depth understanding of the special characteristics and content followed by facilitators and barriers to these functions. Jansma et al [27] stressed that caregivers of patients with palliative cancer need support to communicate better with health care professionals and other caregivers, which is in line with our findings for caregivers of patients with HNC. Köhle et al [7] suggested that peer-to-peer support and information for caregiving are the most important needs of caregivers; however, their study focused only on the partners of patients with cancer and their psychological well-being. The above-described studies give us an idea of caregivers' needs in different contexts; however, they did not suggest how to address the need for a web-based intervention that our study addresses in the form of different functions, such as a web-based forum and virtual meeting place for peer-to-peer support and communication with health care professionals.

This study also provides insights into the context of caregivers when designing a web-based intervention that might support their subjective well-being. Many studies have focused on the needs and preferences of patients for technology-enhanced systems [29-31]; however, caregivers seem to be a neglected user group in eHealth research [32]. To the best of our knowledge, this is the first study to discuss the preferences of caregivers of patients with HNC and the potential facilitators and barriers to the successful implementation of this web-based intervention focusing on caregivers' well-being. The inclusion of caregivers and health care professionals in this study is also a distinct feature not commonly seen in previous research, which provides additional insights.

Previous studies on caregivers of patients with cancer have also suggested the need for a wide range of tailored information [7,8,27,28]. Caregivers want to be more aware of the patient's medical condition but lack information about existing support [7]. Our results also highlighted that caregivers need information about the different impairments caused by HNC, their treatments, and how they (both patients and caregivers) can be prepared for those treatments. After treatment, they also wanted to know the long-term side effects and the recovery process. Caregivers also want a checklist for daily life activities that they need to perform with patients. The checklist includes common items that caregivers may need to consider when their relatives come home. This can help caregivers feel more prepared and confident in their role, which can in turn improve the quality of care that patients receive at home [28].

Previous research has shown that living with severely impaired patients may create depression and anxiety in caregivers, which might affect caregivers' psychological health and well-being [6,28]. In our study, to cope with the problems related to psychological health, both health care professionals and caregivers highlighted the importance of informative and inspirational material. It can be helpful for caregivers to hear about the experiences of others who have faced similar challenges while caring for loved ones with cancer. Inspirational videos featuring stories from other caregivers can provide support and encouragement, as they offer a glimpse of the struggles of others who have experienced similar situations. Previous research on design for well-being suggests basic elements that may enhance users' psychological well-being by addressing their needs [15,33]. In our study, we found that by providing tailor-made and trustable information, some of the needs for psychological well-being can be addressed, namely, virtue, acknowledgment, and competence.

Our findings highlighted the importance of a web-based forum for caregivers to communicate and share their views with other caregivers and ask questions to health care professionals. In some cases, caregivers experience loneliness, depression, and anxiety, and they believe that connecting and interacting with other caregivers can be helpful [34]. In addition, recent studies have also indicated that feeling connected with a community might reduce the loneliness and social isolation of relatives of patients [34,35]. Previous research on patients with cancer and their relatives has shown the positive effects of peer support and connecting people [36,37]. Köhle et al [7] stressed the need for peer support to overcome depression and anxiety among partners of patients with cancer. They suggested a peer support function in a web-based intervention for patients' partners to support their psychological well-being and to provide them with the acknowledgment of what they are going through in their lives and struggles. In our findings, caregivers also wanted to communicate with each other to acknowledge and confirm their daily life activities with the patients.

It is evident from previous research on designing for well-being that connecting and socializing with other people in the same situation give a sense of happiness and motivation and enhance positive emotions [15,16,38]. Peters et al [17] also highlighted "Relatedness (being connected to other related people)" as a basic element for the psychological well-being of people. Studies have highlighted that informal caregivers tend to search for relevant web-based forums and communities to feel a sense of relatedness and social belonging through them [35]. In this study, we found that a web-based forum may address the needs of caregivers' subjective well-being by providing relatedness, acknowledgment, confirmation, and engagement. Our findings on the need and effectiveness of a web-based forum are in line with previous research; however, we provide detailed characteristics and content of the web-based forum so that the facilitators of technology adoption can be enabled and barriers can be minimized. For instance, the risk of spreading wrong information is huge in the web-based forum; to overcome this issue, our findings suggest that health care professionals should moderate the forum, and the communication between the users should be permanently available so the moderator may monitor the communication and make corrections if needed.

Our findings suggest a virtual meeting place in which caregivers can meet on the web and share their feelings, experiences, and knowledge. The caregivers described that web-based forums were good for written communication, but web-based meetings and sessions with health care professionals and other caregivers provided better interaction. The positive effects of the web-based forum and the virtual meeting place are the same; however, virtual meetings provide some additional benefits such as trust building, knowing each other better, and emotional engagement with others who are in the same situation. Therefore, in virtual meetings, the components of well-being are the same as those suggested in the web-based forum, with social trust as an additional component. The caregivers suggested that web-based meetings or seminars should be conducted with other caregivers and health care professionals. The basic idea here is to provide caregivers with peer support and valuable information from health care professionals about caregiving to the patients and taking care of their own well-being.

Our findings also suggest that virtual meetings cannot be a complete substitute for real-life meetings, but they should complement real-life meetings. Caregivers considered virtual meetings good because of their easy accessibility, but they also met people in real life and miss human contact. Recent studies have shown that virtual meetings may positively influence users' well-being [39], such as engagement and motivation; however, people still prefer physical meetings [40]. Hence, virtual meetings complement traditional physical meetings and should be used only when real-life meetings are impossible or feasible. As most Swedish populations are dispersed throughout the country, virtual meetings may be a good alternative to real-life meetings.

Previous research on patients with cancer and their caregivers highlights the importance of peer support in the informal caregiving context [7,36,37]; however, the questions of how this support should be given to caregivers and which medium should be used have not been explicitly answered from the end users' perspective. In this study, we discussed the different methods and mediums for providing peer support such as the web-based forum and virtual meeting place; both provide peer support and connect caregivers with their facilitators and barriers.

Generally, our study participants did not like the idea of a chatbot asking questions and retrieving information. Caregivers wanted human contact while communicating their concerns and feelings. Previous studies on the role of chatbots in cancer caregiving also suggest that human elements are important and cannot be replaced by robotics [41,42]. In our study, the lack of trust in robotics technologies was another barrier to chatbot adoption. In particular, caregivers who did not know how chatbots worked were reluctant to use them. The trust issues on chatbots are also evident in previous research on chatbots for cancer caregiving [41-43]. People doubt the credibility and accuracy of the information received from chatbots. The lack of knowledge about how artificial intelligence and machine learning work behind retrieving information and data also create distrust in chatbots [43]. Therefore, we suggest proper education and training for users to adopt chatbots successfully in their daily lives.

The study participants suggested that the chatbot should cooperate with health care professionals rather than exclude them from each other. Caregivers and health care professionals have suggested that chatbots can be used for general and noncritical information. However, health care professionals should directly ask questions regarding medical treatment and patient health. Previous research also suggests that chatbots have the potential to integrate into the health care system, but they should not replace health practitioners, and both might work side by side [42,44].

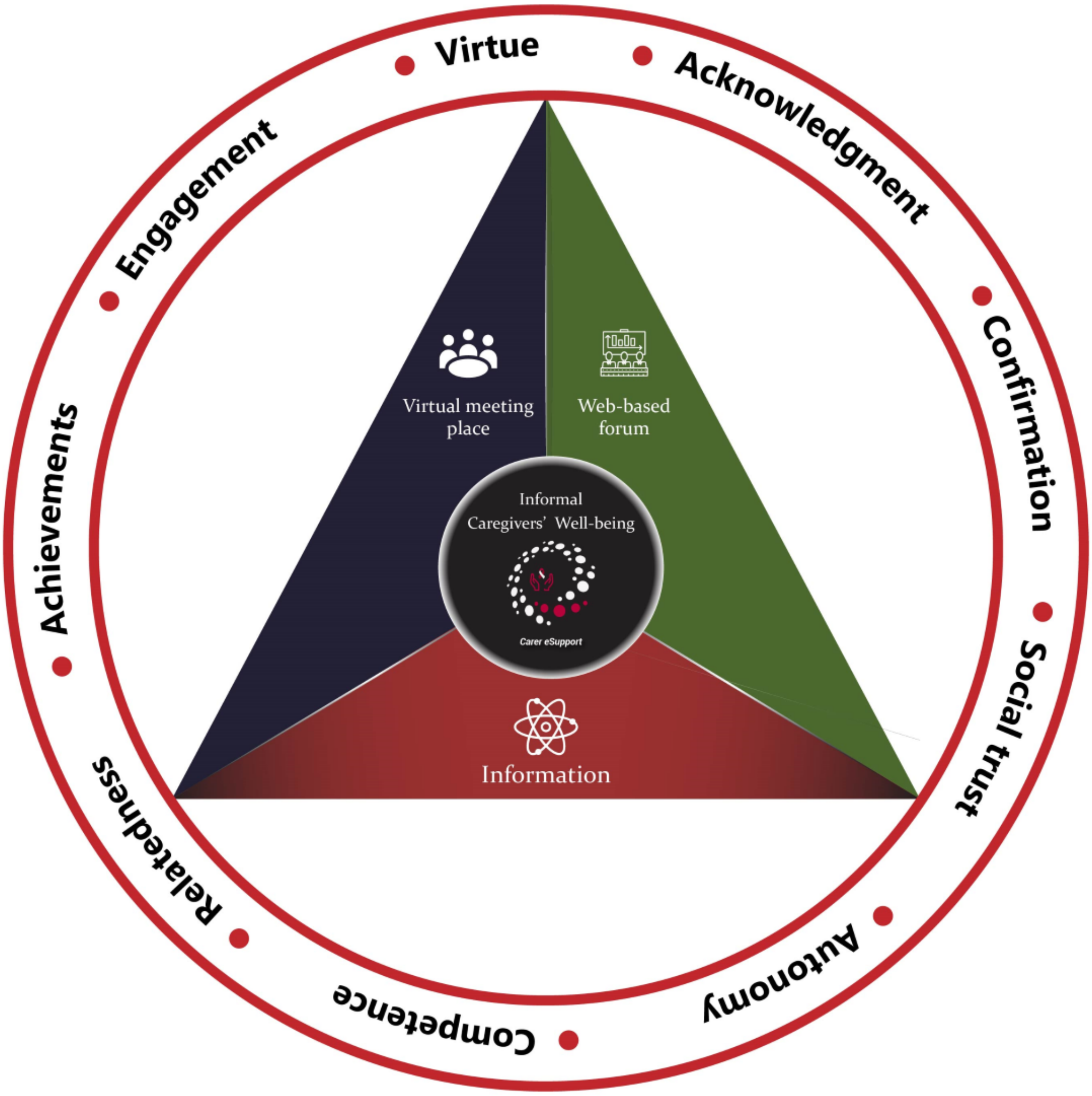
Positive Design Framework for Informal Caregivers' Well-being

A general understanding of overall human well-being might be helpful for HCI researchers and designers when designing eHealth interventions; however, user interactions and experiences are usually contextual and can vary based on their circumstances and dynamics [45]. The user context also plays a vital role in the successful adoption of eHealth interventions. Designers should involve users in the design process and deliberately focus on their well-being and positive emotions. Hence, the user-centered design approach is of utmost importance for caregivers' well-being; after all, they are the true evaluators of their well-being [4].

In this study, we incorporated general guidelines of designing for well-being and positive design in the context of caregivers of patients with HNC. We drew from 3 studies (as presented in the introduction section) that used positive psychology principles to propose general guidelines and frameworks for well-being design [15-17]. These studies highlighted 8 components of human psychological needs that should be considered when designing for well-being: virtue, personal significance, pleasure, autonomy, competence, relatedness, achievements, and engagement. Empirical evidence from our study and previous related studies indicates that not all 8 components of designing for well-being are applicable in the caregivers' context; personal significance and pleasure were found to be not applicable to caregivers of patients with HNC. Instead, we explored 3 other components not explicitly proposed in previous studies but relevant to caregivers' contexts: acknowledgment, confirmation, and social trust. These components emerged from the focus groups.

In Figure 2, we present the positive design framework to support caregivers' well-being. In total, 3 major preferences of caregivers emerged as the main functions of Carer eSupport: information, web-based forum, and virtual meeting place. Each function independently stimulates caregivers' well-being, and the intersection of these functions is where caregivers may feel supported and flourish. The outer circle presents the basic components of caregivers' well-being that these 3 functions can achieve: virtue, acknowledgment, confirmation, social trust, autonomy, competence, relatedness, achievements, and engagement. Each function may independently address many components, and each component can be achieved by more than one function (also indicated in the *Results* section). For example, acknowledgment and confirmation can be achieved in all 3 functions: information, web-based forum, and virtual meeting place. Similarly, relatedness can be achieved with 2 functions: web-based forum and virtual meeting place. However, social trust or trust in other people is easier to achieve in a virtual meeting place.

Figure 2. Positive design framework for informal caregivers.



Limitations

In this study, we introduced a positive design framework to support caregivers' well-being. A limitation of our study is that it was performed with a rather small group of caregivers. To explore the detailed implications of the proposed framework, more empirical evidence with a larger group of caregivers is needed. Another limitation is that the framework was not tested for usability and user experience (UX); therefore, we might not have established the framework's effectiveness from a UX perspective. However, in future research, we will test the usability and feasibility of Carer eSupport and the proposed framework.

This study was undertaken during the pandemic (COVID-19), and all focus groups were conducted on the web to ensure the study participants' health. Research on the ethical aspects of qualitative studies shows that the well-being and overall health of study participants should always be prioritized over research objectives and strict timelines [46]. Therefore, we could not use the full potential of focus groups in real-life settings. The use of a nonprofessional translator to translate the data collected in the focus groups conducted in the Swedish language could be another potential limitation. There is a risk that translations may not fully capture the nuances of the original language, which could affect the study's overall results.

Conclusions

The design strategies for caregivers' subjective well-being, especially the caregivers of patients with severe diseases such as cancer, have been scarce in previous HCI research. This study revealed an in-depth understanding of caregivers' contexts and their preferred functions for a web-based intervention (Carer eSupport). Health care professionals' valuable input on the preferred functions gave us important insights into the adoption and practical implementation of Carer eSupport in routine cancer care. Our empirical findings on the potential facilitators and barriers to adopting Carer eSupport allowed us to define the special characteristics of caregivers' preferred functions so that facilitators can be included and barriers can be omitted in the intervention. We used the theoretical foundation of designing for well-being and positive design in the informal caregiving context and proposed a positive design framework to support informal caregivers' well-being. Our proposed framework might be helpful for HCI and UX researchers to design meaningful eHealth interventions with a clear focus on users' well-being and positive emotions, especially for caregivers of patients with HNC. The importance of involving users in the design and development process to solve objective problems has been demonstrated in previous research. However, the HCI research community should focus more on holistic approaches and the subjective well-being of end users.

Acknowledgments

This research was funded by the Swedish Research Council (reference 2019-01231) and Swedish Cancer Society (reference 20 1014 PjF) and the Department Oncology Foundations Research Fund in Uppsala. This work was also supported by the European Union's Horizon 2020 research and innovation program under Marie-Sklodowska Curie grant agreement number 814 072.

Authors' Contributions

AA was the principal author of the study. AA designed and analyzed the study, interpreted the interviews, and finalized the manuscript. SP contributed to the interpretation of data, wrote parts of the paper, and edited subsequent manuscript drafts. ÅC contributed to the study design and critical revision of the manuscript. UL, YTE, ÅC, and AA conducted the focus groups. BJ and MC provided critical inputs for finalizing the empirical data and overall manuscript. All the authors provided critical feedback on the final version of the manuscript. All the authors approved the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

HCI: human-computer interaction
HNC: head and neck cancer
RQ: research question
UX: user experience

Edited by A Mavragani; submitted 15.01.23; peer-reviewed by A Efthymiou; comments to author 11.02.23; revised version received 13.03.23; accepted 18.04.23; published 30.05.23.

Please cite as:
Ahmad A, Premanandan S, Langegård U, Cajander Å, Johansson B, Carlsson M, Tiblom Ehrsson Y
Positive Design Framework for Carer eSupport: Qualitative Study to Support Informal Caregivers of Patients With Head and Neck Cancer in Sweden
JMIR Cancer 2023;9:e45748
URL: https://cancer.jmir.org/2023/1/e45748
doi:10.2196/45748
PMID:37252765

Original Paper

Cancer Pain Experience Through the Lens of Patients and Caregivers: Mixed Methods Social Media Study

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Abstract

Background: Cancer pain represents a challenge for cancer patients and their family members. Despite progression in pain management, pain is still underreported and undertreated, and there is limited information on the related needs that patients and caregivers may have. Online platforms represent a fundamental tool for research to reveal the unmet needs of these users and their emotions outside the medical setting.

Objective: This study aimed to (1) reveal the unmet needs of both patients and caregivers and (2) detect the emotional activation associated with cancer pain by analyzing the textual patterns of both users.

Methods: A descriptive and quantitative analysis of qualitative data was performed in RStudio v.2022.02.3 (RStudio Team). We analyzed 679 posts (161 from caregivers and 518 from patients) published over 10 years on the "cancer" subreddit of Reddit to identify unmet needs and emotions related to cancer pain. Hierarchical clustering, and emotion and sentiment analysis were conducted.

Results: The language used for describing experiences related to cancer pain and expressed needs differed between patients and caregivers. For patients (agglomerative coefficient=0.72), the large cluster labeled *unmet needs* included the following clusters: (1A) *reported experiences*, with the subclusters (a) *relationship with doctors/spouse* and (b) *reflections on physical features*; and (1B) *changes observed over time*, with the subclusters (a) *regret* and (b) *progress*. For caregivers (agglomerative coefficient=0.80), the main clusters were as follows: (1A) *social support* and (1B) *reported experiences*, with the subclusters (a) *psychosocial challenges* and (b) *grief*. Moreover, comparison between the 2 groups (entanglement coefficient=0.28) showed that they shared a common cluster labeled *uncertainty*. Regarding emotion and sentiment analysis, patients expressed a significantly higher negative sentiment than caregivers ($z=-2.14$; $P<.001$). On the contrary, caregivers expressed a higher positive sentiment compared with patients ($z=-2.26$; $P<.001$), with trust ($z=-4.12$; $P<.001$) and joy ($z=-2.03$; $P<.001$) being the most prevalent positive emotions.

Conclusions: Our study emphasized different perceptions of cancer pain in patients and caregivers. We revealed different needs and emotional activations in the 2 groups. Moreover, our study findings highlight the importance of considering caregivers in medical care. Overall, this study increases knowledge about the unmet needs and emotions of patients and caregivers, which may have important clinical implications in pain management.

(JMIR Cancer 2023;9:e41594) doi:10.2196/41594

KEYWORDS

pain; cancer; quality of life; social support; emotion; personality; decision-making

Introduction

Background

Cancer pain represents a challenge for cancer patients at different time points of their medical path, from diagnosis to long-term survivorship and palliative care. In a recent meta-analysis [1], cancer pain was demonstrated to be most prevalent after and during anticancer treatments (prevalence rate from 39% to 55%), followed by advanced, metastatic, or terminal disease (66%). According to Dame Cicely Saunders [2,3], pain is not just a physical experience in oncology. It involves all components of human functioning, including psychological, social, and spiritual aspects, resulting in a “total pain” experience.

From a psychological point of view, cancer pain may represent a source of emotional distress, anxiety, depression, fear of suffering, and even suicidal thoughts [2,4-6]. Social aspects might lead to various types of social loss (loss of social role, status, connection, or job), financial concerns, worries about the family’s future, and dependency [2,4,5]. Moreover, cancer pain seems to lead patients to existential thoughts. It has been associated with spiritual concepts, such as finding meaning, losing faith, fear of uncertainty, and anger toward fate or anger with God [2].

Moreover, cancer pain interferes with the quality of life of patients, and its impact reverberates in the family context [7]. According to the Systematic Transactional Model (STM) [8,9], illnesses encompass a relational dimension and could be viewed as a “*we disease*” since both patients and caregivers share the stress related to pain and coping with it. Specifically, the STM assumes that an interdependence exists between 2 partners in a relationship and postulates that stressors interfere directly or indirectly with both partners in a close relationship [8]. In other words, one partner’s suffering can impact the well-being of another, resulting in the increased suffering of the first partner and so on. This process activates a co-dependence mechanism between patients and caregivers [10] since a family member with a chronic condition needs help from their partner. Still, patients simultaneously feel dependent, perceiving themselves as burdens to their partners [11]. Consequently, caregivers might indirectly perceive an emotional commitment, with feelings of guilt and inability to care for their loved ones, as demonstrated by previous research [7,11,12]. However, even though both patients and their caregivers experience pain, these experiences seem to be represented differently, and little is known about the perspective of caregivers and the patient-caregiver dyad.

Several studies [4,5] on cancer patients emphasized the link between pain and psychoemotional distress, including depressive feelings, anxiety, worries, and fear. The literature mostly focused on the 2 negative states of anxiety and depression in relation to cancer pain [5,13,14]; however, other discrete negative emotions may be activated by pain as well. Sela et al [15] demonstrated that patients with pain tend to mainly experience frustration and exhaustion, followed by anger, helplessness, fear of suffering, and hopelessness. Yet, patients find it difficult to express their emotions, and often some feelings may be overshadowed by others. For example, negative emotions, such as fear, panic, frustration, anxiety, and helplessness, could be hidden by anger [16]. Indeed, anger may be toward cancer, toward those who provide care, or against God, if the patient is a believer [2,16].

A few studies [7,17] have focused on the emotional experiences of caregivers. Sharing the suffering and pain with another person may activate empathetic involvement, making a person more vulnerable to psychological symptoms, including distress, fatigue, and pain. The emotional burden and perceived responsibility of caregivers compromise their ability to care for their loved ones [7,18,19]. Coherently, they seem to be exposed more to feelings of guilt, blame (blaming the pain for the changes caused in the family), anger, or fear (regarding the uncertain future of their loved ones) [20]. Moreover, they may be overwhelmed by feelings of sadness, anxiety, grief, frustration, and helplessness [21].

Despite this evidence and progression in pain management, pain is still underreported and untreated [22-24], representing a major medical unmet need in psycho-oncology [25]. One of the main barriers is patients’ difficulty in reporting pain [26]. This reluctance seems to be related to the lack of knowledge and education about cancer pain. This may result in misbeliefs about pain management. For example, patients may be worried about how to communicate pain, may prioritize curing cancer instead of having relief from pain, or may be convinced that pain is inevitable [26]. A similar challenge is present from the perspective of caregivers, who need adequate education to manage their time and roles, and attend to self-care to reduce the emotional distress related to caregiving [19,27]. Additionally, they need to be provided with problem-solving strategies and to be seen by physicians for their role in pain management [27].

As suggested by Wang et al [28] in a recent systematic review on the unmet needs of cancer patients and their caregivers, qualitative data provide precious insights into the unmet needs of a disease-related experience, such as cancer pain.

Online social groups represent a rich source for qualitative data, as they provide space for users to share their first-hand experiences and receive social support and advice. These platforms have been demonstrated to create a sense of belongingness that helps users (patients and caregivers) feel more understood and less alone, and receive the information needed [29,30]. Moreover, they are useful tools for revealing basic and complex emotions that otherwise are more difficult to capture in traditional settings [31].

Aims of the Study

This study aimed to capture the whole representation of the cancer pain experience from the perspectives of patients and caregivers. Given that patients directly experience the pain whereas caregivers react to that experience, we were interested in the perspectives of these 2 groups separately.

Specifically, the first aim was to identify the unmet needs of patients and caregivers in relation to cancer pain. Second, this study aimed to detect the reaction to cancer pain in terms of emotions and sentiments by analyzing the textual patterns of both patients and caregivers. Comparisons were made to reveal the difference in reactions to patients' cancer pain experiences in these 2 groups.

Methods

Data Collection

Data were collected following Pushshift Reddit API Documentation [32] in November 2021. Comments posted on the cancer patient support group on Reddit (with 45,900 subscribers) were sourced from the subreddit [33] using keywords related to cancer pain classification [34,35]: temporal pattern ("acute*pain" and "chronic*pain"), pathophysiology ("somatic*pain," "visceral*pain," "neuropathic*pain," and "nociceptive*pain"), and descriptors of neuropathic pain ("pain*sensation," "burning*sensation," "numbness," "soreness," "tingling," "shooting," "pricking," and "pins/or needles"). We then manually added common words used by users to refer to pain: "pain," "hurting," "aching," and "discomfort." All collected posts were screened by the authors CP and MC independently. Duplicate posts were removed, and those unrelated to cancer pain were excluded.

For each post, we collected the following information: data created, number of comments, and username of the poster. Years of posting were determined to convert epochs to human-readable data. The analysis did not consider any reference to names or people mentioned in the posts to respect the anonymity of users.

Ethical Considerations

Ethical committee approval was not requested since data collection and analyses involved public online materials.

Statistical Analysis

Descriptive Statistics and Word Frequency

This study involved a manual categorization procedure whereby posts were read and assigned to pre-existing categories. Two reviewers (authors CF and MC) created these pre-existing categories based on 100 posts that were randomly generated by Google's random generator.

Guided by the preliminary codes, the 2 reviewers categorized all posts (n=783). When preliminary codes did not match the content of posts, new codes were added to the broad categories after agreement between the 2 coders. Conflicting codes were solved through discussion to generate the final list. Both reviewers coded all posts.

Quantitative data analyses were performed using RStudio v.2022.02.3 [36]. Interrater reliability was assessed by calculating the Cohen kappa, with values of <0 indicating no agreement, 0.01-0.20 indicating slight agreement, 0.21-0.40 indicating fair agreement, 0.41-0.60 indicating moderate agreement, 0.61-0.80 indicating substantial agreement, and 0.81-1 indicating almost perfect agreement [37].

Text mining was performed to clear the data and compare how patients and caregivers describe their experiences in relation to cancer pain, and a word cloud (ie, a method to identify the most frequently used words in text) was generated with the "tm" [38] and "wordcloud" [39] packages in R.

Emotion and Sentiment Analysis

Emotion and sentiment analysis was performed on the posts of patients and caregivers with the "syuzhet" R package [40]. We considered 8 basic emotions (anger, fear, anticipation, trust, surprise, sadness, joy, and disgust) and 2 sentiments (positive and negative) based on the NRC Emotion Lexicon [41,42]. The lexicon allows for determining the emotions and sentiments associated with each word. The association between the target word and the emotion was indicated with either 0 (no association) or 1 (association present). Each term can be related to more than one emotion and have a positive, negative, or polarity orientation. Negative words are mostly associated with anger, fear, disgust, and sadness, whereas positive words are primarily associated with anticipation, joy, and trust. Surprise may be categorized with positive or negative emotions and sentiments depending on the target words.

We followed a series of steps to assess the distribution of our data. First, we used the R software to select relevant posts and "unnest" the text. This involved breaking down the text into individual sentence units. Consequently, we obtained a total of 5577 sentences for patients and 2052 sentences for caregivers. Each sentence was then treated as a separate data point within the R software. Next, we applied the emotion analysis to this data set of sentences using the "get_nrc_sentiment" function. This analysis produced a new data set with rows representing individual sentences and columns representing different emotions. The association between a sentence and an emotion was established when one or more words within the sentence matched that emotion. Hence, each sentence in the resulting table was assigned a numerical value for each emotion, indicating the emotional intensity of that sentence. Subsequently, we organized the data frame in this format to examine whether the distribution of emotions across the sentences (data points) followed a normal distribution. To achieve this, we employed the Shapiro test, a statistical test used to assess the conformity of data to the assumption of normal distribution. Our results indicated that the *P* value obtained from the Shapiro test was less than the predetermined significance level (.05). Therefore, we concluded that the distribution of emotions across the sentences did not adhere to the normal distribution assumption.

Since the data did not follow a normal distribution, we proceeded to perform the Wilcoxon rank sum test. This test is a nonparametric alternative when the normality assumption is not confirmed. The test performs well with unequal sample sizes as well [43].

Hierarchical Clustering

Hierarchical clustering was performed on comments from caregivers and patients, using the "dendexten" R package [44]. Hierarchical clustering is a k-means–based method used to identify clusters in a data set. This technique groups observations into clusters without a prespecified number of sets and creates a tree-based representation of observations called a dendrogram. We used the agglomerative clustering method AGNES (Agglomerative Nesting), which follows a bottom-up approach and considers each data point as a separate cluster. It iteratively merges the most similar clusters based on a distance metric until a stopping criterion, such as a predetermined number of clusters, is reached. The resulting dendrogram provides a hierarchical representation of the clusters that can be used to determine the optimal number of clusters.

Moreover, the agglomerative coefficient (ie, the amount of clustering structure found) was calculated. A coefficient closer to 1 is considered to indicate a strong clustering structure. The Ward method, which minimizes the total within-cluster variance, was used to create the cluster dendrogram.

Finally, dendrograms were compared using the function “tanglegram,” which plots 2 dendrograms side by side with their labels connected with lines. The alignment quality was calculated with the function “entanglement” to determine the optimal number of clusters and the validity of the results. A good alignment is guaranteed with a lower entanglement coefficient (ranging from 1 [whole entanglement] to 0 [no entanglement]).

The labels of each cluster were attributed after agreement between the authors CF and MC. For details, see the guidelines provided by Galili [44] and Kassambara [45].

Finally, we interpreted the product clusters and labeled them depending on the hierarchical clustering performed, considering the context from which the words come.

Results

Descriptive Statistics and Word Frequency

Interrater reliability for manual coding indicated perfect agreement (from 0.98 to 1) for all broad categories and codes (Table 1).

A total of 783 public comments between April 2011 and November 2021 were identified. Of the 783 comments, 679 (161 from caregivers and 518 from patients) were included in the final database since our aim was to focus on the perspectives of patients and caregivers. Therefore, 104 posts were excluded from the analysis since the user type was unknown (n=93) or there was a referral to a health care professional (n=11). Details are provided in Multimedia Appendix 1.

Table 1. Broad categories, related codes, and interrater reliability results.

Broad categories and codes	Interrater reliability (n=783)	*P* value
Pain dimension	0.99	<.001
Physical		
Psychological		
Both[a]		
Type of comment	0.98	<.001
Advice		
Experience		
Both[b]		
Question		
Type of user	1.00	<.001
Patient		
Caregiver		
HC[c]		
Unknown		
Type of pain	0.99	<.001
Acute		
Chronic		
Acute neuropathy		
Chronic neuropathy		
Neuropathy		
Somatic		
Visceral		
Unknown		
Type of cancer[d]	0.98	<.001
Blood[e]		
Breast		
Gynecological[f]		
Pancreatic		
Melanoma		
Sarcoma		
Lung		
Colorectal		
Brain		
Others		
Not diagnosed		
NA[g]		

[a] Physical and psychological.

[b] Advice and experience.

[c] HC: health care professional.

[d] Type of cancer of patients discussed in the posts.

[e] Leukemia, lymphoma, and myeloma.

[f] Ovarian, cervical, uterine, vaginal, and vulvar.

[g] NA: not available.

Patients' Comments

Among the 679 comments included, 518 (76.3%) were posted by patients. Regarding cancer pain, the most frequent dimension was the physical dimension (359/518, 69.3%). In comparison, 23.7% (123/518) of the comments were focused on both dimensions of pain (physical and psychological), and only 7.1% (37/518) were focused on the psychological dimension.

Among the 518 comments, 219 (42.3%) did not specify the type of pain. Among the comments that did specify the type of pain, the most frequent type was neuropathy (95/518, 18.3%), followed by chronic (80/518, 15.4%), acute (51/518, 9.8%), somatic (2/518, 0.4%), and visceral (1/518, 0.2%) pain. Regarding neuropathy, we found that 10.0% (52/518) of posts involved chronic neuropathy, while 3.5% (18/518) involved acute neuropathy.

In most posts (422/518, 81.5%), patients shared their first-hand experiences and provided information to others in a similar condition. A smaller portion of posts (53/518, 10.2%) provided advice, and some posts (9/518, 1.7%) posed a question. Further details are provided in Multimedia Appendix 1. Table 2 shows the top 35 most used words and their frequencies.

Table 2. The top 35 words regarding cancer pain most frequently used by patients and caregivers.

Number	Patients (N=87,136)		Caregivers (N=33,583)	
	Word[a]	Value, n	Word[a]	Value, n
1	Pain	615	Pain	217
2	Feel	405	Cancer	196
3	Cancer	384	Time	159
4	Day	335	Can	148
5	Can	328	Feel	138
6	Time	300	Help	107
7	Treatment	260	Want	101
8	Week	232	Mom	96
9	Help	230	Know	96
10	Chemotherapy	223	Day	93
11	Year	218	Dad	90
12	Back	189	Doctor	78
13	Know	189	Week	74
14	Take	189	Thing	72
15	Now	183	Think	71
16	Say	170	Treatment	70
17	Month	169	Now	68
18	Surgery	164	Hospital	64
19	Side	158	Take	63
20	Life	158	Sorry	62
21	Doctor	152	Chemotherapy	62
22	Lot	146	Need	62
23	Good	142	Back	59
24	Start	138	Family	59
25	Try	136	Lot	58
26	Work	136	People	58
27	Need	136	Hope	56
28	Effect	135	Last	54
29	Think	133	Love	54
30	Soreness	132	Month	54
31	Hurt	130	Life	52
32	Cause	129	Try	51
33	Radiation	129	Care	50
34	Use	127	Work	50
35	Thing	123	Way	50

[a] Common words: pain, can, cancer, chemotherapy, day, doctor, feel, help, know, lot, need, now, thing, think, time, week, back, life, month, take, treatment, try, and work.

Caregivers' Comments

Among the 679 comments included, 161 (23.7%) were posted by caregivers. Most caregiver posts discussed pain, focusing on the psychological and physical dimensions (67/161, 41.6%). Some focused only on the physical dimension (50/161, 31.1%), and others focused only on the psychological dimension (44/161, 27.3%).

Among the 161 comments, 123 (76.4%) did not specify the type of pain. Among the comments that did specify the type of pain, the most frequent type was chronic pain (18/161, 11.2%), followed by neuropathy (12/161, 7.5%) and acute pain (4/161, 2.5%). Somatic and visceral pain was not found in their comments. Regarding neuropathy, we found that only 2.5% (4/161) of posts involved chronic neuropathy, while 0.6% (1/161) involved acute neuropathy.

In general, caregivers mostly shared the experience of their loved ones with cancer in their posts (130/161, 80.7%). Caregivers shared their experience as well as provided information in 11.2% (18/161) of posts, and they only provided advice in 8.1% (13/161) of posts. Further details are provided in Multimedia Appendix 1. Table 2 shows the top 35 most used words and their frequencies.

Word Cloud Comparison

A word cloud comparing patients’ and caregivers’ words when discussing the cancer pain experience is presented in Multimedia Appendix 2.

The word cloud was created by analyzing the most frequent words. Patients more frequently used terms describing the physical aspects of pain (“neuropathy,” “sensation,” “nerve,” “hurt,” “fatigue,” etc), causes of pain related to treatment (including “radiation,” “surgery,” and “chemotherapy”) or a specific procedure to detect cancer (“biopsy” and “scan”), aspects related to pharmacological treatments taken for managing pain (“drug,” “oxaliplatin,” “dose,” and “addiction”), and their related side effects (“nausea,” “soreness,” “hair” loss, “scar,” “numbness,” “cold” sensation, etc) compared with caregivers. The only psychological terms used frequently in relation to pain were “worry” and “scary.”

On the other hand, caregivers used words related to psychosocial aspects of pain (“family,” including “dad,” “mom,” “wife,” etc; “sorry,” “help,” “memories,” “care,” “doctor,” “death,” “understand,” “remember,” etc) more frequently compared with patients. In their case, the physical aspects or related side effects of pain and treatments were described less frequently (eg, “morphine,” “stage,” and “acute”).

Emotion and Sentiment Analysis

Patients’ Comments

Multimedia Appendix 3 displays 8 emotions (anger, fear, anticipation, trust, surprise, sadness, joy, and disgust) and 2 sentiments (positive and negative) associated with the target words used by patients when discussing cancer pain. The total number of patients’ words was 87,136, and the total number of sentences extracted was 5577.

Based on the associations with target words, the negative sentiment (mean=0.83) was higher than the positive one (mean=0.58), with sadness (mean=0.57) and fear (mean=0.56) being the most prevalent negative emotions, followed by anger (mean=0.30) and disgust (mean=0.26). On the other hand, trust (mean=0.40) and anticipation (mean=0.35) were the most pervasive positive emotions, followed by joy (mean=0.25). The least prevalent emotion was surprise (mean=0.17).

The following extracted sentences (from post IDs P2 and P258) well exemplify these sentiments and emotions:

- Sentences extracted from post ID P2

  The worst thing about cancer is the fear, and the fear is driven by lack of knowledge.

  The more you know about your situation -- and the treatment options, and the side effects, and the medical team, and the support services -- the easier it is to handle it.

  I'm not saying it becomes easy, full-stop, but it does make it easier.

  Knowledge is power, it pushes back the darkness.

  And that goes for the people you love, too, the ones you're trying to spare from pain and worry.

  If they don't know what's going on, they'll worry more.

  Giving yourself and them, information will make things less opaque and scary.

  Having a skilled team of medical experts and a support system will, too.

  Finally, it is TOTALLY NATURAL to feel the way you're feeling!

  And as always, #FUCKCANCER.

- Sentences extracted from post ID P258

  My cancer returned when I was 22, my leg was amputated a week later.

  I had an endless supply of drugs to deal with the pain, both” real” and phantom limb pains.

  I’ve felt a lot of the things you currently feel.

  I hate feeling weak, and I hate relying on people around me.

  Some days is worse than others, but I have something I can look back on and use as a reference that it can get better.

  I initially got the cancer diagnosis when I was 14, after 5 years of unexplainable pain. I did chemo for 2 years, radiation therapy for 6 weeks, and 6 surgeries in total.

  One of these surgeries involved temporarily cutting off the blood supply between my leg and the rest of my body, pumping my leg with extremely toxic chemo that took my leg to 47C (or 117F) degrees.

  I was a kid when I lost everything.

  I experienced insane amounts of pain between 14-17.

  But after treatment, my foot was still broken, and I suffered from osteoporosis in my lower leg; I was shattering bones in my foot just from walking.

  I’ve had chronic pain for 14 years and I’m 24 years old.

  I can vividly remember all of the times I nearly died.

  I remember bleeding in my mouth from eating, waking up in the middle of the night screaming in pain from the full-body cramps, the painful wound on my foot

> *from the radiation therapy, and a seemingly endless list of side effects.*

Caregivers' Comments

Multimedia Appendix 4 displays 8 emotions (anger, fear, anticipation, trust, surprise, sadness, joy, and disgust) and 2 sentiments (positive and negative) associated with the target words used by caregivers when discussing cancer pain. The total number of caregivers' words was 33,583, and the total number of sentences extracted was 2052.

Based on the associations with target words, the negative sentiment (mean=0.78) was higher than the positive one (mean=0.64), with sadness (mean=0.61) and fear (mean=0.55) being the most prevalent negative emotions, followed by anger (mean=0.31) and disgust (mean=0.25). On the other hand, trust (mean=0.45) and anticipation (mean=0.38) were the most pervasive positive emotions, followed by joy (mean=0.28). The least prevalent emotion was surprise (mean=0.16).

The following extracted sentences (from post IDs C717 and C100) well exemplify these sentiments and emotions:

- Sentences extracted from post ID C717

> *My gf has stage IV lung cancer, and I cried a few times (I haven't cried for several years before that) but I feel like I am mostly in a "functioning" mode that keeps me going, but I am absolutely over the top overwhelmed with emotions and thoughts, but I know I am no good for my gf either if I just give up.*
>
> *With long times of sickness and going through all that with someone, some people even feel relieved when their loved ones die and feel very guilty, but I think in most cases it is a relief that their loved one don´t have to suffer anymore, I didn´t cry when my dad died after months of being in and out of the hospital and intensive care, but it hit me later.*

- Sentences extracted from post ID C100

> *I lost my husband 47 days ago (this is day 48), and as devastatingly painful as it was to lose him after 24 years together, every time I: 1) remember his struggles in the two months prior to losing him; 2) remember all the times he said he didn't want to be sicker from the treatment from the disease; 3) look at pictures and videos from his final days; it helps me accept that he is gone.*
>
> *I absolutely loathe the "he's no longer in pain" sentiment, but I've realized what I actually miss most of all are the times before he got sick.*
>
> *Truth be told, his last two months were increasingly terrible with every passing day.*
>
> *I can't tell you how many times he said to me, «this is not living».*
>
> *I share this in case it helps.*
>
> *If your mom is not yet hospitalized and can take care of her own needs, there is still hope for her.*
>
> *In my husband's case, that hope evaporated early, though, and if and when it begins evaporating for your mom, the best thing you can do is remind yourself that « keeping her alive » doesn't mean she's actually «living».*
>
> *That could help you let her go.*

Wilcoxon Rank Sum Test for the Emotional Scores of Patients and Caregivers

The Wilcoxon rank sum test was used to analyze the differences in emotion and sentiment scores between patients and caregivers.

The test showed that patients expressed a negative sentiment more often than caregivers (mean$_{\text{P\_rank}}$=3845.24 vs mean$_{\text{C\_rank}}$=3732.81; z=−2.14; *P*<.001), whereas caregivers expressed a positive sentiment more often than patients (mean$_{\text{P\_rank}}$=3784.53 vs mean$_{\text{C\_rank}}$=3897.81; z=−2.26; *P*<.001), with trust (mean$_{\text{P\_rank}}$=3763.79 vs mean$_{\text{C\_rank}}$=3954.18; z=−4.12; *P*<.001) and joy (mean$_{\text{P\_rank}}$=3792.90 vs mean$_{\text{C\_rank}}$=3875.06; z=−2.03; *P*<.001) being the most prevalent positive emotions. Details are provided in Table 3.

Table 3. Wilcoxon rank sum test results for emotion and sentiment scores between patients and caregivers.

Emotion	Caregiver mean$_{\text{rank}}$ (n=2052)	Patient mean$_{\text{rank}}$ (n=5577)	*U*	z	*P* value
Anger	3843.45	3804.53	5663619.00	−0.908	.36
Disgust	3782.24	3827.06	5654769.50	−1.09	.27
Fear	3810.52	3816.65	5712817.00	−0.12	.90
Sadness	3868.65	3795.26	5611917.00	−1.47	.14
Anticipation	3862.46	3797.54	5624621.50	−1.45	.15
Joy	3875.06	3792.90	5598766.00	−2.03	<.001
Surprise	3821.11	3812.75	5709462.50	−0.24	.81
Trust	3954.18	3763.79	5436407.50	−4.12	<.001
Negative[a]	3732.81	3845.24	5553344.50	−2.14	<.001
Positive[a]	3897.81	3784.53	5552077.00	−2.26	<.001

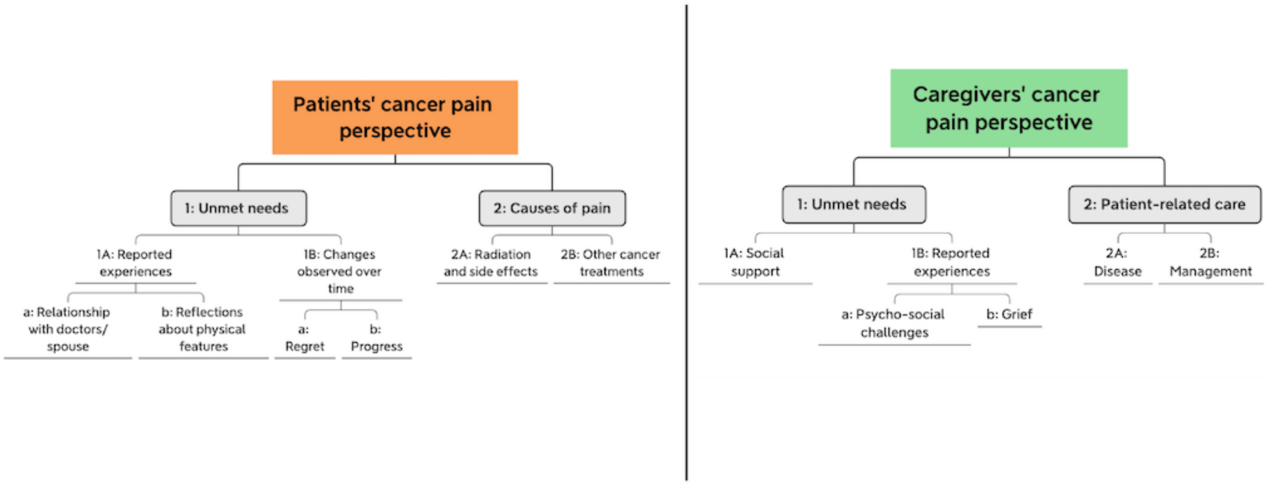
[a] A target word may be associated with one or more emotions and 1 of the 2 polarities (negative or positive). While a target word is always associated with 1 of the 2 polarities, it is not always associated with a specific emotion.

Hierarchical Clustering

Multimedia Appendix 5 shows the hierarchical clustering findings. The optimal number of clusters for patients was 2, which belonged to 1 root representing patients' pain perspective. The agglomerative coefficient with the Ward method was 0.72, which demonstrated a solid clustering structure. Similarly, in the hierarchical clustering of caregivers, the optimal number of clusters was 2, which belonged to 1 root representing caregivers' pain perspective. In this case, the agglomerative coefficient was 0.80.

Figure 1 shows the labels applied to interpret the product clusters.

Figure 1. Patients' and caregivers' product clusters with labels.



In the case of patients, the 2 main clusters were labeled as (1) *unmet needs* and (2) *cause of pain*. This first cluster of *unmet needs* included 2 nodes named (1A) *reported experiences*, with the subclusters (a) *relationship with doctors/spouse* and (b) *reflections on physical features*; and (1B) *changes observed over time*, with the subclusters (a) *regret* and (b) *progress*. The second cluster of *cause of pain* included 2 nodes named (2A) *radiation and side effects* and (2B) *othercancer treatments*.

Regarding patients' reported experiences (cluster 1A), the relationship with the spouse (subcluster a of cluster 1A) is well represented in the following post (post ID P478):

> *I got diagnosed about 5 weeks ago with stage IV. It has completely changed the relationship…From my end, I now see my spouse as a caregiver instead of a spouse. I feel horrible about it and try and remind myself that he is my sexy husband who I adore, but when he is wiping my butt and stuff, it's hard to remember that. Sometimes I see him and just cry because I want to see him as my sexy husband, but it just seems impossible right now.*

The relationship with doctors (subcluster a of cluster 1A) was related to the need of reassurance. This is evident in the following post (post ID P399):

> *I know how bone cancer feels and how recovery feels.*
>
> *This is cancer. But everyone thinks I'm just "imagining" it because I'm afraid of it returning. But I truly know I'm not. I know my body.*
>
> *I'm just waiting for my doctor to tell me so I can get on with treatment.*

Regarding physical features (subcluster b of cluster 1A), patients shared the impact of pain on different parts of their bodies. Moreover, they described the physical symptoms (eg, numbness and soreness) experienced.

> *Had Stage 0 breast cancer (DCIS) and a lumpectomy with a scar on the side of my breast, but close to the armpit. Has been a year and it was slightly painful/sensitive for many months afterward. Even now I still get some pain where the scar tissue is (burning and/or aching). From what I have read in blogs/chatrooms online, this is normal and can last for many years .... Glad to hear you do NOT have cancer. :-)* [Post ID P429]

Concerning the changes observed over time (cluster 1B), patients reported regret (subcluster a of cluster 1B) about the action taken during recovery because of the difficulty of waiting and wish to have quick progress (subcluster b of cluster 1B) regarding the right time and the need to be as they were before the diagnosis.

> *I'm hoping to move on to using a stationary bike soon but like you said I have to take it easy. I've been pushing myself and regretting it afterwards. Progress is never fast enough.* [Post ID P127]

As for caregivers, the first large cluster was labeled (1) *unmet needs*. This cluster included 2 nodes named (1A) *social support* and (1B) *reported experiences*, with the subclusters (a) *psychosocial challenges* and (b) *grief*. The second cluster was labeled (2) *patient-relatedcare*. This cluster included 2 nodes named (2A) *disease* and (2B) *management*.

Regarding social support (cluster 1A), caregivers expressed this need due to the responsibility they felt in relation to making a choice for the patients. For example, a caregiver wrote:

> *I would do ask for support and make his time as comfortable as possible. It is not your fault and you*

> *need to remember that. It is no ones fault. I do hope he is comfortable, and whatever choice you make, I'm sure will be the right one.* [Post ID C128]

Regarding their experiences (cluster 1B), caregivers also shared the need to be understood for the burden related to the psychosocial challenges (subcluster a of cluster 1B) of pain management, the care of their loved ones, and the grief related to losing someone (subcluster b of cluster 1B).

The following extracted posts are some examples of what caregivers shared on the platform with other caregivers:

> *I'm so terribly sorry for your loss. I lost my mom to cancer in August too. I wish I could say it gets easier but I found it comes to you in waves. One second you'll be fine and the next second you'll be crying. Followed by numbness. It's hard to watch them slowly fade away from us. And there's nothing we could've done to help save them. It's hard. Reach out for help with extended family to see if they can help take some of the burden off of you. If you ever need someone to talk to you can always shoot me a message here.* [Post ID C697]

> *…Not many people can verbalize what I am feeling…Our pains and struggles are different but hauntingly similar…. Often people don't and cannot understand. Even worse, they often don't *want* to understand, especially when you're young….My grief and suffering make people uncomfortable. My husband's suffering and mortality make them uncomfortable…They don't want to see it, so they only see what they want to see. They see a young guy that looks good for having cancer. They dismiss his deficits as "well sometimes I forget things, get lost, or have brain farts! Totally normal!" This isn't a brain fart or a slight delay in finding words. This isn't a "shit I forgot to bring my lunch today." It's much deeper and more consistent than that. This isn't normal…* [Post ID C356]

Additionally, the comparison between the 2 dendrograms demonstrated good entanglement (entanglement coefficient=0.28), with only partial similarity regarding the clade consisting of the 2 words "help" and "may" in both the patient and caregiver dendrograms. Based on the dictionary of Loughran and Mcdonald [46], both words represent uncertainty. Thereby, we labeled the textual node shared by both dendrograms as *uncertainty*. See Multimedia Appendix 5 for more details.

For example, patient #340 reported uncertainty (*what if*) related to the disease condition and unpredictable future. This uncertainty can bring worries and fears.

> *What I came to realize (with the help of therapy) is, that there are a lot of What ifs attached to cancer and the anxiety that comes with it. What if my cancer spreads?, What if it won't go away?, What if it comes back?, What if they find something on my next scan?, or my personal favorite: What if they overlook something on my next scan?. But for every What if we will worry about, there is an infinite number of What ifs we don't even think about. We can't predict the future or how it will develop but if we worry what bad could happen, we might miss the good that can happen too. Or frankly speaking if it's a beautiful sunny day outside, I won't run around with an open umbrella because it might start raining or a I could get shit on by a bird.*

As for caregivers, uncertainty was related to the grief and fear of losing a loved one. For example, caregiver #159 expressed these feelings by supporting another caregiver.

> *Your story caught my attention immediately. I know the pain, fear and the uncertainty you are going through. You see, my daughter died 3 weeks ago after a 3 1/2 year battle with leukemia. She was 12 years and 5 months old to the day. I will elaborate some, not to compound anything you are going through, but to let you know, you are not alone.*

Discussion

General Overview of the Findings

This study aimed to investigate the whole representation of cancer pain, considering the perspective of patients and caregivers. Overall, we found that patients and caregivers shared 3 types of content on the Reddit cancer social group about pain: experience, advice, and questions. The most frequent type of shared content in both groups was experience, followed by advice. The questions asked were only by patients. Moreover, different types of pain were covered in the narratives of both users. The most frequent types of pain discussed were neuropathy, chronic pain, and acute pain.

The language used to describe the experiences differed in these 2 groups. This was expected since the experiences of patients and caregivers differ regarding cancer pain. While patients have first-hand experience of pain, the experience of caregivers refers to their reaction to it. This said, patients described pain focusing more on the physical dimension ("neuropathy," "sensation," "chronic," "fatigue," etc), causes of pain related to treatment ("radiation," "surgery," and "chemotherapy") or a specific procedure to detect cancer ("biopsy" and "scan"), side effects of treatment ("nausea," "soreness," "hair" loss, "scar," "numbness," "cold" sensation, etc), and aspects related to pharmacological treatments taken for managing pain ("drug," "oxaliplatin," "dose," etc). As for caregivers, they described the experience in terms of the reaction to the suffering of their care and the impact that the experience had in their life, discussing the psychosocial aspects when confronting other caregivers ("family," "sorry," "help," "memories," "grief," etc). Coherently, regarding patients' posts, 69.3% (359/518) covered the physical aspects of pain solely, whereas only 31.1% (50/161) of caregivers' posts discussed them. As for the psychological dimension of the pain experience, 27.3% (44/161) of caregivers' posts covered this dimension, whereas this percentage was only 7.1% (37/518) for patients.

According to the STM, each disease may be viewed as a "we disease," affecting patients and their family members. This process results from the interdependence between the 2 actors [8]. Specifically, patients often depend on their caregivers [11] when they have a chronic condition. This may be due to patients' loss of autonomy and functionality that can contribute to creating a co-dependence mechanism of the patients on their partners [10]. Such an increased need for care may result in a perceived burden on the family members [47,48]. For instance, this sense of burden was well represented in one of the posts from our data. A caregiver who shared their experience was providing another caregiver with support and understanding:

> *As for those witnessing his pain: I'm sorry, I am so sorry … My only advice is to take turns. Everyone experiencing this needs some distance from it from time to time…. If I don't spend some time away from the pain, I will lose my mind.* [Post ID C261]

While being a heavy burden, the way in which caregivers deal and cope with caregiving can also be affected by the quality of their relationship with the patient. The closeness between the partners, the time spent together, and the general strength of their relationship may impact multiple aspects of both patients' and caregivers' experiences. As the STM suggests [8], the caregiver's resources may expand the patient's resources, creating new synergies for fighting against pain. This is evident when there is a strong bond present between them. For instance, a caregiver wrote:

> *One could certainly have that reaction of hating every bit of the lifestyle change, and perhaps at times it may seem just 100% detestable and harrowing, but as is the case with any event that occurs in life, a significant amount depends on how you participate in it and how you experience it.*
>
> *I am 32 years old and my husband was 31 when he passed away in early March. We were together for over ten years and got married just before he passed away. My one advice to you is, be the hero you can be. Our job isn't to treat their cancer, medically that is. That's the job of the doctors, rightfully so. Instead, focus on doing what you are capable of doing, which is being her partner, being her companion through this new life* […]
>
> *So in a way, I wanted him to think that it was both of us who got diagnosed. He had to bear the brunt of it obviously... but no one can survive cancer alone. […]. I was there to listen to him and empathize with him as he expressed the different types of pain he was feeling. We both knew I couldn't cure his symptoms, but I did what I could— […].Reading through some of his notes he left behind, I realized I did the right thing. I was so relieved when I read how much it meant to him that I was there for him.* [Post ID C376]

Even if the literature has recently focused more on caregivers' experiences as well [49,50], their unmet needs and implicit emotional side of cancer pain are still underrepresented. This work considers this gap and the importance of the mutual influence between patients and caregivers.

How Patients and Caregivers Live With Cancer Pain: Unmet Needs

A person's significant need that is not fulfilled is referred to as an unmet need [51]. Our first aim was to reveal the critical concerns related to cancer pain expressed by patients and caregivers in their posts and the specific needs related to that experience.

Regarding patients, the hierarchical cluster analysis showed that their pain-related primary needs were *relationships with the doctors/spouse* (ie, seeking the reassurance/opinion of the physician about pain, and seeing the spouse primarily as a caregiver instead of a spouse) and *reflections on the physical features of pain* (eg, location of pain in the body; chronic pain; stage of cancer; and body sensations such as numbness, soreness, etc*)*. Therefore, patients emphasized the physical aspects of pain. Several reasons may explain this narrowed focus.

The first and most obvious reason is that the pain experienced by patients involves physical aspects. It is related to tissue damage from oncological treatments, surgery, or cancer itself [35]. This aligns with cluster 2 of patients' words (*causes of pain*), in which patients mainly discussed *radiation and its related side effects* and *other cancer treatments* (eg, chemotherapy) as the primary causes of pain. Consequently, it may be intuitive for patients to assume that having physical roots, pain would only have physical outcomes.

However, the physical sensation of pain is not the only reason for patients to mostly speak about pain in terms of physical symptoms. Patients are generally directed by their physicians to focus on their physical characteristics during consultation sessions [35,52], with questions such as "What was your pain intensity in the last 24 hours?" This may contribute to their tendency to become aware of their physical experiences rather than their psychological ones. Moreover, the typical response of a medical health care provider to a pain complaint is the prescription of a pharmacological treatment (painkiller) according to the World Health Organization's analgesic ladder [53]. Overall, doctors may implicitly convey to patients that pain is only a biological concern by attempting only physical relief. For instance, this issue was well described in the following extracted sentence of a patient:

> *I just kept adjusting and moving in my seat. My doctor said it was probably the normal side effect of bone pain, but I never thought the pain was that bad until he prescribed me some painkillers, and I fully relaxed and could sit still.* [Post ID P1]

However, interestingly, when patients retrospectively reflected on their pain (cluster of patients' words called *changes observed over time*), they tended to go further. They also shared their psychological needs, such as the desire to return to their old self before the pain, influencing them to push themselves to be more active. This led them to *regret* the action taken and realize that *progress* is never fast enough.

As for caregivers, the primary needs discussed were the *psychosocial challenges* that they experience because of the condition of their loved ones (eg, economic and work issues, reflections on the time passed, worsening of the disease, wishing for a better prognosis, hope that the treatment will work, etc) and *grief* (eg, feeling numb after a death, self-blame, loss, hope for their loved ones, etc).

Grief is a familiar feeling experienced by caregivers, and if not well managed, it could remain after 6 months to 1 year following the loss of their loved ones [54]. However, as also seen in the example above, grief is experienced not only as a response to the death of loved ones but also as a response to the idea of losing them. The caregiver's suffering could be caused by the caregiving itself (when it becomes a burden), or by the grief about losing or the idea of losing a loved one. As recognized by Allen et al [54], it is fundamental to take care of the suffering experienced by caregivers by identifying those more at risk in order to target interventions for them.

Thereby, caregivers mainly focused on the psychological dimension of pain rather than the physical dimension (which they only mentioned when discussing the patient's care; see cluster 2 of caregivers' words).

The reasons for this may be multiple. First and most obvious, they are not experiencing cancer pain in the first person, and they live these experiences through the lens of a caregiver. Second, their primary role is to provide care and support to reduce the impact of pain in the patients. However, when this goal is not fully achieved, family members may experience anger, helplessness, powerlessness, exhaustion, spiritual distress, lack of confidence, self-blame, and burden from caring [20,27]. All of these represent the psychological challenges that caregivers face every day living with the suffering of their loved ones (presented in the cluster of *psychological challenges*). Third, to avoid getting overwhelmed, caregivers may need to seek support from others and create a sense of community as represented in the cluster of *social support*. Social support has been demonstrated to be one of the most critical unmet needs for caregivers and patients [28], which could reduce pain perception in cancer patients [5,55] and mitigate emotional distress in caregivers [27,56]. Still, it is fundamental to see the patients' and caregivers' needs in the overall well-being of the patient-caregiver dyad rather than just that of the patients [57], as the STM [8] explains.

Despite caregivers and patients having different concerns and expressing different needs, we found that they share a common theme. This theme is represented by *uncertainty*. Uncertainty is a familiar feeling among patients with cancer pain [28,58,59]. As suggested by the theory of uncertainty [60], it comes when the illness is unpredictable, the prognosis is bad, the disease is still progressing, and symptoms worsen. For patients, uncertainty is expressed as "*what if*" in relation to the condition's progression and their future, as reported above. It has been demonstrated that cancer patients with pain compared to those without pain showed a higher level of uncertainty. In these patients with pain, uncertainty predicted a lower level of hope [58].

Moreover, it may lead the patients to lose control of the situation and may worsen their pain management [59]. As for caregivers, the uncertainty is often in relation to their loved ones. For them, uncertainty may lead to anticipating grief and may consequently increase the burden of caregiving [61].

As shown in a recent systematic review [62], uncertainty management interventions are composed of a wide array of components in which information support has a key role in managing uncertainty. Lack of education is one of the most prevalent barriers to pain management. This is true for not only patients and their caregivers, but also health care providers who still have misconceptions about morphine and pain treatment (eg, painkillers will lead to addiction, cancer pain is inevitable and patients cannot fully achieve relief through therapy, etc) [63]. The focus on pain management is crucial as it can inform the health care professionals who tailor interventions for patients and their caregivers faced with uncertainty. Such interventions are especially needed for those experiencing chronic pain. eHealth tools may represent a possible option for such interventions [64-66].

Emotional Narratives of Patients and Caregivers

In this study, our second aim was to detect the emotional activation associated with cancer pain in the textual patterns of both patients and caregivers. It is worth noting that there existed a disparity in the number of posts made by patients and caregivers, with patients' posts being twice as many as those made by caregivers. Thus, in the subsequent sections pertaining to the outcomes, we compared the emotional proportions and distributions between the 2 groups. The comparison was not intended to be numerical but rather proportional, focusing on the emotional distribution between patient and caregiver posts.

Overall, we found that the emotional activation in both users' narratives was high. Compared with caregivers, the negative sentiment expressed by patients was significantly higher. Contrarily, caregivers more frequently expressed positive feelings than patients. The prevalence of negative sentiments among patients with cancer is in line with other findings in the literature [4,5,15]. Still, to our knowledge, no studies have focused on patients' and caregivers' reactions to pain in terms of emotions and sentiments expressed.

The differences in positive and negative sentiments in our groups may be due to the divergent experiences and the roles that patients and caregivers adopt to cope with pain. Patients live the experience of pain in the first person. They may have to confront the difficulty of managing their disease over time from diagnosis to long-term survivorship (eg, receiving treatments and facing their side effects). Therefore, they focus more on the negative aspects. On the other hand, caregivers often have to adopt the role of a supporter, who maintains an optimistic mindset for both of them, and they sometimes underestimate the difficulties that may emerge on the medical pathway. Indeed, our data showed that caregivers expressed significantly higher trust and joy among positive emotions than patients, representing an optimistic outlook.

As for the specific emotions (anger, disgust, fear, and sadness) primarily associated with negative sentiment, we did not find significant differences between the 2 groups, with a homogeneity in terms of the negative emotions felt. Looking at each group separately, the 2 most frequently expressed negative emotions were sadness and fear in patients' and caregivers' narratives. This finding aligns with the fear-avoidance model [67,68], which assumes fear and avoidant behaviors as the primary mechanisms of the experience of pain, activating feelings of depression and disability. Our results stress that the first-hand experience of pain by patients and the third-hand experience of pain by caregivers elicit the same negative emotions outlined in the fear-avoidance model (fear and sadness). However, both groups may express these emotions for 2 different reasons. Specifically, patients may be scared of cancer reoccurrence [69,70], and the misconception of pain may elicit this fear as a sign of failure of treatment or disease progression [71]. On the other hand, caregivers may blame themselves for being incapable of caregiving [72] or feel fear and uncertainty for the future of their loved ones [20].

Limitations

Our study has some limitations. First, given that the data were retrieved from an online social network, demographics and user personal characteristics (eg, personality, anxiety, depression, etc) were missing from our analyses.

As for interpersonal characteristics, we could not match patients to their caregivers. The source of the data (the cancer subreddit) did not provide such information. Even though some descriptors of the relationship were described in some comments (eg, time spent together), the number of such comments was too small for creating separate variables for relationship characteristics.

Another consideration we would like to make is regarding the users' cultural backgrounds. Reddit users are mostly based in the United States, followed by the United Kingdom and Canada [73]. This should be considered when interpreting and generalizing the results from our work. Cultural background plays an important role in patients' and caregivers' expressions and experiences regarding pain. Therefore, some of the findings outlined in this work may not apply to people with different cultural backgrounds.

Moreover, it is important to note that we used word clouds as a descriptive analysis in this study. While word clouds can provide a visual summary of frequently mentioned words, they may not fully capture the nuanced nature of individuals' experiences or account for contextual factors and connotations associated with specific words. We would like to emphasize the need for caution in interpreting word clouds, as they may oversimplify or misunderstand the intricacies of the data. By discussing these limitations, we aim to provide a more balanced understanding of the strengths and weaknesses of word clouds. Finally, information about cancer type and treatment type was lacking (variables that may have specific implications for the patients' pain). Therefore, we could not consider these variables in our analyses. This may impact the generalizability of the findings.

Overall, the lack of participant characteristics represents the primary limitation of not just this study but most studies that use online public data. However, simultaneously, such data allows for anonymity and invisibility, which have been demonstrated to facilitate self-disclosure [74]. This is especially advantageous when studying emotions [31] and unmet needs.

Conclusion

Cancer pain is an "emotional provoker" [4] that may drastically decrease the quality of life of patients and caregivers [7]. Therefore, it is crucial to consider the caregiver as part of pain management. As our study shows, they too are emotionally affected by the experience of their loved ones. Patients and caregivers are part of a common system, and taking care of the whole system could favor a better quality of life and pain relief for both. Within this study, we emphasize the importance of considering the perspectives of patients and caregivers. This allows identifying their needs and emotions that may affect pain management. Increasing knowledge among patients, caregivers, and health care providers is crucial for better pain management and decision-making processes. eHealth applications and technological infrastructure may help navigate the cancer journey; increase awareness of knowledge, needs, preferences, and expectations about treatments; and improve patient-doctor communication, empowerment, and involvement in the decision-making process [64,66].

Further studies are still needed to understand the interconnectedness of the behavioral and emotional reactions of caregivers and patients to cancer pain. Given that these reactions are formed in dyadic (or family) relationships (eg, patient-caregiver), dyadic analyses should be implemented to explore the mutual influence between two or more actors [75-77].

Acknowledgments

This work was partially supported by the Italian Ministry of Health with Ricerca Corrente and "5x1000" funds. CF and MC are PhD students in Medical Humanities at the European School of Molecular Medicine (SEMM) at the University of Milan, Italy.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Distribution of posts based on the broad categories referencing patients' and caregivers' comments.

[DOCX File , 30 KB - cancer_v9i1e41594_app1.docx]

Multimedia Appendix 2

Word cloud comparison between patients' and caregivers' words used for describing the cancer pain experience. The words used by patients are in orange, and those used by caregivers are in green.
[PNG File , 237 KB - cancer_v9i1e41594_app2.png]

Multimedia Appendix 3
Patients' emotion and sentiment frequencies. Sentiments and emotions associated with a negative affect are represented in red, and those associated with a positive affect are represented in green. Surprise may be associated with a positive or negative affect; thus, red and green are combined.
[PNG File , 26 KB - cancer_v9i1e41594_app3.png]

Multimedia Appendix 4
Caregivers' emotion and sentiment frequencies. Sentiments and emotions associated with a negative affect are represented in red, and those associated with a positive affect are represented in green. Surprise may be associated with a positive or negative affect; thus, red and green are combined.
[PNG File , 26 KB - cancer_v9i1e41594_app4.png]

Multimedia Appendix 5
Dendrograms based on the posts of patients and caregivers, and comparisons between them.
[PPTX File , 447 KB - cancer_v9i1e41594_app5.pptx]

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Abbreviations

STM: Systematic Transactional Model

Edited by T de Azevedo Cardoso; submitted 01.08.22; peer-reviewed by E Bantum; comments to author 28.04.23; revised version received 12.05.23; accepted 05.06.23; published 03.07.23.

Please cite as:
Filipponi C, Chichua M, Masiero M, Mazzoni D, Pravettoni G
Cancer Pain Experience Through the Lens of Patients and Caregivers: Mixed Methods Social Media Study
JMIR Cancer 2023;9:e41594
URL: https://cancer.jmir.org/2023/1/e41594
doi:10.2196/41594
PMID:37399067

Original Paper

The Effect of Clinical Decision Prompts in Improving Human Papillomavirus Vaccination Rates in a Multispecialty Practice in a Predominantly Hispanic Population: Quasi-Experimental Study

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Abstract

Background: The human papillomavirus (HPV) is implicated in the causal pathway of cancers of the vulva, vagina, penis, cervix, anus, and oropharyngeal region. It is the most common sexually transmitted infection in the United States. Despite the documented safety and effectiveness of the HPV vaccine, rates lag behind those of other vaccines given at the same age.

Objective: Provider recommendation is identified as a robust predictor of HPV vaccine uptake, and physician-prompting is shown to increase the provision of preventive care services in general. Theoretically, providing reminders to providers should increase opportunities for providing HPV vaccine recommendations and therefore affect vaccination rates. The objective of our study was to assess the effectiveness of an electronic medical record (EMR) prompt in improving HPV vaccination rates in an academic clinic setting caring for a predominantly Hispanic border population.

Methods: We used a quasi-experimental design with a retrospective chart audit to evaluate the effect of a clinical decision prompt (CDP) on improving HPV immunization rates in different specialty settings. We introduced an EMR prompt to remind providers to recommend the HPV vaccine when seeing appropriate patients in an obstetrics and gynecology (OBGYN), pediatrics (PD), and family medicine (FM) clinic in a large multispecialty academic group located along the Texas-Mexico border. We assessed HPV vaccination rates in all the departments involved before and after introducing the prompts. Participants included male and female patients between the ages of 9 and 26 years, presenting at the clinics between January 2014 and December 2015.

Results: We reviewed over 2800 charts in all 3 clinics. After adjusting for age, ethnicity, race, type of insurance, preferred language, and clinic, the odds of immunization were 92% (*P*<.001) higher in patients after the prompt implementation of the EMR. In addition, there was an overall statistically significant increase in the overall HPV vaccination completion rates after implementing the CDP (31.96% vs 21.22%; *P*<.001). Again, OBGYN saw the most significant improvement in vaccination completion rates, with rates at follow-up 66.02% higher than baseline rates (*P*=.04). PD and FM had somewhat similar but no less impressive improvements (57.7% and 58.36%; *P*<.001).

Conclusions: Implementing an EMR CDP improved our overall odds of HPV vaccination completion by 92%. We theorize that the decision prompts remind health care providers to discuss or recommend the HPV vaccination during clinical service delivery. CDPs in the EMR help increase HPV vaccination rates in multiple specialties and are a low-cost intervention for improving vaccination rates.

(JMIR Cancer 2023;9:e42890) doi:10.2196/42890

KEYWORDS

HPV; HPV vaccination; electronic clinical decision support; EMR prompt; clinical; decision; vaccine; pediatrics; age; ethnicity; race; language; immunization

Introduction

The human papillomavirus (HPV) is implicated in the causal pathway of cancers of the vulva, vagina, penis, cervix, anus, and oropharyngeal region [1,2]. HPV is the most common sexually transmitted infection in the United States [3] and accounts for over 30,000 cancers annually [4]. In addition, persistent infection with oncogenic strains of HPV has been associated with over 90% of cervical cancers [5], with HPV infection also associated with 63% of penile cancers [4,6].

The Federal Drug Administration approved the HPV vaccine in 2006 for use in female individuals aged 9 to 26 years; the indication was expanded 3 years later, in 2009, to include male individuals [7,8]. Despite the proven efficacy of these vaccines in the prevention of persistent HPV infection as well as Cervical Intraepithelial Neoplasia 2+ lesions [9], HPV vaccination uptake has been slow, and rates of initiation and completion still lag behind those of other adolescent vaccines recommended at the same age [10]. Rates of HPV vaccination among adolescents aged 13 to 17 years are approximately 41%, compared with rates for tetanus-diphtheria-acellular pertussis and meningococcal conjugate vaccine at 87.6% and 60%, respectively [11]. Hispanic female participants, especially those living on the US-Mexico border, bear an unequal burden of incident cervical cancer. The cervical cancer mortality rate among female individuals living on the US-Mexico border is the highest in the nation at 5.7/100,000 compared to the national average of 2.4/100,000, age-standardized to the year 2000 population [12]. Most penile cancers (63%) are associated with HPV infection [4], and Hispanic male individuals have the highest incidence in the country at 1.9 per 100,000 compared to 1.1 per 100,000 among non-Hispanic White male participants. [13].

Numerous factors are identified as barriers to the increased uptake of the HPV vaccine, including parental concerns about cost, vaccine safety, potential side effects, and possible promotion or condoning of youth sexual behavior [14-16]. Provider recommendation is identified as a robust predictor of HPV vaccine uptake [17,18]. The acceptability of the HPV vaccine is higher in individuals who received a recommendation from their providers or believed their providers would recommend it [16,19].

Despite the documented efficacy of provider recommendations, reports suggest that providers tend to give weak or inconsistent recommendations for the HPV vaccine compared to other adolescent vaccines [20] and are more likely to portray it as optional rather than routine [21]. Barriers reported by providers include perceived perception of parental hesitancy, poor provider knowledge, concern about the discussion of the sexual mode of transmission, and HPV requiring more time and effort to discuss when compared to other vaccines [22-26].

Dorell et al [27] reported that 66% of parents of unvaccinated adolescents (HPV) said they had not received a recommendation from their providers. Additionally, across the differing specialties, only approximately 50% of providers always recommend the HPV vaccine at visits, pointing to numerous missed opportunities to discuss HPV vaccination [26]. Physician-prompting is shown to increase the provision of preventive care services in general [28]. Theoretically, providing reminders to providers should increase opportunities for providing HPV vaccine recommendations and therefore affect vaccination rates. However, the evidence of the effect of prompts on improving adolescent vaccine rates has not been consistent, with some studies showing no difference [29] and others showing a significant improvement in adolescent vaccine rates with electronic prompting [30]. The objective of this study was to assess the effectiveness of an electronic medical record (EMR) prompt in improving HPV vaccination rates in an academic clinic setting caring for a predominantly Hispanic border population. Evaluating the significance of this low-cost intervention in a high-risk population can help inform structural changes to improve HPV vaccination rates in clinical settings with limited resources.

Methods

Settings

We carried out our study at an academic medical center near the US-Mexico border. The Medical Center comprises 13 clinical departments with over 200,000 patient visits a year. The center is also home to training for medical and nursing students, residents, and fellows. The City of El Paso has a population of over 700,000, with approximately 80% of Hispanic origin, and a median household income of US $32,000 [31].

Population

We selected the 3 departments that were most involved in the care of individuals in the HPV vaccination age range. These were the family medicine (FM), pediatrics (PD), and obstetrics and gynecology (OBGYN) departments. These were also the only departments that stocked the HPV vaccine in their clinics.

All patients aged 9 to 26 years who received care at these 3 clinics during the period of interest were eligible. For the department of PD, we excluded their specialty clinics (oncology, cardiology, endocrinology, gastroenterology, and nephrology).

Study Design

We conducted a quasi-experimental design with a retrospective chart audit to evaluate the effectiveness of a clinical decision prompt (CDP) in improving HPV immunization rates. In addition, we provided 1 live educational lecture for each department separately to increase our knowledge of the HPV disease process and the HPV vaccine product for our physicians. The same attending OBGYN physician gave the lecture to each department and included residents, attending physicians, and any midlevel providers. Table 1 contains the characteristics of clinical providers for descriptive purposes. These lectures were held during 3 different periods in the final quarter of 2014. We introduced EMR prompts in January 2015.

Table 1. Characteristics of clinical providers participating in the educational session.

Characteristics	Clinical specialty			Overall (N=84)	*P* value
	PD[a] (n=32)	OBGYN[b] (n=22)	FM[c] (n=21)		
Age (years), mean (SD)	35.28 (11.7)	37.89 (10.14)	38.2 (10.96)	37.06 (10.8)	.62
Years of practice, mean (SD)	18.33 (14.61)	10.55 (10.99)	11.7 (14.74)	12.07 (12.9)	.38
Gender, n (%)					.19
Male	17 (48.6)	7 (20)	11 (31)	35 (47)	
Female	13 (34)	15 (39)	10 (26)	40 (53)	
Race, n (%)					.02
White	12 (30)	17 (43)	11 (28)	41 (49)	
Other races or unknown	20 (57)	5 (14)	10 (29)	43 (51)	
Hispanic, n (%)					.001
Yes	6 (20)	9 (30)	15 (50)	30 (40)	
No	24 (56)	13 (30)	6 (14)	45 (60)	
Years of practice, n (%)					.15
≤10 years	3 (19)	7 (44)	6 (38)	18 (21)	
11-20 years	0 (0)	2 (50)	2 (50)	4 (5)	
>20 years	3 (43)	2 (29)	2 (29)	7 (8)	
No experience or in training or residency	26 (54)	11 (23)	11 (23)	55 (65)	

[a] PD: pediatrics.

[b] OBGYN: obstetrics and gynecology.

[c] FM: family medicine.

Data Abstraction

All departments use the same EMR. We received a list of all individual visits per department for the year in question. We conducted a random audit of 10% (3120/31,200) of the charts of patients within the age range of 9 to 26 years who visited these clinics in the calendar year January to December 2014 to assess our baseline HPV vaccination in 3 departments: OBGYN, PD, and FM. We used a random number generator to obtain a random sample of the patients based on our sample size calculator. We assessed that obtaining 10% of the clinic visits for the year would get us to our appropriate number per sample size calculation. Individually selected charts were abstracted by volunteer students using our chart abstraction tool. Volunteers were instructed in all charts to check the vaccine flow sheet, orders tab, and nurse and clinician office visits. Patients had completed the series if all 3 doses were documented in their chart or if providers noted historical completion during the clinic visit. Historical vaccination status was documented in a chart for patients with shot records or immunization records indicating they received the vaccines elsewhere. We repeated this process for the data audit in the post intervention data for the calendar year 2015.

We calculated our sample size based on a national estimate of the prevalence of HPV vaccination [11]. We powered our study to detect at least a 10% change in our HPV vaccination rates after implementing our CDP. Based on these estimates, 2460 participants (1500 female and 960 male participants) would be required to achieve greater than 90% power to detect a difference between group proportions using a 2-sided Fisher exact test at a 1% significance level. We estimated the sample size using PASS 12 (NCSS LLC) [32].

We instituted a CDP in our EMR to flag patients aged 9 to 26 years whenever they came in for office visits to encourage providers to discuss HPV vaccination and vaccinate as appropriate. The prompt appeared once after the provider accessed the patient's chart. Providers could ignore this prompt and continue their clinic visit if they so decided. The prompt was set to lapse once the clinic staff documented the HPV vaccination in the patient's chart. Following the initiation of the electronic prompt, we carried out a second chart audit on another 1230 randomly selected charts for the 12 months starting in January 2015.

Ethical Considerations

Before beginning the study, we obtained approval from the Texas Tech University Health Science Center El Paso Institutional Review Board (reference number 059324), and the study was determined to be exempt. Participant information was obtained via abstraction from patient records conducted as a chart audit. No individual patient identifier was stored in the data set used for analysis. Since this was done as part of the evaluation of a clinical process, separate patient consent was not required.

Analysis

Age was collected as a continuous variable in years from the participant chart. Race in medical records is categorical: Black, White, Asian, American Indian or Alaska Native, and Hawaiian or Pacific Islander. Due to small numbers and unstable estimates in racial categories, race was dichotomized as White participants and non-White participants. Ethnicity is documented in the chart as a categorical variable (Hispanic participants vs non-Hispanic participants).

We described continuous variables using the mean and SD, while categorical variables were described using frequencies and proportions. We used chi-square statistics to assess the differences in study arms for categorical variables. In contrast, for continuous variables, we used the *t* test and the Wilcoxon rank-sum test (for skewed variables). Using a logistic regression model, we assessed the adjusted and unadjusted association between baseline factors and HPV immunization in the pre- and postintervention arms. The variables adjusted for were age, ethnicity, race, type of insurance, preferred language, and clinic. For patients in the OBGYN clinic, we also adjusted for sexual activity since this information was only collected in the OBGYN clinic and may affect the acceptability of HPV vaccines [33]. We excluded the age of first intercourse and the age of HPV vaccination since these variables were not consistently documented and there was not enough data to assess. Therefore, we considered it statistically significant, with *P* values less than 5%, and performed all analyses using SAS V. 9.4 (SAS Institute).

Results

We reviewed 2,851 charts (we oversampled male participants in the other clinics to ensure we represented males well, especially given that the OBGYN department was bound to have only female patients). Patients in the postintervention cohort were older (age in years 17.6 vs 16.5, *P*<.001), more likely to be female (784/1290, 60.8% vs 745/1561, 47.8%, *P*<.001), and more likely to be Hispanic in origin (1045/1290, 81% vs 1208/1561, 77.4%, *P*=.02), and for the OBGYN department alone, 9% (27/272) and 2.9% (7/232) reported being sexually active (*P*=.004; see Table 2).

There was an overall statistically significant increase in the overall HPV vaccination completion rates after implementing the CDP (412/1289, 31.96% vs 331/1560, 21.22%, *P*<.001). OBGYN saw the greatest improvement in vaccination completion rates, with rates at follow-up 66.02% higher than baseline rates (*P*=.04). PD and FM had somewhat similar but no less impressive improvements, 57.7% and 58.36% (*P*<.001). Rates at baseline were higher in the PD department when compared to FM and obstetrics (221/659, 33.5% vs 88/651, 13.5% vs 22/250, 8.8%), and this difference was maintained even after the intervention (see Table 3).

After adjusting for age, ethnicity, race, type of insurance, preferred language, and clinic, the odds of immunization completion were 92% higher in all patients after the CDP implementation (odds ratio [OR] 1.92, 95% CI 1.59-2.32). Factors significantly associated with receipt of vaccination include having private insurance (OR 3.16, 95% CI 1.76-5.65), attending PD and FM clinics (OR 4.01, 95% CI 2.8-5.76 and OR 1.7, 95% CI 1.18-2.45, respectively), and being of Hispanic origin (OR 1.43, 95% CI 1.07-1.89; see Table 4).

Table 2. Patient baseline characteristics comparing pre- and postintervention cohorts.

Variables	Preintervention (n=1561)	Postintervention (n=1290)	*P* value
Age (years), mean (SD)	16.5 (5.75)[a]	17.6 (5.46)[a]	<.001
Age (years) at first sexual intercourse, mean (SD)	17.4 (2.16)[a]	16.68 (1.86)[a]	.17
Number of sexual partners, median (IQR)	2 (1-4)[a]	2 (1-4)[a]	.60[a]
Age (years) vaccine was received, mean (SD)	11.69 (3.42)[a]	12.19 (3.17)[a]	.05
Insurance, n (%)			.09
Private insurance	365 (25.8)	282 (23.7)	
Medicaid or CHIP[b]	919 (65.0)	818 (68.7)	
Hospital discount program, clinic discount program, breast and cervical cancer screening program, or other	131 (9.3)	90 (7.6)	
Ethnicity, n (%)			.02
Hispanics	1208 (77.4)	1045 (81.0)	
Non-Hispanics	352 (22.6)	245 (19.0)	
Race, n (%)			.41
White	1187 (76.0)	963 (74.7)	
Non-White	374 (23.96)	327 (25.35)	
Language preferred			.72
English	1024 (65.9)	855 (66.5)	
Spanish or other	531 (34.2)	430 (33.5)	
Gender			<.001
Female	745 (47.8)	784 (60.8)	
Male	815 (52.2)	505 (39.2)	
Is the patient sexually active?[c], n (%)			.004
No	7 (2.9)	27 (9.0)	
Yes	232 (97.1)	272 (91.0)	
Which valent vaccine was given?, n (%)			.46
Bivalent (ie, Cervarix)	149 (45.4)	137 (34.2)	
Quadrivalent (ie, Gardasil)	96 (29.3)	105 (26.2)	
9-valent	83 (25.3)	159 (39.7)	

[a] Wilcoxon sum rank test.

[b] CHIP: Children’s Health Insurance Program.

[c] Data collected only in obstetrics clinic.

Table 3. HPV vaccination completion rates by clinics[a].

Has the patient had immunizations for HPV[b] (HPV vaccination rates): for all FM[c], PD[d], and OBGYN[e] clinics	Preintervention (n=1560), n (%)	Postintervention (n=1289), n (%)	*P* value
Response for all FM, PD, and OBGYN clinics			<.001
No	1229 (78.78)	877 (68.04)	
Yes	331 (21.22)	412 (31.96)	
Response for on PD clinic only			<.001
No	438 (66.46)	235 (47.09)	
Yes	221 (33.54)	264 (52.91)	
Response for FM clinic only			<.001
No	563 (86.48)	378 (78.59)	
Yes	88 (13.52)	103 (21.41)	
Response for OBGYN clinic only			.04
No	228 (91.2)	263 (85.39)	
Yes	22 (8.8)	45 (14.61)	

[a] Completion is defined as receiving 3 doses of the HPV vaccine.

[b] HPV: human papillomavirus.

[c] FM: family medicine.

[d] PD: pediatrics.

[e] OBGYN: obstetrics and gynecology.

Table 4. Adjusted and unadjusted association between HPV vaccination completion and study arm for all clinics[a,b].

Variables (dependent variable: HPV[c] immunizationyes)	Unadjusted association		Adjusted association	
	OR[d] (95% CI)	*P* value	OR (95% CI)	*P* value
Study arm				
Before implementation	1	N/A[e]	1	N/A
After implementation	1.74 (1.47-2.07)	<.001	1.92 (1.59-2.32)	<.001
Age (in years)	0.96 (0.95-0.98)	<.001	1.01 (0.99-1.03)	.33
Race				
White	1	N/A	1	N/A
Non-White	0.76 (0.62-0.93)	.007	1.04 (0.82-1.32)	.85
Insurance				
Medicaid or CHIP[f]	2.23 (1.26-3.93)	.006	1.69 (0.92-3.13)	.17
Private insurance	7.23 (4.24-12.33)	<.001	3.16 (1.76-5.65)	<.001
UMC, Texas Tech Discount, breast and cervical cancer screening program, or other	1	N/A	1	N/A
Clinic				
PD[g]	5.28 (3.99-7)	<.001	4.01 (2.8-5.76)	<.001
FM[h]	1.49 (1.11-2.01)	.009	1.7 (1.18-2.45)	<.001
OBGYN[i]	1	N/A	1	N/A
Ethnicity				
Hispanics	2.16 (1.7-2.74)	<.001	1.43 (1.07-1.89)	.006
Non-Hispanics	1	N/A	1	N/A
Language preferred				
English	1	N/A	1	N/A
Spanish or other	2.34 (1.97-2.78)	<.001	1.38 (1.12-1.70)	.003
Gender				
Female	1	N/A	N/A	N/A
Male	1.06 (0.90-1.26)	.47	N/A	N/A

[a] Completion is defined as receiving 3 doses of the HPV vaccine.

[b] Adjusted for age, ethnicity, race, type of insurance, preferred language, and clinic.

[c] HPV: human papillomavirus.

[d] OR: odds ratio.

[e] N/A: not applicable.

[f] CHIP: Children’s Health Insurance Program.

[g] PD: pediatrics.

[h] FM: family medicine.

[i] OBGYN: obstetrics and gynecology.

Discussion

Principal Findings

Implementing an EMR CDP improved our overall odds of completing HPV vaccination by 92%. This result differed from a previous randomized controlled trial that did not find increased vaccine uptake in adolescent vaccines using EMR prompts [29]. This previous study was a large multiclinic study using primarily pediatric and FM clinics and evaluating all adolescent vaccines. There was no difference in vaccination status for all vaccines and HPV between those clinics that initiated a prompt and those centers that did not. We theorize that the difference in population demographics may have played a role (only 11% to 19% of participants were Hispanic). However, we found studies that agreed with our findings and showed an increase in vaccination following the introduction of CDPs [34]. Ruffin et al [30] reported increased HPV vaccination rates using comparative community clinics. This study population was also not similar to ours and consisted mostly of White and African participants.

We theorize that the decision prompts remind health care providers to discuss or recommend the HPV vaccination during clinical service delivery. Studies show that while a strong recommendation is more effective, discussing the HPV vaccine also increases HPV vaccine rates [35]. Our study adds to this body of knowledge, confirming that low-cost interventions such as CDPs significantly improve HPV vaccination rates (at least in the short term) in a primarily Hispanic cohort.

After adjustment, the odds of HPV vaccination remained significantly higher for pediatric and FM clinics and were highest for PD at baseline. This higher rate for HPV vaccination in PD is consistent with reports showing higher initiation and completion rates in pediatric clinics compared to FM and other specialties [36]. We theorize that this may be due to systems set in place (vaccines are routinely given in pediatric clinics) and the possibility that pediatricians are more invested in vaccinations in general and may provide more robust recommendations. In addition, studies have shown that the consistency and strength of recommendation are higher among pediatric practitioners than FM practitioners. This finding may partially account for the higher vaccination initiation and completion rates in these clinics [37]. This difference in the strength of recommendation opens up a target area of focus for intervention with FM and OBGYN providers who are likely to see older adolescents and young adults who may have missed the HPV series when they were younger.

The strengths of our study include the large number of patient charts that were audited across 3 different clinics. As a result, our pre- and postintervention groups were not identical, eliminating any duplication of charts. In addition, we have a large, predominately Mexican-American population, which is underrepresented in the literature. Other studies have found that physicians can ignore prompts or skip over them due to “prompt fatigue” [38]. To limit “prompt fatigue,” we restricted this study to 1 year. However, we think it is important to look forward to the future to see if the gains made will persist.

Limitations

There are limitations to this study. Our study was not a randomized controlled trial of HPV prompts versus no prompts. Therefore, we were limited by using the same EMR in all clinics we evaluated, and it would have been technically challenging to randomize by clinic. The differences in the baseline rates by clinic also made randomization by clinic not feasible. Other possible confounding factors include changes in awareness about the vaccine over time and variations in rates over the year. We accounted for these potential differences by reviewing the same periods (January to December) in both years. In addition, we provided lectures for each department separately to increase the knowledge of the HPV disease process and the HPV vaccine product for our physicians. Our patient population is 85% Mexican-American and has been shown in previous studies to be open to HPV vaccination, with reports as high as 66% vaccination rates in El Paso County [30,37]. In the FM clinic and PD clinics, an electronic vaccination record within the EMR documents historical vaccine administration. All vaccines given in the 3 clinics are recorded electronically in the vaccine administration record. However, the OBGYN clinic does not consistently record historical vaccines administered in an electronic vaccination flowsheet and instead may record vaccine history within the medical note, usually within the History of Present Illness, creating a poor tracking record of the vaccines that may have skewed actual vaccine rates in this clinic. To correct this, the guideline for chart audits included reviewing all clinic notes in all the clinics for documentation of HPV vaccination during the year in question.

We carried out our study at an academic institution along the Texas-Mexico border. We did not include community-based clinics and private physician offices. Thus, our findings may not apply to all populations across the United States. Our patient population also has a high level of uninsured or underinsured patients, which may have affected our before and after HPV vaccination rates. We also did not include data on the timeliness of vaccination for all 3 doses of the HPV vaccine for each patient.

Conclusions

Our study shows that a simple, inexpensive EMR prompt for vaccination and provider education on HPV disease and the HPV vaccine increased our vaccination rates in all 3 clinical settings. Prompts in the EMR are a low-cost intervention for improving vaccination rates and may have an unmeasurable impact on our patients and their risk of cervical, anal, vaginal, and oropharyngeal cancers.

Future directions for improving HPV vaccination rates may include better tracking of vaccine status among patients in the EMR for an accurate rate. Medical staff may require further education, including standardizing provider counseling points, to promote vaccination to all eligible patients. Clinic staff may need training on the importance of screening for unvaccinated patients to alert the physicians to offer the vaccine. Explicitly targeting certain patients, such as those coming in for late vaccination past the 9- to 11-year-old start time, male patients, and perhaps postpartum patients may also increase the HPV vaccine uptake rates. Providing free vaccines and patient visits through grants in the patient's neighborhood or school may increase the HPV vaccine rate.

Data Availability

The data sets generated during and analyzed during the current study are not publicly available due to the source being chart audits from patient data. However, they are available from the corresponding author upon reasonable request.

Conflicts of Interest

None declared.

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Abbreviations

CDP: clinical decision prompt
EMR: electronic medical record
FM: family medicine
HPV: human papillomavirus

OBGYN: obstetrics and gynecology
PD: pediatrics

Edited by A Mavragani; submitted 22.09.22; peer-reviewed by J Erves, C Rand; comments to author 03.01.23; revised version received 05.01.23; accepted 26.01.23; published 15.03.23.

Please cite as:
Molokwu J, Mendez M, Bracamontes C
The Effect of Clinical Decision Prompts in Improving Human Papillomavirus Vaccination Rates in a Multispecialty Practice in a Predominantly Hispanic Population: Quasi-Experimental Study
JMIR Cancer 2023;9:e42890
URL: https://cancer.jmir.org/2023/1/e42890
doi:[10.2196/42890](https://doi.org/10.2196/42890)
PMID:[36920453](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=36920453&dopt=Abstract)

Original Paper

Policy Preferences Regarding Health Data Sharing Among Patients With Cancer: Public Deliberations

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Abstract

Background: Precision health offers the promise of advancing clinical care in data-driven, evidence-based, and personalized ways. However, complex data sharing infrastructures, for-profit (commercial) and nonprofit partnerships, and systems for data governance have been created with little attention to the values, expectations, and preferences of patients about how they want to be engaged in the sharing and use of their health information. We solicited patient opinions about institutional policy options using public deliberation methods to address this gap.

Objective: We aimed to understand the policy preferences of current and former patients with cancer regarding the sharing of health information collected in the contexts of health information exchange and commercial partnerships and to identify the values invoked and perceived risks and benefits of health data sharing considered by the participants when formulating their policy preferences.

Methods: We conducted 2 public deliberations, including predeliberation and postdeliberation surveys, with patients who had a current or former cancer diagnosis (n=61). Following informational presentations, the participants engaged in facilitated small-group deliberations to discuss and rank policy preferences related to health information sharing, such as the use of a patient portal, email or SMS text messaging, signage in health care settings, opting out of commercial data sharing, payment, and preservation of the status quo. The participants ranked their policy preferences individually, as small groups by mutual agreement, and then again individually in the postdeliberation survey.

Results: After deliberation, the patient portal was ranked as the most preferred policy choice. The participants ranked no change in status quo as the least preferred policy option by a wide margin. Throughout the study, the participants expressed concerns about transparency and awareness, convenience, and accessibility of information about health data sharing. Concerns about the status quo centered around a lack of transparency, awareness, and control. Specifically, the patients were not aware of how, when, or why their data were being used and wanted more transparency in these regards as well as greater control and autonomy around the use of their health data. The deliberations suggested that patient portals would be a good place to provide additional information about data sharing practices but that over time, notifications should be tailored to patient preferences.

Conclusions: Our study suggests the need for increased disclosure of health information sharing practices. Describing health data sharing practices through patient portals or other mechanisms personalized to patient preferences would minimize the concerns expressed by patients about the extent of data sharing that occurs without their knowledge. Future research and policies should identify ways to increase patient control over health data sharing without reducing the societal benefits of data sharing.

(JMIR Cancer 2023;9:e39631) doi:10.2196/39631

KEYWORDS

public deliberation; data sharing; precision health; health information exchange

Introduction

Background

Precision medicine is a growing effort to use state-of-the-art molecular markers and clinical decision supports to enable the customization of patient care. The first major successes have been in the field of precision oncology, where patient data (laboratory results, tumor pathology, treatment, survival time, etc) are routinely matched with the genome sequencing of tumors to enable cancer clinics, as well as pharmaceutical and commercial companies, to refine diagnostics and treatments to improve patient outcomes [1-3]. Although some precision oncology approaches have evolved under the regulatory standards associated with research, the vast majority of health data sharing and creation of new clinical regimes have occurred as part of the quality improvement processes, which are not subject to the regulations governing human participant research. Health data, which can be derived from biological, clinical, tracking, administrative, or patient registry information, are routinely collected from individual patients and shared electronically among doctors, nurses, hospitals, commercial laboratories and diagnostics, insurance companies, public health departments, and other information networks [4-6]. Sharing this information has become an essential component of care delivery and coordination as well as population health [7].

However, patients are generally unaware of the extent of data sharing that occurs in the context of health care delivery. Although the notification of data sharing policies is described in Health Insurance Portability and Accountability Act forms, health institutions fail to make them accessible to patients [8]. For instance, a study found that patients were not aware that the precision medicine biobank consent form they signed permitted the commercialization of their data; upon discovering this, both the patients and referring physicians expressed concerns about privacy [9]. This suggests that despite some of the benefits of health information sharing for advancing research and clinical care, the lack of transparency and privacy risks pose a threat to trust [10,11]. At a minimum, posting information in clinical settings in plain language would promote greater transparency in how health information is shared. Health organizations could also leverage the existing systems used to signal data breaches—via SMS text messages or a patient portal—to increase the awareness of data sharing practices; these systems could also be adopted by commercial companies. In addition to these strategies, patients could be offered the option to opt out of commercial data sharing entirely or be paid for the use of their data.

Goal of This Study

We used a deliberative method to obtain a rich qualitative understanding of the key attributes of patient preferences for systems that share clinical health data in the context of precision oncology. Deliberation reveals the complexity and nuances that inform specific recommendations for the ethical governance of health information [12-14]. The objectives of this study were to apply the method of public deliberation to (1) describe the policy preferences of current and former patients with cancer regarding clinical health information sharing and (2) identify the values, as well as the perceived risks and benefits associated with health data sharing, that participants called upon when formulating their preferences.

Methods

We conducted 2 public deliberation sessions with English-speaking adults who were either current or former patients with cancer in Southeastern Michigan in October and November 2019. The purpose of the deliberations was to learn about patient concerns and preferences about how health information should be used, shared, and regulated.

Ethics Approval

This study was approved by the University of Michigan Institutional Review Board and was deemed exempt from federal regulations (ethics approval number: HUM00158768). All the participants provided written informed consent before participation. The participants were compensated with US $100 and were provided with breakfast and lunch.

Participants

We recruited participants through a research platform and database developed and managed by one of the Clinical Translational Science Institutes designed to facilitate the recruitment of research participants [15]. The database contained a pool of approximately 48,000 individuals. The inclusion criteria for our study were as follows: the participants had to be comfortable with speaking in English, had to be aged ≥21 years, and had to have a former or current diagnosis of any type of cancer. We purposively recruited participants to ensure diversity in terms of race or ethnicity, age, education, and sex. Eligible participants who expressed interest were contacted by the recruitment coordinator. From previous deliberation studies, we found that approximately 75% of enrolled participants ultimately attend a public deliberation [16]. Of the 79 participants who were enrolled, 61 (77%) attended 1 of 2 deliberation sessions. Given factors such as space and logistical considerations, we conducted 2 deliberations, with approximately 30 participants in each. This allowed for effective large- and small-group discussions [17].

Materials

We developed educational presentations and a booklet for the participants (Multimedia Appendix 1). The educational presentations provided an overview of how health information is collected, stored, and shared in general and with commercial companies and the ethical considerations associated with information sharing [17]. The booklet was mailed to the participants before the session and included a description of the study and key terms. These materials were developed iteratively by the study team, which included a community partner and liaison, who reviewed the materials for accessibility. We used a variety of approaches, including visuals, narrative text, and use case scenarios, to further support accessibility and understanding. The participants also completed predeliberation and postdeliberation surveys on health system use, identified versus deidentified health information, comfort with commercial and noncommercial health data sharing, and preferences about notification of health data sharing. The surveys were informed by our previous nationally representative surveys [4,10,18,19].

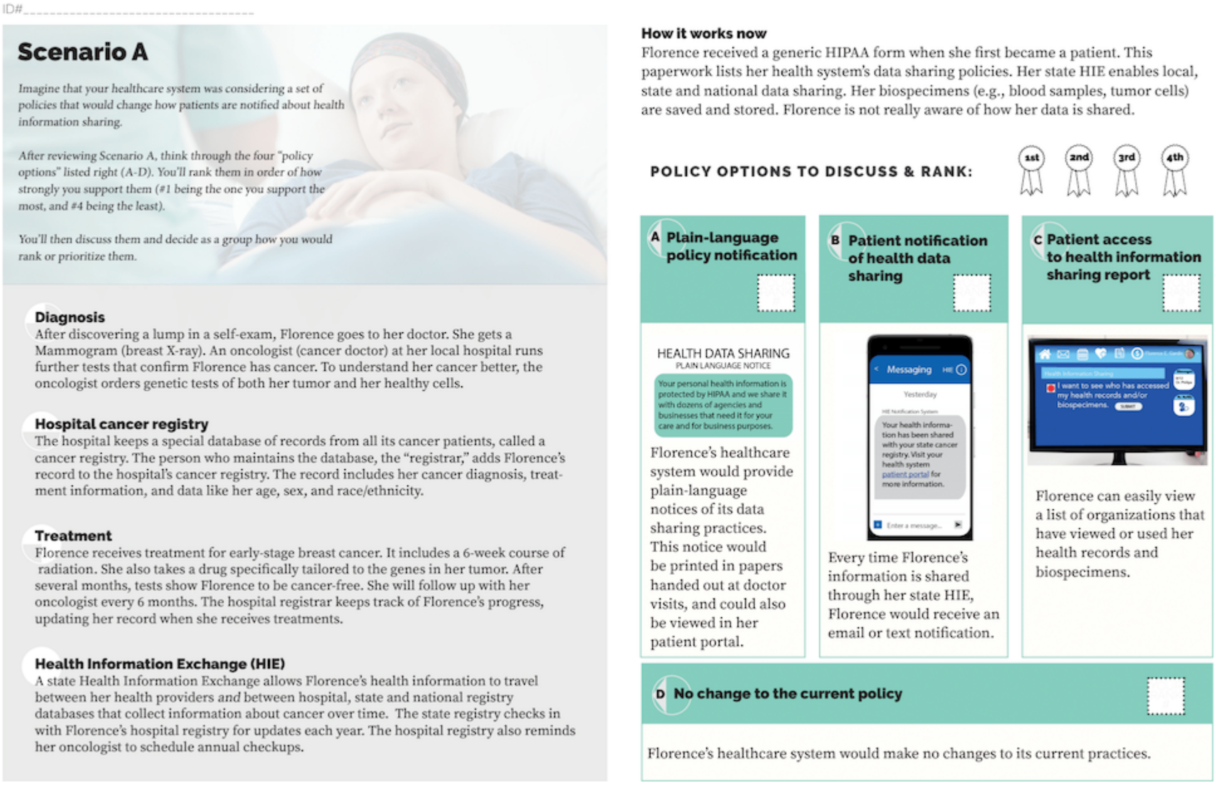
Procedures

The purpose of a deliberative session is to convene members of the public to obtain their input about a particular topic (here, health information sharing), gain insight into how they understand the complexities surrounding the topic, and solicit their preferred options for policy [13,14,20]. There are many different ways of conducting a public deliberation; for instance, deliberations could be varying in duration (eg, 1 day vs 2 days) and may include components such as opinion polls and issue forums [21,22]. The current deliberation was guided by Kim et al’s [23] deliberative approach [16], and the procedures are further described in our previous publication [17].

At the beginning of the day-long session, the participants completed a predeliberation survey, which included questions about knowledge and attitudes about data sharing as well as demographic information. The participants listened to presentations by experts on precision oncology, data practices, and the ethics of data sharing. They were randomly assigned to 1 of 5 small groups (6 to 8 people in each group) and participated in discussions led by trained facilitators. The goal of the small-group discussions was to have the participants rank a series of policy options related to 2 *scenarios* based on their preferences. In the first small-group session, scenario A, the participants were asked to deliberate over 4 policies for informing patients about clinical health information sharing. In the second small-group session, scenario B, the participants were asked to deliberate over 5 policies for informing patients about health information being shared with and used by commercial companies (Figures 1 and 2). These policy options were developed iteratively through discussions within the study team, which included members with expertise in policy, ethics, law, and precision oncology, and with health system and public health experts. The options were selected to balance feasibility and patient accessibility and were informed by previous literature considering different options such as payment for the use of health data [24]. Further information about our procedures and the deliberative process, along with the deliberation session agenda; the educational booklet given to the participants; and the postdeliberation survey can be found in our previous work [17].

At the beginning of each small-group discussion, the participants first ranked the options individually. These ranks were then reviewed and tallied in small groups to generate a score representing their group ranking. After a discussion focusing on the reasons for their preferences and the benefits and risks of each option for individuals and the larger society, the small groups had the option to revise their scores to come up with a final list of preferences. The group discussions also included, as needed, alternatives to or modifications of the policies as presented. This process was repeated for scenario B, which focused on the sharing of information with commercial companies. The participants then convened in a large group session to review and discuss the combined small-group results for both scenarios A and B. At the end of the session, the participants completed a postdeliberation survey, which included questions about knowledge and attitudes about data sharing as well as final individual policy rankings for scenarios A and B.

Figure 1. Scenario A policy options.



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Scenario A

Imagine that your healthcare system was considering a set of policies that would change how patients are notified about health information sharing.

After reviewing Scenario A, think through the four "policy options" listed right (A-D). You'll rank them in order of how strongly you support them (#1 being the one you support the most, and #4 being the least).

You'll then discuss them and decide as a group how you would rank or prioritize them.

Diagnosis
After discovering a lump in a self-exam, Florence goes to her doctor. She gets a Mammogram (breast X-ray). An oncologist (cancer doctor) at her local hospital runs further tests that confirm Florence has cancer. To understand her cancer better, the oncologist orders genetic tests of both her tumor and her healthy cells.

Hospital cancer registry
The hospital keeps a special database of records from all its cancer patients, called a cancer registry. The person who maintains the database, the "registrar," adds Florence's record to the hospital's cancer registry. The record includes her cancer diagnosis, treatment information, and data like her age, sex, and race/ethnicity.

Treatment
Florence receives treatment for early-stage breast cancer. It includes a 6-week course of radiation. She also takes a drug specifically tailored to the genes in her tumor. After several months, tests show Florence to be cancer-free. She will follow up with her oncologist every 6 months. The hospital registrar keeps track of Florence's progress, updating her record when she receives treatments.

Health Information Exchange (HIE)
A state Health Information Exchange allows Florence's health information to travel between her health providers *and* between hospital, state and national registry databases that collect information about cancer over time. The state registry checks in with Florence's hospital registry for updates each year. The hospital registry also reminds her oncologist to schedule annual checkups.

How it works now
Florence received a generic HIPAA form when she first became a patient. This paperwork lists her health system's data sharing policies. Her state HIE enables local, state and national data sharing. Her biospecimens (e.g., blood samples, tumor cells) are saved and stored. Florence is not really aware of how her data is shared.

POLICY OPTIONS TO DISCUSS & RANK:

A Plain-language policy notification

HEALTH DATA SHARING
PLAIN LANGUAGE NOTICE
Your personal health information is protected by HIPAA and we share it with dozens of agencies and businesses that need it for your care and for business purposes.

Florence's healthcare system would provide plain-language notices of its data sharing practices. This notice would be printed in papers handed out at doctor visits, and could also be viewed in her patient portal.

B Patient notification of health data sharing

Messaging
Yesterday
HIE Notification System
Your health information has been shared with your state cancer registry. Visit your health system patient portal for more information.
Enter a message...

Every time Florence's information is shared through her state HIE, Florence would receive an email or text notification.

C Patient access to health information sharing report

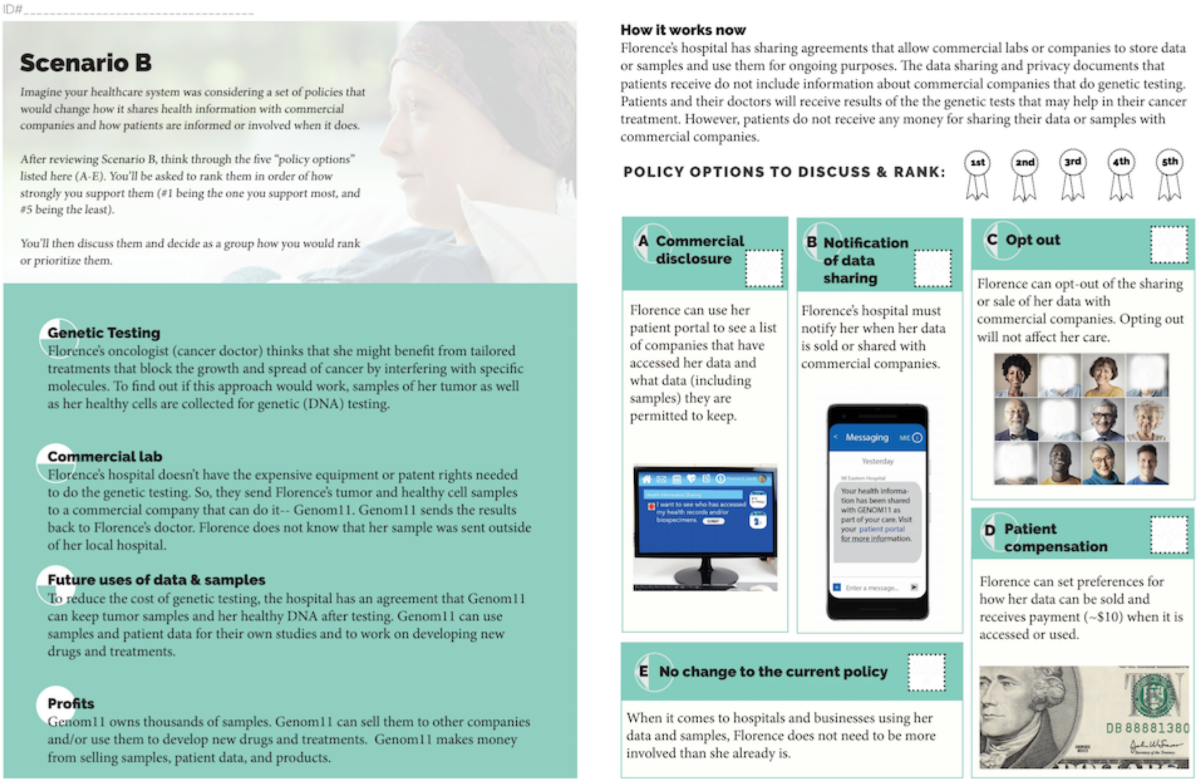
Health Information Sharing
I want to see who has accessed my health records and/or biospecimens. SUBMIT

Florence can easily view a list of organizations that have viewed or used her health records and biospecimens.

D No change to the current policy

Florence's healthcare system would make no changes to its current practices.

Figure 2. Scenario B policy options.



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Scenario B

Imagine your healthcare system was considering a set of policies that would change how it shares health information with commercial companies and how patients are informed or involved when it does.

After reviewing Scenario B, think through the five "policy options" listed here (A-E). You'll be asked to rank them in order of how strongly you support them (#1 being the one you support most, and #5 being the least).

You'll then discuss them and decide as a group how you would rank or prioritize them.

Genetic Testing
Florence's oncologist (cancer doctor) thinks that she might benefit from tailored treatments that block the growth and spread of cancer by interfering with specific molecules. To find out if this approach would work, samples of her tumor as well as her healthy cells are collected for genetic (DNA) testing.

Commercial lab
Florence's hospital doesn't have the expensive equipment or patent rights needed to do the genetic testing. So, they send Florence's tumor and healthy cell samples to a commercial company that can do it-- Genom11. Genom11 sends the results back to Florence's doctor. Florence does not know that her sample was sent outside of her local hospital.

Future uses of data & samples
To reduce the cost of genetic testing, the hospital has an agreement that Genom11 can keep tumor samples and her healthy DNA after testing. Genom11 can use samples and patient data for their own studies and to work on developing new drugs and treatments.

Profits
Genom11 owns thousands of samples. Genom11 can sell them to other companies and/or use them to develop new drugs and treatments. Genom11 makes money from selling samples, patient data, and products.

How it works now
Florence's hospital has sharing agreements that allow commercial labs or companies to store data or samples and use them for ongoing purposes. The data sharing and privacy documents that patients receive do not include information about commercial companies that do genetic testing. Patients and their doctors will receive results of the the genetic tests that may help in their cancer treatment. However, patients do not receive any money for sharing their data or samples with commercial companies.

POLICY OPTIONS TO DISCUSS & RANK:

A Commercial disclosure

Florence can use her patient portal to see a list of companies that have accessed her data and what data (including samples) they are permitted to keep.

Health Information Sharing
I want to see who has accessed my health records and/or biospecimens. SUBMIT

B Notification of data sharing

Florence's hospital must notify her when her data is sold or shared with commercial companies.

Messaging
Yesterday
Your health information has been shared with GENOM11 as part of your care. Visit your patient portal for more information.
Enter a message...

C Opt out

Florence can opt-out of the sharing or sale of her data with commercial companies. Opting out will not affect her care.

D Patient compensation

Florence can set preferences for how her data can be sold and receives payment (~$10) when it is accessed or used.

E No change to the current policy

When it comes to hospitals and businesses using her data and samples, Florence does not need to be more involved than she already is.

Data Analysis

Our data analysis comprised a summarization of the participants' demographic information and policy rankings and a qualitative analysis to assess the participants' policy preferences and values and concerns related to health data sharing.

Participant Demographics and Policy Ranking

We collected demographic data from the presession survey and summarized them. Frequency, mean, and SD were calculated using SPSS (IBM Corp). We collected individual rankings before first small-group deliberation and in the postsession survey. The initial individual rankings informed the subsequent small-group discussions about policy preferences and concerns and benefits and risks of each option to individuals and the society. Small-group rankings were collected at the end of each small-group deliberation [17].

Qualitative Data Analysis

Audio recordings of the small-group discussions were professionally transcribed and deidentified. We used an iterative approach to design a codebook. An initial draft of the codebook was developed deductively based on previous deliberations on related topics [23,25,26] and our small-group discussion questions. Next, we had 4 members of the study team independently read through the 7 small-group discussion transcripts and suggest additional codes and edits to the existing codes. Three members of the study team tested and further refined the codebook via the double coding of 2 small-group discussions. The final codes reflected (1) policy preferences and (2) participant values and concerns related to health data sharing. Two members of the study team used the final version of the codebook to independently code all 20 small-group transcripts (10 from each session), after which they met to discuss and reconcile disagreements. The qualitative data analysis software MAXQDA 2018 (VERBI Software) was used for all analyses. The codebook is available in Multimedia Appendix 1.

Results

Participant Demographics

Table 1 summarizes the demographic characteristics of the participants. The mean age of the participants (n=61) was 62.1 (SD 10.2) years, and over half (36/61, 59%) of the participants identified as female. The reported race or ethnicity of the participants reflected the demographics of Southeastern Michigan residents: 72% (44/61) identified as White, 18% (11/61) identified as African American or Black, and 10% (6/61) as other races or ethnicities. Likewise, consistent with the community characteristics, just under half of the participants had a college (bachelor’s) degree (20/61, 33%) or higher level of education (25/61, 41%). Nearly three-quarters (45/61, 73%) were either working or retired. Over one-third (23/61, 38%) made less than the median household income of US $50,000. Most participants were in good health (42/60, 70% reported good or very good health status).

Table 1. Demographic characteristics of participants (n=61).

Characteristics	Values
Sex, n (%)	
Female	36 (59)
Male	25 (41)
Age (years), mean (SD)	62.1 (10.2)
Race or ethnicity[a], n (%)	
African American or Black	11 (18)
American Indian or Alaska Native	2 (3)
Asian American or Asian	2 (3)
Hispanic or Latino	3 (5)
Middle Eastern or Arab American	0 (0)
Pacific Islander or Hawaiian Native	0 (0)
White	44 (72)
Other	1 (2)
Highest educational qualification, n (%)	
Less than bachelor’s degree	16 (26)
Bachelor’s degree	20 (33)
More than bachelor’s degree	25 (41)
Working in the health care field (yes), n (%)	16 (26)
Household income (US $), n (%)	
<50,000	23 (38)
50,000-75,000	9 (15)
75,000-100,000	9 (15)
100,000-150,000	9 (15)
>150,000	5 (8)
Prefer not to answer	6 (10)
Employment status, n (%)	
Working	21 (34)
Not working (retired)	24 (39)
Not working (person with disability)	11 (18)
Not working (other)	4 (7)
Prefer not to answer	1 (2)
Health status[b], n (%)	
Excellent	7 (12)
Very good	21 (35)
Good	21 (35)
Fair	10 (17)
Poor	1 (2)

[a] The participants selected all the options that applied.

[b] Total number of participants is less than 61 owing to missing information from 1 (2%) participant.

Ranked Policy Preferences

Across both scenarios, the participants ranked “No change to current policy” as the least preferred policy option. This was also reflected in the results of the individual postdeliberation survey, with the “No change to current policy” option obtaining a mean rank of 3.97 (SD 0.18) in scenario A (1 being the first rank and 4 being the fourth rank) and 4.46 (SD 0.92) in scenario B (1 being the first rank and 5 being the fifth rank). By contrast, the use of a patient portal was the most preferred policy option in both scenarios, although it was tied to the preference for email or text notifications in scenario B in the first deliberation session. Preference for the use of a patient portal was also reflected in the results of the individual postdeliberation survey, with the use of a patient portal option obtaining a mean rank of 1.46 (SD 0.59) in scenario A and 1.69 (SD 0.67) in scenario B.

In scenario A, other preferred notification options included the use of plain language signs and email or SMS text messages. The first deliberation session group preferred the use of email or text, whereas the second session group preferred the use of plain language signs. In the survey results, plain language was ranked slightly higher than email or text (2.18 vs 2.36) overall.

In scenario B, the participants also considered the option to opt out of sharing health information with commercial companies and the option to receive payment for the use of their data. In the first deliberation session, these 2 options tied. In the second session, opting out was ranked second, followed by notification via text or email and then payment. In the combined survey results, text or email ranked second overall (2.33), followed by opt out (2.85) and then payment (3.66). Table 2 summarizes the combined small-group policy preferences for each session and the mean ranks from the results of the individual postdeliberation survey.

Table 2. Small-group and individual survey rankings across both deliberation sessions.

Scenario and policy option	Rank in first deliberation session[a] (n=28)	Rank in second deliberation session[a] (n=33)	Mean rank (SD[b]; n=61)
Scenario A: policy options for the sharing of clinical health information			
A.3. Disclosure: information posted on patient portal	1	1	1.46 (0.59)
A.1. Notification: plain language signage	3	2	2.18 (0.85)
A.2. Notification: text or email	2	3	2.36 (0.78)
A.4. No change	4	4	3.97 (0.18)
Scenario B: policy options for the sharing of clinical health information with commercial companies			
B.1. Disclosure: information posted on patient portal	1/2 (tie)	1	1.69 (0.67)
B.2. Notification: text or email	1/2 (tie)	3	2.33 (0.94)
B.3. Opt out of sharing with commercial companies	3/4 (tie)	2	2.85 (1.48)
B.4. Payment	3/4 (tie)	4	3.66 (1.05)
B.5. No change	5	5	4.46 (0.92)

[a] Final small-group ranking across the 5 small groups combined.

[b] On the basis on individual responses to the postdeliberation survey.

Qualitative Findings

Overview

Across both scenarios, the participants felt that a change from the status quo is warranted, based on their hopes and concerns for individuals and the society. In their discussions, the participants weighed issues related to transparency and awareness, convenience, accessibility, individual autonomy and control, and respect. As the participants balanced the positives and negatives of each option, alternative solutions emerged, which we have described briefly in the subsequent sections.

Challenges With the Status Quo

There was little support for the status quo in either scenario A or B. The participants across both sessions agreed that the current policy is problematic because it lacks transparency, and subsequently, they said that they were unaware of their data were being shared:

> *I guess I just didn’t realize how much stuff was going out. That’s my biggest concern, and I’d like to be more aware of it.* [Scenario A]

In addition, in the context of commercial sharing (scenario B), the current policy does not allow for patient control over health data sharing:

> *Right now, we don’t know anything. We’re totally in the dark, and what we do know isn’t good. Basically, what we know now is if you want to be treated, then just sign all your rights away. It’s either that or don’t get treated, and that’s not really an option. Again, it’s not a choice.* [Scenario B]

> *No changes because Florence isn’t being given a choice about what her options are. She’s not even being informed of what her options are.* [Scenario B]

Hopes and Concerns: Individual and Societal Perspectives

Overview

Rationales for the need for a change from the status quo drew on participants' concerns about the effects of the existing system on individuals and the larger society and hopes for a better approach. When considering both individual and societal levels, people were hopeful that information sharing would contribute to better cancer treatment and continuity of care; however, at the same time, they were concerned that sharing of data could lead to the denial of insurance coverage. Discussions also reflected individuals' discomfort with not knowing about health information sharing (including how, with whom, and for what purpose it is shared) and with a general lack of control over how information is shared and used. The participants described several of such issues (eg, denial of insurance coverage and privacy and security), expressing concerns for themselves and others in the society. Other societal concerns were rising health care costs, discrimination and stigma and social injustice, public trust, and security. Simultaneously, the participants valued altruism and stressed on the importance of sharing information in the interest of benefiting all.

Individual Perspectives

The participants discussed personal reasons why they would support or have concerns about health data sharing in general. They perceived many benefits of sharing health data across networks, including the likelihood of personal benefit from cancer treatment because of previous health data sharing:

> *It may help me the next time, if I get [cancer] again.* [Scenario A]

They also saw value in improved communication among health systems facilitated by information sharing. For instance, one of the participants conveyed this as follows:

> *I guess the biggest benefit would be that it improves communication between healthcare systems...You don't have to go to this doctor to get your MRI results and take them to this [other] doctor.* [Scenario A]

However, the participants were concerned about the personal risks associated with health data sharing, including potential discriminatory practices (eg, denial of health or life insurance) and the risk of private information being leaked to outside entities:

> *The main fear I have, and I don't know if it's real, but is an insurance company at some point getting my record and seeing I have a pre-existing condition and denying insurance to me. And I'd like to know other downsides besides that because when I think about the downside, that's what always comes up for me.* [Scenario A]

The preference for options that notified patients about data sharing (email or text [Scenario A], portal [Scenarios A and B], and plain language signs [Scenario A]) was often stated by the participants in the context of a desire to know that their health information is being shared:

> *I would want the [email or text] notifications. It's a high priority in terms of being advised if my information is distributed.* [Scenario A]
>
> *I chose disclosure [via patient portal] as my number one because I feel like I should have the option of knowing where my tissue is going and how it's being used.* [Scenario B]
>
> *Simply because it's [signs are] easy to read if it's short and is in language that I understand and not in the medical terms...* [Scenario A]

However, there was also concern about a lack of detail in the plain language policy option, which involves putting signs in clinics and visible spaces about data use. For example, one of the participants conveyed this as follows:

> *While I like the idea of plain language and brevity, I also think it's just too short. There's just not...I mean it's just... Boom. All of a sudden it's like, "Well, you can get more information," and I think it's too plain and too easy and doesn't really...In my opinion, it doesn't protect my privacy and make me aware of my rights as a patient and as a consumer.* [Scenario A]

The participants described valuing control and rights over where their information goes, the nature of it, under what circumstances it is shared, and the implications of this sharing of data. They expressed emotions ranging from annoyance to anxiety and fear related to the life cycle of their data, which was seemingly out of their control. However, some were concerned that their preferences may ultimately not matter because their information was already "out there":

> *In other words, the playing field as far as insurance, as far as healthcare is concerned doesn't seem to be level at all. The people that's making the rules don't have to abide by the rules. So consequently, we're caught between a rock and a hard place. So, whatever is going to happen to my medical records, it doesn't do me any good to worry about it because it's...already a done deal...* [Scenario A]

For others, the issue of identifiability was a meaningful concern, as they raised the question of how health information is shared (eg, deidentified vs identified) and what it would be used for (eg, research and care vs profit and commercialization). Some participants were concerned that deidentified data are not always truly deidentified. For example, one of the participants expressed the following:

> *Yeah, like if they found out there's a 54-year-old guy in [hometown] with cancer on his neck...I mean, people would know it's me.* [Scenario A]

However, other participants were comfortable with data sharing as long as the information was deidentified:

> *Yeah, I kind of see both sides. It's like pharmaceutical. With some information, they can develop better treatments, better drugs, but at the same time they would have your...As long as things are de-identified, I don't have a problem with sharing with whoever you want.* [Scenario A]

When discussing the potential for the commercialization of health information (scenario B), one of the most salient risks that the participants perceived was the lack of awareness of whether and with whom their information was being shared as well as the lack of control over its uses:

> *I think that it's part of you or it was part of you, and you may not have any control over where it goes, but you should at least have the knowledge of where it's going.* [Scenario B]

They were also troubled by the notion that commercial companies could be using their personal health information for profit with little obligation to the patient. Despite this, the participants were somewhat skeptical about the possibility of the system compensating them for their data through payment. Although our policy option proposed a US $10 payment, the participants wondered how to identify an appropriate valuation of their health data:

> *[I] for example, would want to use every opportunity to make that $10, but the next person would say, "I don't need $10, even if it's $100."* [Scenario B]

Some participants worried that accepting payment for health data could be likened to "selling" themselves and presented a risk of compromising on privacy in the logistical aspect of actually receiving the payments; however, others felt that compensation to patients or data contributors might actually motivate companies to act more responsibly.

Societal Perspectives

Because of their personal experience with cancer, the participants were highly attuned to the role of the data life cycle in the development of treatments, advancement of research, and quality improvement. They described health data sharing as having the potential to help many other patients like them and were altruistic in their intentions, that is, they were willing to allow their health data to be used with nothing in return in hopes that it would be used to benefit others:

> *If that's going to help somebody, then to me it's somewhat worth it, regardless of who ends up with my records. But do I like it just being all willy nilly out there? No, I don't, but I'm not going to lose sleep over the fact that it is. So, I think somewhere down the line, somebody is benefiting from it. Somebody is going to benefit from it, and that makes it somewhat more palatable for me.* [Scenario A]
>
> *My moral compass in all of that as "do something with it. Do something good. [Cancer] was a horrible thing. You got rid of it. So, make something good out of something bad."* [Scenario B]

In fact, when discussing the possibility of the commercialization of health data, the participants valued the impact this approach could have on expanding treatment options to help patients like themselves. However, they did not trust that advancing research would be the extent of the data life cycle and thus saw many risks to society. One of the most common concerns was that insurance rates could increase because of greater access to information on individual health risks. They also described concerns about the risk of identity theft and discrimination, reflecting a broader societal perspective:

> *...it always used to be taxes and death were the two things you could...you know, you had to deal with and just couldn't do anything about...so why bother fighting it. But it sounds like our health information is also now one of those things being free to everyone and anyone. To some extent, it's a third now thing that you don't have any control over. ...I guess what's important is that there be teeth in people using it for reasons that end up being discriminatory. I'm more worried of that than anything else.* [Scenario A]

Beyond the issues of identifiability and privacy, the participants were concerned about the lack of transparency around procedures and the oversight and perceived lack of governance around the health data life cycle in general and for commercial purposes. These concerns were reflected in their policy preferences as well. For example, one of the participants described their concerns in this regard as follows:

> *I think [plain language] is not much better than [no change] because, once again, they're telling you they're sharing. You don't know where it's going. You have no control over where it goes. I think [notification] and [disclosure] give you the most knowledge about where your health information is being shared and gives you recourse if you don't want it being shared with specific things...like [another participant's] concern about insurance companies, and then once people are aware of where it's going, then, yes, we can contact Congress and put pressure on them to enact laws that will give people more control over where their information goes.* [Scenario A]

However, the participants lacked the belief that commercial entities would be trustworthy in their use and sharing of health data, much less in reporting their uses of health data. The participants were especially struck by an expert presentation on the ethical implications of health data sharing and commented about their fear emerging from the historical misuse of health data, such as that experienced by the Havasupai Tribe in Arizona [27]:

> *I was frightened though when I saw that example of the Indian tribe that was...You know, their information was taken from them. The idea was sold to them that it would benefit A, and somebody used it for B, C, and D in a detrimental way. Maybe it's helpful that they found the schizophrenic gene, but certain things do have a stigma to them. When you're talking about a small group, an intimate group of a society, that could have a lot bigger effect than if they had said it to me.* [Scenario A]

How health information was used was of particular concern. Although some saw its use for advancing research and improving care as a primary benefit to the society, others were concerned about its potential misuse for profit:

> *I didn't realize that tissue samples and vital information were being sold from company to company just for certain people to make money. The money should be rolled into real research that helps more people. ...I'd just like to see a system that had some dignity and respect for everybody in it, period, you know? We have certainly a checkered history of people being disrespected. If we could just learn from what has happened and try to remember...What's shameful is to find out that even today dirty stuff is happening and people think they can cut corners and not notify and not respect and get away with it, and that hurts.* [Scenario B]

The potential for social injustices, ranging from discriminatory practices based on social identities and stigmatization of entire communities to the denial of individual health or life insurance, was salient in the participants' conversations. Notably, this was not a consideration presented to the participants at the beginning of the session; they arrived at this concern on their own. They also wondered about the fairness of certain policies; for instance, they worried that older individuals with discomfort in using technology or individuals in areas without reliable internet access would not be able to engage in the email, text, or portal policy option. They also worried about the consequences and risks of injustices for others, including their biological relatives. For instance, one of the participants expressed her fear as follows:

> *One concern that I have is that, I had cancer at a young age, breast cancer, and so the implications for my girls is really...is really high, and I feel the ethical decision, "Do I find out more information for their sake," or "do I protect them in a sense by not having the information and allowing them to choose when they want the information?"...I think that's been my dilemma over the last...over the 15 years since I had cancer. Do I want to put the burden on them of knowing that they carry the gene? That is something that is going to be weighing on their shoulder every day. I know how it has affected one thing for me, getting life insurance. I can't even get life insurance. Every time I try to get life insurance, it's like, "How long have you had cancer? How long have you been cancer-free?"...You know, all this information that's being shared is...It kind of scares me. It scares me for, their future.* [Scenario A]

The participants weighed these different values and individual and societal risks and benefits as they considered different policy options and compared their merits and challenges.

Specific Policies: Notification via Plain Language or Text or Disclosure via Patient Portal

Overview

In scenario A, the participants considered 3 different types of mechanisms for notifying patients about information sharing: posting signs in plain language in clinics and hospitals, sending SMS text or email messages to patients, and using a patient portal to notify patients about information sharing. In scenario B, which dealt with the sharing of information with commercial companies, email or text and patient portal options continued to be part of the deliberation. In both scenarios, 3 themes emerged as key considerations for the participants: the transparency and awareness of information sharing, convenience associated with each policy option, and accessibility of the policies.

Transparency and Awareness

In small-group discussions about their policy preferences, the participants primarily focused on the transparency issues in the system and their consequent lack or minimal awareness of data sharing practices when discussing the pros and cons of different policy options. The participants wanted policies to make patients aware of health data sharing, to make patients better understand health data sharing, and for organizations to be more open and provide details about health data sharing:

> *Okay, so [plain language] would have to be part of the package because this gobbily gook that we sign when we're lying there in the emergency room ain't no help, and it's not telling you anything.* [Scenario A]
>
> *I chose the patient notification because I agree with having the information shared, and I just do want to know when it is shared with anyone else.* [Scenario A]
>
> *One of the reasons I chose the portal is because I could log into my chart and see all the information, and to me that's very comparable to getting a free copy of my credit report every year.* [Scenario A]

Convenience

The participants were also asked whether the policy options were convenient or placed a burden on patients. They discussed issues regarding patient comfort, familiarity, ease of navigation, and simplicity and concerns about overloading patients leading to frustration and annoyance:

> *I guess it would be much easier just to get it on your phone versus a text message versus having to go into the file through the portal.* [Scenario A]
>
> *I guess it's sort of like the portal answer on the other is to receive the information if they want it, but, you know, not get overloaded.* [Scenario B]

Accessibility

Finally, the participants considered accessibility issues. They discussed whether policies were inclusive and expressed concerns about individual- and community-level gaps in access:

> *I'm liking the plain language more and more because the generations above me have the least amount of access to the Internet, and they're the ones that need the information the most.* [Scenario A]
>
> *I see it a text notification as an issue with the amount of senior citizens. ...the difficulty in people seeing the text messages or understanding it, and the inability to see the keyboard.* [Scenario A]
>
> *Everyone has access to the portal. There are public libraries where you can use the computer. Nobody is*

> *excluded from it, even if they don't own a device.* [Scenario A]

Specific Policies: Opt Out of Data Sharing With Commercial Companies

The introduction of the opt out policy option had the participants more explicitly reflecting on individual and societal trade-offs, weighing individual control and ownership versus the societal benefits of research progress. When discussing the "opt out" option, the participants appreciated the autonomy granted by the policy option but expressed concerns about losing the opportunity to advance research and benefit society:

> *My gut tells me that everybody should have the right to opt out. My brain tells me that if we have that option, it is going to too much limit benefits to everybody.* [Scenario B]

> *I think there's more of a personal benefit, you controlling your own stuff, but there's more of a social risk, you know? The bigger society is affected. So it's hard. You know, who's more important? You to yourself or the greater good? Now that's going to be totally...Everyone is going to have their own opinion on that one.* [Scenario B]

Specific Policies: Payment

The payment policy option, which ranked low overall, had the participants weighing the benefits of getting paid or profit sharing in a commercial context versus a host of concerns around commercialization, such as the lack of feasibility, loss of privacy, and "ick" factor of buying and selling health data. The participants had mixed views and concerns regarding payment:

> *I do like the payment to the patient because while that could reduce bad usage, probably not. It also sort of puts a price on you, and I don't like...And that feels icky.* [Scenario B]

> *When patients seek compensation, they think, Well, it's about time. All these other companies are making beaucoup bucks. Why can't I? But, like I said, if you get on...You know, you're sharing your information with 3,000 companies, you know, nobody can keep track of, you know, where your information is going and, you know, when you get payment for something.* [Scenario B]

Modifications

Across both scenarios, the participants suggested several modifications and suggestions to build on the policies presented. Among these, the main suggestions included the following: (1) combining the policies to increase accessibility and awareness; (2) greater emphasis on patient education on data sharing; and (3) greater control over data sharing, including the ability to opt in or out of specific types of data sharing:

> *Why couldn't we do more than one option? ...I just think you cover your bases that way, of people who don't have technology and people who do have technology. That way, it covers more of the society in general, and that way...Especially as far as notifications of portal or push, that could be an opt-in/opt-out to either way via the portal. You know, say I want a push or just put it on my portal type of thing.* [Scenario A]

> *To me, it's all about education. Doing all of this, but it's educating the public to know how and what they can access. So, again, that's my focus is education.* [Scenario B]

Discussion

In this study, we report findings from 2 public deliberation sessions conducted with patients with cancer to learn about their policy preferences related to health information sharing in general and for commercial purposes. The participants weighed complex information and identified trade-offs between individual- and societal-level issues in the process of reaching a prioritized set of preferences for policies that could govern clinical health information sharing [17,20].

Perceived Risks and Benefits of Health Information Sharing

The participants expressed a range of concerns and benefits associated with health information sharing for precision health, from individual- to family- to community-level issues. For example, they had concerns related to privacy and to employment and health insurance discrimination. Our findings are consistent with concerns found in previous studies that suggest that the perceived risks of sharing health information extend beyond threats to privacy [28]. For example, when considering the potential for data sharing, including with commercial companies, the participants were frustrated that the commercialization of health data emphasized the lack of patient ownership and that companies could make money from something as personal and private as health information. These concerns about the commercialization of health data echo issues raised in multiple studies, wherein the participants expressed a willingness to share data for "public benefit" but lacked clarity about how commercial uses of data—likely for profit—could also benefit the public [29]. Moreover, they worried about potential repercussions, such as identity theft or collective harm to communities, given the far-reaching movement of health data beyond the context of their provider. Although most people may not be directly harmed because of a privacy breach, it is emblematic of the kinds of concerns voiced in the deliberations.

The patients also perceived benefits to health data sharing; in particular, they attributed their cancer treatment to the exchange of information about previous patients with cancer. They recognized that sharing their own information has the potential to benefit others, and the discussions reflected high levels of altruism, wherein many participants expressed a willingness to sacrifice the privacy of their health information if it meant that others could benefit in the future [30]. These findings are consistent with previous studies demonstrating the perceived benefits of health data sharing, including supporting knowledge about diseases, advancing science, and helping patients learn more about their health conditions [31]. Even in the context of commercialization, the participants acknowledged that scaling treatments could be beneficial to other patients.

Policy Preferences and Implications

The participants agreed that the status quo of tacit notification about the extent to which health data are shared beyond the immediate context of their clinical encounters is insufficient and expressed, nearly unanimously, a preference that the health care system modify this practice. The desire for greater transparency and information about health data sharing was grounded in their personal and societal concerns and expectations for the health care system and is consistent with previous studies finding that individuals value transparency about the data sharing process and subsequent uses of data [32,33]. Discussions of the status quo made it clear that the patients felt that the current practices do not honor the core bioethical foundations of patient autonomy or respect for persons.

Alternative forms of notification, including via an SMS text or email message or disclosure via a patient portal, were the most supported policy options. Disclosure through the portal was agreed upon as the most preferred policy for informing patients about health information sharing because it has the potential to enable patients to see where their health information has gone and for what purpose it is being used, in a place and time of their choice. However, the participants noted limitations of this type of policy related to accessibility, with the identified barriers similar to those to notification via SMS text messages. In particular, the use of the patient portal requires patient comfort with technology and internet access, and it requires being notified that there is new information in the portal. SMS text messages may be slightly more accessible but may not go far enough; in other words, the participants expressed a preference for not only being notified but also being able to actually view information about the health data sharing process. These digital disparities have been discussed in previous literature; here, we found that digital disparities not only might prevent access to care but, when compounded with disparities in health literacy, also present a barrier to understanding where one's health information is going and for what purpose it is being used [34-36]. Although notification and disclosure may be promising policy approaches, more work is required to understand the impact of such approaches on disparities and to identify alternatives to ensure equitable access to information on health data sharing practices. Indeed, such policies could be highly effective in increasing transparency, yet they may not fully address some of the issues raised related to commercialization. Notably, our participants were concerned about the equity implications of any policy aimed at increasing transparency about health information sharing.

Support for a proposed scheme to pay patients for the broad use of their data was mixed, and we identified several key nuances around payment that make it potentially complicated. For instance, a previous study found that the median consumer is willing to pay US $5 per month to maintain data privacy but expects US $80 to allow access to personal health information [24]. Here, we focused on the latter option of payment to allow access to health information. Some participants in our study viewed payment as a positive way to affirm the value of the contributions made by patients, whereas others were put off by the prospect of being "bought off." Robust discussions around the appropriate monetary value of a single instance of data use (is US $10 sufficient?) were inconclusive but illustrated the challenge of devising a policy that would be accepted as fair without being coercive. In addition, some participants raised the concern that offering compensation would only create more confusion around who owns individual patient information and to what extent patients might retain any rights after such a transaction. The story of Henrietta Lacks was invoked by a number of participants in these exchanges around compensation, and some participants suggested that instead of paying individuals, companies that benefit from information sharing in a commercial manner could be encouraged or required to support patients at a collective level (eg, through donations to patient support networks or patient advocacy organizations) [37]. This would respond to the ways in which the sharing and use of health data may harm (or benefit) individuals but often impact groups or communities and the society as a whole. Furthermore, certain groups may be unfairly or inequitably solicited for their data or may feel coerced into sharing data for income at the risk of later harm [38]. Instead, considering data as a collective resource could inform the development of policies that govern data use in a way that ensures collective benefits and harm reduction [39]. Findings from our study are consistent with other studies that have shown patients' concerns about the privacy of their information [11,28], need for understanding the motives of commercial companies, and desire for policies and procedures that enhance transparency about the purposes, risks, and benefits of data sharing and use [40,41].

Given the strong reactions of our participants to the status quo and their general prior lack of awareness of the extent to which health information sharing pervades precision medicine, it may be tempting to counter the various concerns patients that have about health data sharing with a major information campaign focused on transparency, either at the point of care or through other means. However, as sociologist Gil Eyal [42] cautions, "a transparency blitz coming after a long period of being relatively opaque does not inspire trust. The provision of information as part of routine interactions, responding with openness when the trusting party wants to know more, does inspire trust." On a broad level, our study suggests a need for the reorientation of practice in precision medicine toward increased disclosure and transparency around information sharing practices. Introducing the idea of health data sharing arrangements in a patient encounter, in the office waiting room, or more proactively through a patient portal or notification system could help minimize the uncanny experience of learning ex post facto how far patient data travel.

Limitations

This study has some limitations. First, this analysis focuses on the perspectives and priorities of patients with cancer, which may not represent the needs or preferences of the general patient population or the perspectives of patients with other specific conditions. Although this narrow scope is important for understanding one of the most active types of precision medicine, future work will need to expand to broader patient populations to ensure that policies and regulations are responsive to their concerns as well. Second, although the diversity of the participants in this study was appropriate for the geographic setting of the study, future research should account for variations in diversity in other regions. Larger, population-based studies will be critical to testing our findings in a sample that represents greater diversity in background characteristics, health conditions, and experiences. In addition, findings from this study are within the context of the US health care system; concerns raised by the participants (eg, those related to implications for insurance) may be different in other health care systems. Research in different health systems may reveal different themes and policy preferences.

Findings from our study suggest that the current approach is not working; therefore, policies that inform patients of the accessibility and use of their health information must be developed. However, the policies discussed in this study are only a first step. Beyond awareness and notification are questions of ethical data use and governance. Future policies will need to be explicit about the conditions under which and by whom health information can be used.

Conclusions

The expansion of precision medicine challenges our current frameworks for ensuring patient autonomy and respect. Creating regulations and policies that respond to public preferences is critical to ensuring that precision health initiatives honor these core bioethical principles. Transparency through patient access to information about data sharing and notification may facilitate patient engagement, whereas commercialization without patient notification may threaten the trust in health care systems. Patients are concerned about personal benefits and risks as well as benefits and risks to the society in general and will likely support systems that can demonstrate a thoughtful balance between individual- and societal-level concerns. At the same time, ensuring the responsiveness of regulations for data sharing in precision medicine requires continued solicitation of patient perspectives, desires, and concerns.

Acknowledgments

The authors are grateful for the support from the National Cancer Institute (5R01CA21482904; SK and JP), the National Institute of Biomedical Imaging and Bioengineering (1R01EB030492-01; JP), and Clinical and Translational Science Awards grant #: UL1TR002240. They also thank the community partners for their support in recruiting participants and the deliberation facilitators.

Data Availability

Data from this study are available upon request to the authors.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Codebook.
[DOCX File , 22 KB - cancer_v9i1e39631_app1.docx]

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Edited by A Mavragani; submitted 16.05.22; peer-reviewed by JM Ferran, C Marten, J Bell; comments to author 25.11.22; revised version received 20.12.22; accepted 21.12.22; published 31.01.23.

Please cite as:
Raj M, Ryan K, Amara PS, Nong P, Calhoun K, Trinidad MG, Thiel D, Spector-Bagdady K, De Vries R, Kardia S, Platt J
Policy Preferences Regarding Health Data Sharing Among Patients With Cancer: Public Deliberations
JMIR Cancer 2023;9:e39631
URL: https://cancer.jmir.org/2023/1/e39631
doi:10.2196/39631
PMID:36719719

Original Paper

A Digital Solution for an Advanced Breast Tumor Board: Pilot Application Cocreation and Implementation Study

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Abstract

Background: Cancer treatment is constantly evolving toward a more personalized approach based on clinical features, imaging, and genomic pathology information. To ensure the best care for patients, multidisciplinary teams (MDTs) meet regularly to review cases. Notwithstanding, the conduction of MDT meetings is challenged by medical time restrictions, the unavailability of critical MDT members, and the additional administrative work required. These issues may result in members missing information during MDT meetings and postponed treatment. To explore and facilitate improved approaches for MDT meetings in France, using advanced breast cancers (ABCs) as a model, Centre Léon Bérard (CLB) and ROCHE Diagnostics cocreated an MDT application prototype based on structured data.

Objective: In this paper, we want to describe how an application prototype was implemented for ABC MDT meetings at CLB to support clinical decisions.

Methods: Prior to the initiation of cocreation activities, an organizational audit of ABC MDT meetings identified the following four key phases for the MDT: the instigation, preparation, execution, and follow-up phases. For each phase, challenges and opportunities were identified that informed the new cocreation activities. The MDT application prototype became software that integrated structured data from medical files for the visualization of the neoplastic history of a patient. The digital solution was assessed via a before-and-after audit and a survey questionnaire that was administered to health care professionals involved in the MDT.

Results: The ABC MDT meeting audit was carried out during 3 MDT meetings, including 70 discussions of clinical cases before and 58 such discussions after the implementation of the MDT application prototype. We identified 33 pain points related to the preparation, execution, and follow-up phases. No issues were identified related to the instigation phase. Difficulties were grouped as follows: process challenges (n=18), technological limitations (n=9), and the lack of available resources (n=6). The preparation of MDT meetings was the phase in which the most issues (n=16) were seen. A repeat audit, which was undertaken after the implementation of the MDT application, demonstrated that (1) the discussion times per case remained comparable (2 min and 22 s vs 2 min and 14 s), (2) the capture of MDT decisions improved (all cases included a therapeutic proposal), (3) there was no postponement of treatment decisions, and (4) the mean confidence of medical oncologists in decision-making increased.

Conclusions: The introduction of the MDT application prototype at CLB to support the ABC MDT seemed to improve the quality of and confidence in clinical decisions. The integration of an MDT application with the local electronic medical record and the utilization of structured data conforming to international terminologies could enable a national network of MDTs to support sustained improvements to patient care.

(JMIR Cancer 2023;9:e39072) doi:10.2196/39072

KEYWORDS

digital health; multidisciplinary meeting; advanced breast cancer; cancer; breast cancer; tumor; clinician; confidence; treatment; pathology; genomic; care; patient; software; data; neoplastic; pain; follow-up; electronic medical records; records

Introduction

Cancer care has been improved by many new therapeutic approaches in the last decade, with the emergence of immune checkpoint blockade treatment and new targeted therapies [1-4]. The wide spread of new treatments can be seen for advanced breast cancer (ABC), with the use of cyclin-dependent kinase 4 and 6 inhibitors in hormone receptor–positive ABC [5-7] and the development of many new drugs that target human epidermal growth factor receptor 2 (HER2) [8,9], resulting in an update to the classification of HER2-positive ABC [10]. These new approaches are implemented in clinical routines, and to ensure that all patients receive timely care, multidisciplinary team (MDT) meetings have been introduced in Europe, the United States of America, and most high-income countries [11-14]. Since the French law of March 4, 2002, the MDT approach in oncology has been structured with quality point requirements. MDT work is generally associated with better adherence to updated clinical guidelines [15], and to conduct such work, a detailed medical history of all presented patients should be highlighted to make the best clinical decision. However, the conduction of MDT meetings can be challenged by time restrictions, the unavailability of all members, and increased administrative work [16,17]. The development and uses of new applications have already been tested for daily health decisions [18-21].

In order to better facilitate patient case review during MDT meetings, ROCHE Diagnostics and Centre Léon Bérard (CLB) coimagined a new MDT application prototype. This digital application was tested during ABC MDT meetings, beginning in January 2021. In this paper, we discuss how this application was implemented within ABC MDT meetings at CLB and how the MDT application prototype supported clinical decisions based on accurate clinical histories.

Methods

Usual MDT Meeting Organization for ABC

MDT meetings are mandatory for all patients with cancer in France. ABC MDT meetings were selected as a model for evaluation and cocreation activities. The following four distinct phases were identified: (1) the instigation phase, (2) the preparation phase, (3) the execution phase, and (4) the follow-up phase.

In the first phase, a medical oncologist informs the medical assistant office that an MDT discussion is needed for a patient, who is then registered on UltraGenda (UltraGenda; instigation phase). UltraGenda is a medical appointment scheduling software used at CLB [22]. Based on time availability, the patient's medical history is ideally prepared by medical oncologists or residents (preparation phase). The completion of this task may facilitate an MDT decision. In the execution phase of the MDT meeting, based on the UltraGenda list, each patient is discussed. Medical histories are shared by the medical oncologist in charge of the patients, and data are exposed thanks to the electronic medical record (EMR). MDT advice is audio-recorded. After the MDT meeting (follow-up phase), the medical assistant transcribes the medical advice based on the recording, and a report is added to the EMR after a final medical validation.

Cocreation of the MDT Application

Version 1 of the MDT application was prototyped based on the challenges and needs identified during the ABC MDT audit. Subsequently, version 1 of the MDT application was used routinely for 2 months during the weekly ABC MDT meetings. After each MDT meeting, a debriefing session was held by the medical team and application development team to refine the prototype based on continuous user evaluations. After the initial 2 months, the cybersecurity for version 1 of the MDT application was evaluated before implementing version 2 of the MDT application for an ongoing routine use test.

The application was developed by an external company, in collaboration with medical oncologists of a French comprehensive cancer center.

The MDT Application Prototype

The MDT application prototype serves as a platform that optimizes the presentation of patient cases for the purposes of MDT discussion and decision-making. The application allows for the importing and exporting of structured data based on the local EMR, imaging, and genomic pathology information. The data within the MDT application conforms to international terminologies.

Two factors—authentication and a personal Répertoire Partagé des Professionnels de Santé (RPPS) number (shared directory of health care professionals)—are needed to access MDT application.

Practical Methods of the Audit and User Feedback Assessment

An audit was carried out prospectively before and after the implementation of version 2 of the digital solution. The cases discussed before and after using the application prototype consisted of ABC cases only and had the same complexity level. The items assessed precisely were the total duration of an MDT meeting, the estimated time lost searching for information in the EMR, the average discussion time per patient, the percentage of clinical cases that were postponed due to a lack of information, the percentage of clinical cases that were registered but already discussed previously, the percentage of clinical cases that were registered but postponed due to a lack of time, the percentage of files processed, and the number of clinical cases that were discussed but not recorded. Based on this audit, a detailed assessment was carried out in order to determine in which phases of the process pain points were identified (the instigation, preparation, execution, or post–tumor board phase) and determine the types of pain points (those linked to problems related to the organization of the process, those linked to the technological limits of the tools used, or those linked to a lack of human resources). Similarly, a before-and-after survey was used to assess the user experience among the health care professionals involved in the ABC MDT. A questionnaire was sent to 15 health care professionals involved in the ABC MDT. The items assessed precisely were the level of satisfaction, the level of confidence in decision-making, and an open question on what would have driven any level change.

Ethics Approval

This study was approved in October 2019 by the local data protection officer, on behalf of French regulatory authorities (Commission Nationale de l’Informatique et des Liberte´s), in accordance with the MR004 methodology (reference number: H001 – 002). This study adhered to the European laws for the protection of personal data (General Data Protection Regulation). All patients were informed of the possibility of their health data being used for research purposes, and none expressed an opposition to this possibility.

The implementation of the MDT application in the ABC MDT meetings did not result in changes to the rules for the application’s use; at least three different medical specialists are required to discuss each case and share the conclusions of the MDT, and a personal RPPS number must be used to access the application. The MDT application was implemented in accordance with current regulations.

Results

The Pain Points and Needs Identified for the ABC MDT

An audit was carried out prospectively before the implementation of version 2 of the digital solution during 3 MDT meetings, including 70 clinical case discussions. The first audit of the original ABC MDT approach identified 33 discrete pain points related to the preparation (n=16), execution (n=11), and post–tumor board (n=6) phases. No issues were identified related to the instigation phase; however, for the other three phases (the preparation, execution, and post-MDT meeting phases), multiple difficulties were identified and subsequently classified as process, technology, or resource issues. In the preparation phase, 8 difficulties were identified with processes (eg, the lack of a systematic approach to informing the medical question and the overbooking of cases with a lack of transparency on time available), 5 pain points were related to technology, and 3 pain points concerned resources. In the execution phase, 6 pain points were related to processes, 3 were related to technology, and 2 were related to resources. In the follow-up phase, there were 4 pain points related to processes, 1 was related to technology, and 1 was related to resources (Table 1).

Table 1. Pain point distribution by tumor board phase.

Pain point type	Instigation phase	Preparation phase	Execution phase	Follow-up phase	Total, N
Process, n	0	8	6	4	18
Resources, n	0	3	2	1	6
Technology, n	0	5	3	1	9
All pain points, N	0	16	11	6	33

New Approach for Tumor Boards Involving a Cocreated MDT Application

Instigation Phase

No issues were identified for this phase. The process for this phase remained the same; a medical doctor informs the medical assistant office of the need for a patient to be registered on UltraGenda for discussion at an upcoming MDT meeting.

Preparation Phase

In the preparation phase, a nurse navigator uses structured data from the MDT application to systematically prepare a patient case.

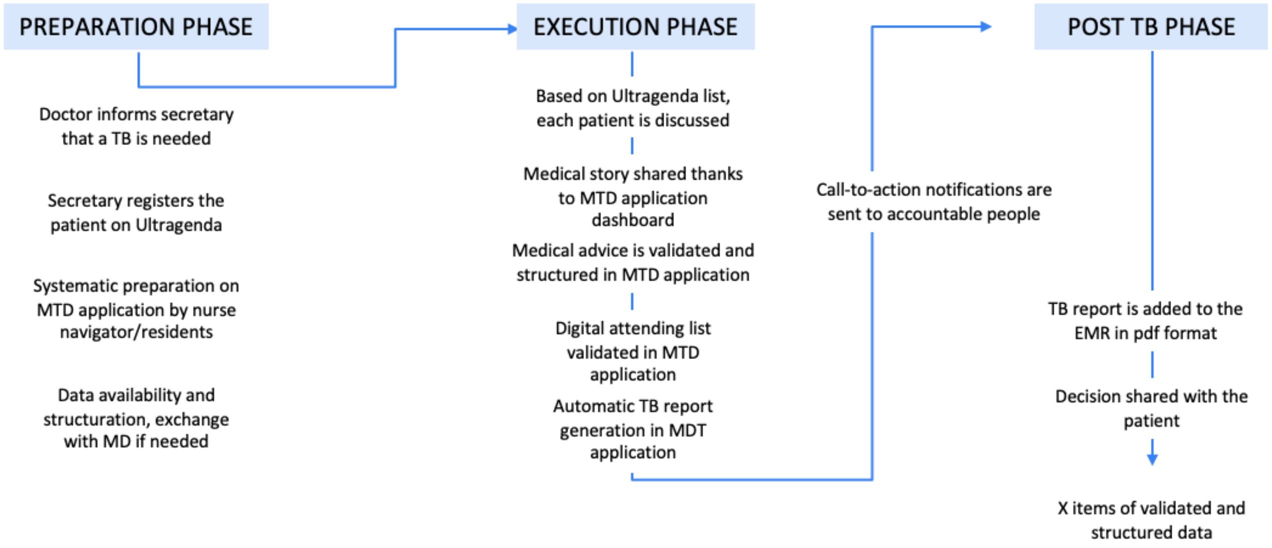
Execution Phase

In the execution phase, patients are discussed by the MDT based on lists generated by UltraGenda. The MDT application presents a single-slide timeline visualization of the medical history, patient characteristics, and previous treatments, superseding the use of the EMR for case presentation. The documentation of case decisions is now captured, structured, and validated within the MDT application, through which an autogenerated MDT report is created as a permanent record. This replaces the use of audio-recorded case decisions.

Post–Tumor Board Phase

An autogenerated MDT report in PDF format is added to the EMR at the conclusion of the meetings. Subsequently, call-to-action notifications are sent to accountable individuals. Patient data remain in the MDT application in a structured format for potential use in future meetings and for audit and reporting purposes. An overview of the new process is shown in Figure 1.

Figure 1. Diagram of the new process for MDT meeting organization via the MDT application. EMR: electronic medical record; MD: medical doctor; MDT: multidisciplinary team; TB: tumor board.



Improvements Made by the ABC MDT After the Implementation of the New Process Involving the MDT Application

A second audit was carried out prospectively after the implementation of version 2 of the digital solution during 3 MDT meetings, including 58 clinical cases.

After the implementation of the MTD application, the time dedicated to patient case discussion slightly decreased, and the percentage of cases for which a therapeutic recommendation was made improved. The mean discussion times per patient were comparable (legacy approach: 2 min and 22 s; new approach: 2 min and 14 s). The total time per meeting dedicated to case discussions fell from 53 minutes and 20 seconds to 42 minutes and 40 seconds; however, this was predominantly driven by the lower average case numbers per meeting (22.7 cases vs 16.3 cases). Most interestingly, no case postponements occurred after the introduction of the MDT application, whereas the legacy process had an average case postponement rate of 31%.

User Feedback Assessments

A before-and-after survey was used to assess user experience. The web-based questionnaire was sent to 15 health care professionals involved in the ABC MDT meetings, and of these 15, 8 (53%) responded. After the introduction of the MDT application, the mean level of satisfaction (a score out of 5) improved from 3.4 to 4. In addition, the mean confidence in decision-making (a score out of 10) improved from 5.6 to 8. The main drivers for this were the standardized presentation of cases and patient history preparation by an oncology nurse navigator or by oncology residents.

Discussion

Optimal decisions for patients with cancer have been related to MDT care [11]. Since its implementation as a regular practice, MDT meetings have shown an impact on management plans, patients, and process outcomes [14]. Nevertheless, successful MDTs require time and coordination for a specialist group of health care professionals to meet regularly, as well as additional time to prepare cases [15]. Considering the increasing number of patients and the increasing complexity of the clinical cases discussed, it appears that the average discussion time for a clinical case is around 5 minutes [23]. This proves the need for intelligent computing systems that integrate and analyze clinical data from the EMR to enable better clinical decision-making.

In CLB, the ABC MDT conducted an audit to optimize its functioning. This assessment identified 33 pains points that were used to inform the development of a new process for ABC MDT work. Difficulties concerned the process (18/33, 55%), the technology (9/33, 27%), and the lack of available resources (6/33, 18%; Table 1). Based on these observations, ROCHE Diagnostics and CLB imagined a new process for the ABC MDT meetings that would be enabled by a dedicated MDT digital application. The introduction of the MDT application into the MDT meetings improved the likelihood of reaching a decision, as this resulted in discussions only for cases where all the required information was available. Moreover, user feedback showed that participants had increased confidence in the decisions made. It is likely that this was due to the improved presentation of data on the MDT application dashboard, as it displays a single-slide timeline visualization of previous treatments, tumors, and patient characteristics, and its use replaces the time-consuming and frustrating process of searching for various key information within distributed reports that the EMR may or may not contain.

The main change enabled by the new process was the systematic preparation of patient medical histories by the oncology nurse navigator or by oncology residents in a structured format within the MDT application. Further, the automatic generation of the MDT decisions removed the need for audio recordings of decisions and additional work to manually record the conclusions.

The main limitation of our results is that the MDT application has only been tested in ABC MDT meetings, limiting its implementation for localized breast cancer boards or other metastatic histology boards. Digital solutions for MDT meetings have already been shown to significantly reduce the overall case preparation time [24]. Moreover, our study shows that an MDT application has the potential to improve MDTs' confidence in making the best decisions for patients. Further work is needed to assess whether the use of an MDT application improves the implementation of decisions and results in better clinical outcomes.

A benefit of an MDT application that collects structured clinical data and conforms to internationally accepted terminologies is its ability to generate a real-world data set, which could be used to answer additional research questions in the future [25]. Digital tools, such as ConSoRe (Continuum Soins Recherche) [26], have been developed to facilitate the collection of large amounts of data, but these tools are limited by the heterogeneity of medical reports. It is envisioned that over time, an MDT application could serve a national network for rare tumors, such as the one supported by the French National Cancer Institute (Institut National du Cancer). This network provides diagnostic expertise and aims to improve the care of patients with rare tumors by using referral MDT boards. It can also facilitate recruitment for clinical trials that are dedicated to only rare cancers and involve international efforts.

MDT meetings are important elements in the management of patients with cancer. However, the number and complexity of the clinical cases treated make organizational and technological development necessary for being able to meet medical and administrative needs. A precise evaluation of ABC MDT practices allowed for the coconstruction of an MDT application that improved the confidence of clinicians in their decisions while structuring health data.

Data Availability

The data sets generated and analyzed during this study are available from the corresponding author on reasonable request.

Conflicts of Interest

None declared.

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Abbreviations

ABC: advanced breast cancer
CLB: Centre Léon Bérard
ConSoRe: Continuum Soins Recherche
EMR: electronic medical record
HER2: human epidermal growth factor receptor 2
MDT: multidisciplinary team
RPPS: Répertoire Partagé des Professionnels de Santé

Edited by A Mavragani; submitted 27.04.22; peer-reviewed by L Guo, K Le Du; comments to author 05.01.23; revised version received 25.01.23; accepted 16.02.23; published 18.05.23.

Please cite as:
Hodroj K, Pellegrin D, Menard C, Bachelot T, Durand T, Toussaint P, Dufresne A, Mery B, Tredan O, Goulvent T, Heudel P
A Digital Solution for an Advanced Breast Tumor Board: Pilot Application Cocreation and Implementation Study
JMIR Cancer 2023;9:e39072
URL: https://cancer.jmir.org/2023/1/e39072
doi:10.2196/39072
PMID:37200077

Original Paper

Using Health-Related Social Media to Understand the Experiences of Adults With Lung Cancer in the Era of Immuno-Oncology and Targeted Therapies: Observational Study

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Abstract

Background: The treatment of non–small cell lung cancer (NSCLC) has evolved dramatically with the approval of immuno-oncology (IO) and targeted therapies (TTs). Insights on the patient experience with these therapies and their impacts are lacking. Health-related social media has been increasingly used by patients to share their disease and treatment experiences, thus representing a valuable source of real-world data to understand the patient's voice and uncover potential unmet needs.

Objective: This study aimed to describe the experiences of patients with NSCLC as reported in discussions posted on lung cancer–specific social media with respect to their disease symptoms and associated impacts.

Methods: Publicly available posts (2010-2019) were extracted from selected lung cancer– or NSCLC-specific websites. Social media users (patients and caregivers posting on these websites) were stratified by metastatic- and adjuvant-eligible subgroups and treatment received using natural language processing (NLP) and machine learning methods. Automated identification of symptoms was conducted using NLP. Qualitative data analysis (QDA) was conducted on random samples of posts mentioning pain-related, fatigue-related, respiratory-related, or infection-related symptoms to capture the patient experience with these and associated impacts.

Results: Overall, 1724 users (50,390 posts) and 574 users (4531 posts) were included in the metastatic group and adjuvant group, respectively. Among users in the metastatic group, pain, discomfort, and fatigue were the most commonly mentioned symptoms (49.7% and 39.6%, respectively), and in the QDA (258 posts from 134 users), the most frequent impacts related to physical impairments, sleep, and eating habits. Among users in the adjuvant group, pain, discomfort, and respiratory symptoms were the most commonly mentioned (44.8% and 23.9%, respectively), and impacts identified in the QDA (154 posts from 92 users) were mostly related to physical functioning.

Conclusions: Findings from this exploratory observational analysis of social media among patients and caregivers informed the lived experience of NSCLC in the era of novel therapies, shedding light on most reported symptoms and their impacts. These findings can be used to inform future research on NSCLC treatment development and patient management.

(JMIR Cancer 2023;9:e45707) doi:10.2196/45707

KEYWORDS

non-small cell lung cancer; data science; machine learning; natural language processing; social media data; patient experience; patient preference; immunotherapy; targeted therapies; lung cancer; social media

Introduction

Background

Lung cancer is the leading cause of cancer mortality worldwide and is second in cancer incidence, with an estimated 1.8 million deaths (18.0% of total cancer deaths) and 2.2 million new cases (11.4% of total cancer cases) in 2020 [1]. In the United States, lung cancer is also the second most commonly diagnosed cancer and the leading cause of cancer deaths, and the National Cancer Institute estimates 235,760 incident cases in 2021 [2]. There are 2 distinct histopathological types of lung cancer: small cell lung cancer and non–small cell lung cancer (NSCLC); the latter accounts for approximately 84% of lung cancer cases [3].

Treatment Landscape

Treatment for NSCLC varies by stage of the disease. In general, patients with early-stage resectable NSCLC undergo surgery with or without (+/-) adjuvant therapy, while patients with advanced or metastatic NSCLC have been traditionally treated with chemotherapy [4]. However, treatment approaches have drastically shifted over the past decade, notably with the emergence of several molecular-targeted and immuno-oncology (IO) agents. Despite the progress of these improved treatments, the prognosis of NSCLC remains poor [5].

Prior Works

Previous studies that assessed patient-reported symptom burden and impacts on health-related quality of life among NSCLC populations using lung cancer–specific and generic scales have highlighted a significant unmet need with the current treatment options [6,7].

Rationale

Health-related social media (ie, lung cancer-specific forums) present a rich source of real-world evidence from the individual perspective that can inform research aiming to understand the overall patient journey through their disease, including but not limited to symptom burden, real-world treatment use, impact on quality of life, and other important issues and concerns. Social media, specifically health-related social media, has become an increasingly common resource used by patients and caregivers to share their journeys and experiences. In June 2018, the United States Food and Drug Administration published a draft guidance encouraging stakeholders to explore the use of social media when conducting studies, particularly to shed light on patients' perspectives and experiences [8,9]. Furthermore, a study comparing 4 methods for obtaining patient-reported outcomes (PROs) to capture patient experiences, including social media, found social media to uncover the most concepts and be the least resource-intensive of the 4 methods.

Goal of This Study

Using publicly available discussions in lung cancer-specific social media, this study aimed to better understand the experience of patients with NSCLC in adjuvant and advanced or metastatic (stage IIIb/IV) stages with regard to their symptoms and symptom impacts.

Methods

Overview

This was an exploratory retrospective analysis of existing publicly available discussions posted between January 2010 and November 2019 on health-related social media websites among patients with self-reported adjuvant or advanced or metastatic NSCLC or their caregivers. In this study, users of the websites were patients and their caregivers (eg, parents, children, and siblings). The decade from 2010 was chosen to reflect the period of the majority of approvals of IO and targeted therapies (TTs) for NSCLC by the Food and Drug Administration.

Selection Criteria

Inclusion Criteria

Social media users (self-identified as patients or caregivers) were included in the study if they started posting on the following lung cancer– or NSCLC-specific social media websites (subforums) between January 2010 and November 2019: MacMillan Cancer Support (lung cancer), LUNGevity Lung Cancer Support Community (NSCLC), Health Boards (lung cancer), Cancer Survivors Network (lung cancer), and Cancer Compass (lung cancer).

All lung cancer–specific social media hosted in the United States or the United Kingdom were initially screened. Generic social media websites (eg, Facebook, Google+, and Twitter) were not considered because of the added complication of filtering out irrelevant material, as were those that used languages other than English.

Exclusion Criteria

Social media users were excluded if they mentioned small cell lung cancer in their posting history or began posting on the website before 2010.

Data Management

Posts in the public domain on the included social media websites were programmatically extracted using validated algorithms in the R Statistical Programming Language (R Core Team). Upon extraction, data were deidentified by removal of identifiable personal information (name, postcode or ZIP, place names, email addresses, phone numbers, or social security numbers) and conversion of raw usernames to unique identifiers. Data were also processed to correct for misspellings, remove non–UTF-8 text, remove duplicate posts, and standardize all drug names to generic names.

Study Subgroups

Social media users who fulfilled the inclusion and exclusion criteria were assigned to a stage-specific subgroup, and within these, they were further classified by the treatment class received: (1) adjuvant, in which patients had had surgery and were subsequently treated with chemotherapy, IO, TT, or radiation therapy (RTx), and (2) advanced or metastatic, in which patients were treated with chemotherapy, IO, or TT. Tables 1 and 2 provide the definition of each treatment-specific subgroup by adjuvant and metastatic stage, respectively. Drugs within each treatment class by stage are listed in Tables S1 and S2 in Multimedia Appendix 1.

Stage-specific subgroups (adjuvant and metastatic) were mutually exclusive, while treatment class subgroups were not, since patients could report their experience with more than one treatment class within the study period, with the exception of the surgery +/- RTx-only subgroup that included those users who did not mention any chemotherapy, IO, or TT drug.

Table 1. Adjuvant subgroups definitions.

Subgroup	Definition
Adjuvant NSCLC[a] subgroup	Mention of adjuvant- or surgery-related terms and no mention of stage IIIb/IV or metastatic terms
Treated with surgery +/- RTx[b] only	No mention of treatment following surgery
Treated with chemotherapy	Mention of a chemotherapy drug indicated at the adjuvant setting following surgery or mention of unspecified "chemotherapy," and no mention of an IO[c] or TT[d] indicated at the adjuvant setting or in clinical trials following surgery
Treated with IO or TT	Mention of an IO or TT indicated at the adjuvant setting or in clinical trials following surgery

[a] NSCLC: non-small cell lung cancer.

[b] RTx: radiation therapy.

[c] IO: immuno-oncology.

[d] TT: targeted therapy.

Table 2. Metastatic subgroups definitions.

Subgroup	Definition
Metastatic NSCLC[a] subgroup	Mention of stage IIIb/IV or a metastatic term and a treatment indicated at the metastatic setting
Treated with IO[b]	Mention of a corresponding IO drug
Treated with TT[c]	Mention of a corresponding TT drug
Treated with chemotherapy	Mention of a corresponding chemotherapy drug

[a] NSCLC: non-small cell lung cancer.

[b] IO: immuno-oncology.

[c] TT: targeted therapy.

Data Analysis

Subgroup Identification

The identification of the study subgroups was driven by the data. Indeed, terms were used to subset users into their corresponding subgroups using natural language processing (NLP). Only social media posts in which social media users mentioned receiving applicable treatments or surgeries were selected. NLP algorithms were developed using the WordVectors [10] R packages to generate clusters of similar words to aid in the identification of relevant stage- and surgery-related terms (eg, "stage III," "stage IV" or "advanced stage," and "lobectomy") within the data. In addition, frequencies of n-grams (unigrams, bigrams, and trigrams) within the data were generated to aid in the identification of multiword terms used to describe relevant terms.

Machine Learning Analyses

In order to ensure that users were referring to true treatment experiences when mentioning symptoms, machine learning (ML) techniques were applied to predict whether sentences that mention a treatment of interest were referring to an actual treatment experience. The input consisted of individual sentences, as opposed to entire posts, which are quite often lengthy and involve a mix of true and untrue experiences. By using sentences, we ensured that only the true treatment experience statements were used for training the ML algorithms. Posts that were predicted to not relate to actual NSCLC treatment experiences (except for the surgery +/- RTx-only adjuvant subgroup) were removed.

Automated Symptom Identification

Automated symptom identification was conducted for all included social media users by subgroup. Posts included in the symptom identification were required to have at least one mention of any one of the treatments of interest (Tables S1 and S2 in Multimedia Appendix 1). Symptoms were captured using the Apache clinical Text Analysis Knowledge Extraction System, an NLP tool mapping concepts from the Uniform Medical Language System to clinical terms in posts, developed by the Apache Software Foundation. Custom lexicons were used to supplement clinical Text Analysis Knowledge Extraction System to capture lay terms present in social media data. The proportions of patients experiencing a symptom were calculated as the number of social media users who mentioned a symptom and a specific treatment out of all social media users who mentioned the respective treatment.

Qualitative Data Analyses

Qualitative data analysis (QDA) was conducted on samples of social media users posting histories for each subgroup. For specificity to the objectives, only posts containing a mention of one or more pain-related (metastatic subgroup only), fatigue-related, respiratory-related, or infection-related symptoms were sampled for the QDA. QDA was conducted in ATLAS.ti (version 8.4.4), developed by Thomas Muhr and Scientific Software Development GmbH. Thematic analysis principles were followed [11,12]. Codes were reviewed, synthesized, and assigned to data-driven themes, categories, and subcategories. Samples of social media users were randomly generated, and their posts were analyzed until saturation was reached.

Ethical Considerations

To date, no firm guidelines on the use of health-related social media data exist; however, this study followed available published ethics frameworks [13,14]. Only publicly accessible sources were used (ie, no login was required to access the material), and the terms and conditions were reviewed to ensure compliance. Following the University of Sheffield Ethics guidelines on the identification of subjects observed in the public setting (Research Ethics Policy Note on Principles of Consent) [14], all measures were taken to ensure anonymity and that no user-generated content was reproduced verbatim.

Data Confidentiality

Because of the nature of the data used for this study, patient consent and ethical approval were not required. All data collected in the study were kept strictly confidential and were fully anonymized (see the *Data Management* section for details). The data collected included usernames (programmatically replaced with unique anonymous IDs), message content, URLs of posts used for quality assurance, and posting dates. Any other metadata on how users interact with the website, such as location data, IP addresses, and so on, were neither collected nor stored. Personal data were removed programmatically, and no posting content was reproduced verbatim in any dissemination; all quotes used were paraphrased to ensure confidentiality. Finally, no researchers registered with any of the sources to gain access to the data, nor did any researchers post to the data sources.

Results

Study Population

A total of 14,060 social media users (153,991 posts) were identified. After applying all selection criteria, ML, and NLP, 2298 social media users (54,921 posts) remained and were assigned to adjuvant (574 users; 4531 posts) and metastatic (1724 users; 50,390 posts) subgroups (Table 3).

Table 3. Study population.

Subgroup	Users, n	Posts, n
Adjuvant NSCLC[a] subgroup[b]	574	4,531
Treated with surgery +/- RTx[a,c] only	289	755
Treated with chemotherapy	282	3754
Treated with IO[d] or TT[e]	27	579
Metastatic NSCLC subgroup[b]	1724	50,390
Treated with IO	170	16,570
Treated with TT	423	26,475
Treated with chemotherapy	1589	49,616

[a] NSCLC: non-small cell lung cancer.

[b] Staging subgroups are mutually exclusive, treatment groups within those are not, with the exception of the surgery +/- RTx only subgroup.

[c] RTx: radiation therapy.

[d] IO: immuno-oncology.

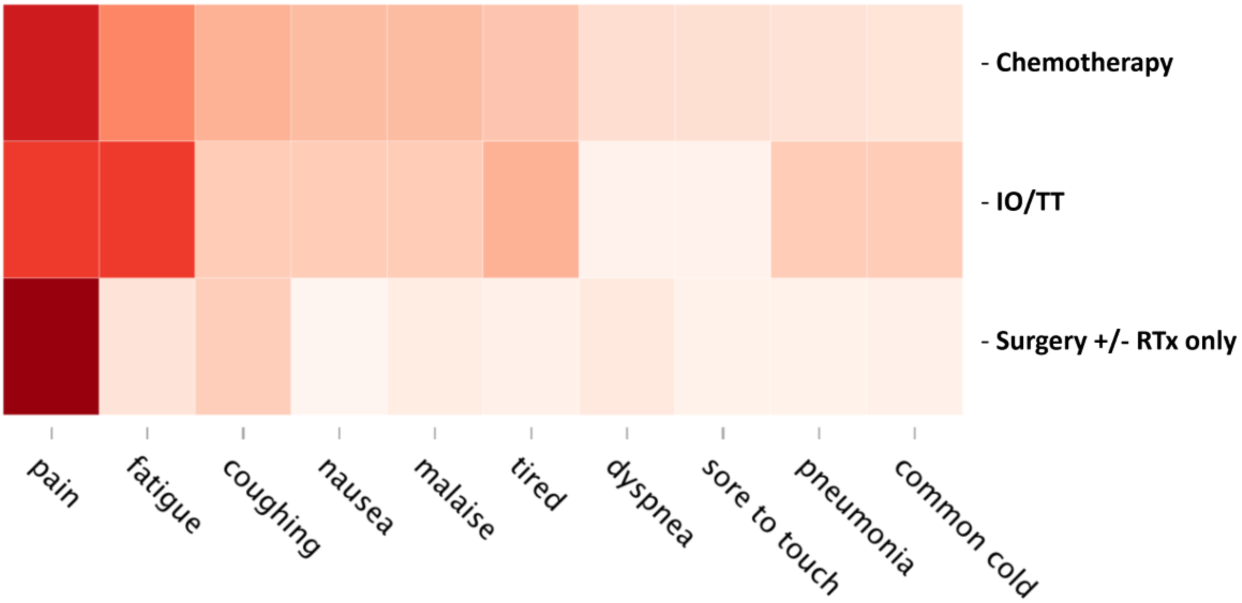
[e] TT: targeted therapy.

Adjuvant Subgroup

Automated Identification of Symptoms

The summary results of the automated symptom extraction can be found in Figure 1. Among adjuvant chemotherapy social media users, the most frequently discussed symptoms were pain (34.4%), fatigue (20.6%), and coughing (14.9%). Among adjuvant IO or TT social media users, the most frequently discussed symptoms were pain (29.6%), fatigue and tiredness (29.6% and 14.8%, respectively), and pleural diseases (14.8%). Among surgery +/- RT-only social media users, the most frequently mentioned symptoms were pain (40.2%), coughing (10.9%), and fatigue (7.1%).

Figure 1. The 10 most frequently mentioned symptoms by patients with adjuvant non-small cell lung cancer (NSCLC) or their caregivers using publicly available health-related social media, by treatment group. IO: immuno-oncology; RTx: radiation therapy; TT: targeted therapy.



QDA Outcomes

A total of 92 adjuvant social media users (154 posts) were included in the QDA (surgery ± RTx only=41 users [62 posts]; chemotherapy=43 users [75 posts]; and IO or TT=8 users [17 posts]), at which point saturation was considered to have been reached. Categories identified in the analyses for chemotherapy and IO or TT social media users were physical impacts, emotional impairments, impacts on eating, impacts on sleep, impacts on health and well-being, and impacts on work. Commonly mentioned symptom impacts among patients who received adjuvant treatment were the need to sleep more than usual due to fatigue, having difficulty walking and standing due to pain or weakness, being unable to eat due to loss of appetite, and feeling frustrated due to symptoms such as fatigue (Table 4). For surgery ± RTx social media users, only physical impairments, impacts on sleep, and impacts on eating were identified.

Table 4. Symptom-related impacts identified in the qualitative analyses of a sample of patients who received adjuvant treatment for non–small cell lung cancer (NSCLC) or their caregivers using publicly available health-related social media (N=51 users).

Category	Physical impairments	Emotional impacts	Impacts on eating	Impacts on sleep	Impacts on health and well-being	Impacts on work
Finding[a]	• Users reported difficulty walking or standing due to pain or weakness. Weight loss as a result of appetite changes was also reported.	• Users reported feeling frustrated, depressed, and sometimes powerless about their symptoms.	Users reported not being able to eat or having little or no appetite.	• Some users reported being so tired they needed to sleep all the time, whereas others reported struggling to sleep due to pain.	• Users reported struggling in general or not feeling well as a result of their symptoms.	Users reported finding work difficult or their performance negatively impacted as a result of their symptoms.
Example[b]	• “He is suffering with severe ankle pain, and it makes it very difficult for him to walk” [caregiver] • “I do not have much appetite. I’ve lost around 5 kilograms” [patient]	• ”I find the hair loss depresses me...” [patient] • “The epileptic fits leave me feeling powerless for a while” [patient with metastases to brain]	“Food he used to like he now turns his nose up at. He’s only able to eat one bite and then does not eat any more” [caregiver]	• “I’ve been sleeping nearly all day every day. I feel way too tired to do anything” [patient] • “The pain is terrible so I am having to try to sleep differently as I struggle on my side” [patient]	• “I am really struggling with the exhaustion [patient] • “Her lung infections have been there for a while, which most likely explains why she felt so terrible” [patient]	“I did not have a good day at work today as I feel sick and tired all the time” [patient]

[a] These symptom impacts were observed among patients with NSCLC and their caregivers who are using publicly available health-related social media and may not be representative of the whole NSCLC population.

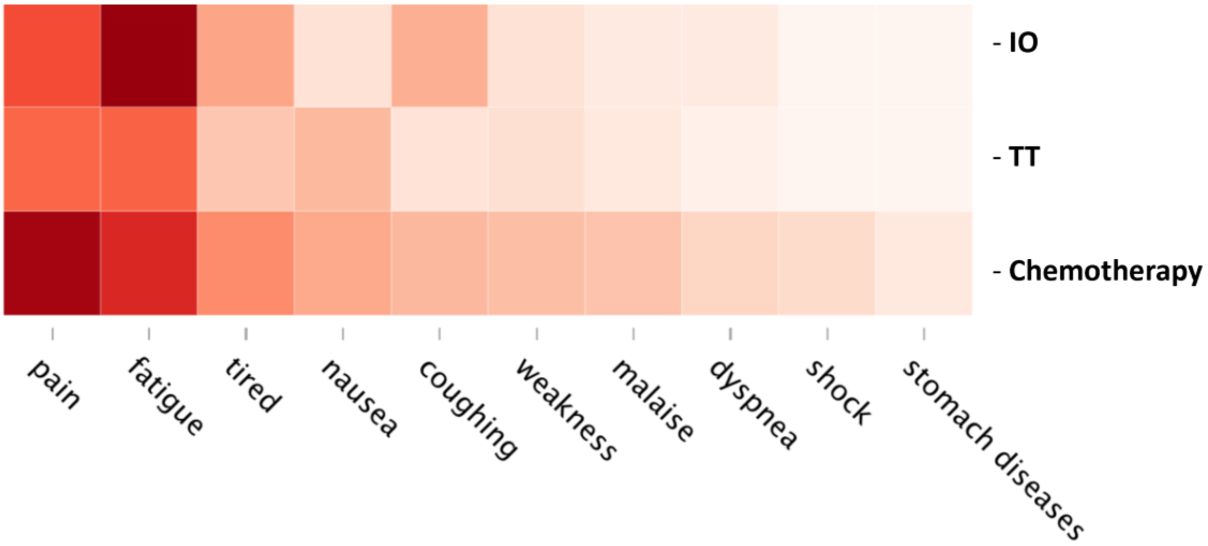
[b] Quotations are paraphrased to protect users’ privacy.

Metastatic Subgroup

Automated Identification of Symptoms

The summary results of the automated symptom extraction can be found in Figure 2. Among the chemotherapy subgroup, the most frequently discussed symptoms were pain (38.4%), fatigue and tiredness (33.0% and 22.0%, respectively), and nausea (18.4%). Among the IO subgroup, the most frequently discussed symptoms were fatigue (39.4%), pain (28.8%), and coughing (17.7%). Among the TT subgroup, the most frequently mentioned symptoms were fatigue (26.5%), pain (26.0%), and diarrhea (17.7%). The proportion of social media users in the metastatic subgroup mentioning the 25 most common symptoms can be found in Table S4 in Multimedia Appendix 1.

Figure 2. The 10 most frequently mentioned symptoms by patients with metastatic non-small cell lung cancer (NSCLC) or their caregivers using publicly available health-related social media, by treatment group. IO: immuno-oncology; TT: targeted therapy.



QDA Outcomes

A total of 134 metastatic users (258 posts) were included in the QDA (chemotherapy=42 users [91 posts]; IO=42 users [87 posts]; IO or TT=50 users [80 posts]), at which point saturation was considered to have been reached. Identified categories of symptom impacts included physical impairments, impacts on sleep, eating, day-to-day activities, and emotional impacts (Table 5). The most frequently reported symptom impacts across all subgroups were the need to rest and sleep a lot due to fatigue or weakness, waking up at night, and not having enough energy to eat.

Table 5. Symptom-related impacts identified in the qualitative analyses of a sample of patients with metastatic non–small cell lung cancer (NSCLC) or their caregivers using publicly available health-related social media (N=134 users).

Category	Physical impairments	Impacts on sleep	Impacts on eating	Impact on family	Impact on activities	Emotional impacts
Finding[a]	• Users reported difficulty performing day-to-day tasks, having mobility issues, and being unable to get out of bed due to weakness and fatigue.	• Some users report being so tired they sleep all the time, whereas others report their symptoms such as pain and cramp prevent them from sleeping.	• Users reported a reduction in appetite. For some users this was associated with a bad taste in the mouth, and others due to lack of energy or sleeping all the time.	• Impacts on families were reported by patients and caregivers. These ranged from increased burden on family to changes in family dynamics.	• Practical impacts reported included changes in normal life, ranging from needing to change skin or hygiene products to not being able to go out.	• Patients expressed that the symptoms they experience have subsequent impacts on their emotions and mental health.
Example[b]	• "He was so weak that he could not even sit up in his bed without help" [caregiver] • "I've been in bed for the last two days, feeling nauseous and retching, with extreme lethargy" [patient] • "She becomes quite out of breath and tired so she needs to rest a lot" [caregiver]	• "I have major cramps, it makes it harder to sleep at night" [patient] • "For years I have had chronic pain and struggle with sleep. I have medication but it doesn't always help" [patient] • "the fatigue is my worse symptom, I sleep into the afternoon all the time" [patient]	• "I did not like eating because I just was too tired" [patient] • "I am struggling to eat as the metallic taste in my mouth makes a lot of the food taste horrible" [patient] • "he finds it hard to stay awake to eat so we are giving him high energy foods when he can eat" [caregiver]	• "worried how I will cope at home…I hate this disease" [caregiver] • "I miss playing with my kid.. He understands that daddy needs to rest but it breaks my heart" [patient] • "His personality change made me start questioning my marriage." [caregiver]	• "he hasn't been able to do much for ages. It means we don't really go out or see people" [caregiver] • "the skin reaction is really bad and I have to be really careful what products I use" [patient] • "the sweating is so bad he has to change clothes multiple times per day" [caregiver]	• "Suffers with depression and anxiety as he is unable to do anything. Prior to this, he was busy and active" [caregiver] • "The on and off hair loss is upsetting me" [patient] • "he doesn't want visitors...he doesn't want to pretend to be in good spirits" [caregiver]

[a] These symptom impacts were observed among patients with NSCLC and their caregivers who are using publicly available health-related social media and may not be representative of the whole NSCLC population.

[b] Quotations are paraphrased to protect users' privacy.

Discussion

Principal Results

In this exploratory NLP and QDA of posts extracted from publicly available health-related social media by patients with NSCLC in the adjuvant setting and their caregivers, the most mentioned symptom was pain, irrespective of treatment status (surgery +/- RTx only or receiving adjuvant treatment). Among users of social media who received surgery +/- RTx only, mentions of respiratory-related symptoms (such as cough and pneumonia) appeared more common than among patients who received adjuvant NSCLC treatment. Symptoms, including pain and fatigue, appeared to be more commonly mentioned among patients who received adjuvant NSCLC treatment than among users who received surgery +/- RTx only. The QDA identified that symptoms were often associated with negative impacts, such as inability to exercise, difficulty sleeping, and taking time off work among surgery +/- RTx-only social media users and difficulty walking, feeling frustrated, oversleeping, and having difficulty at work among the adjuvant subgroup who received treatment after surgery.

In the analysis of posts by patients with metastatic NSCLC or their caregivers, the pain was likewise mentioned as the most common symptom, followed by fatigue, irrespective of the treatment group. The QDA identified that pain and fatigue were frequently mentioned in relation to increased difficulty in performing day-to-day tasks or getting out of bed, reduced interactions with family, and impacting patients' ability to eat. Furthermore, social media users reported an increased burden on family members due to these symptoms, as patients often required assistance in performing routine tasks.

The analysis contains patients' and caregivers' first-hand experiences, which are described in a setting with no researcher or medical professional present. Results are therefore likely to reflect the true opinions of social media users, as the data are less likely to be impacted by information bias. It is also likely that the topics most mentioned by patients and caregivers using publicly available health-related social media represent those that are of the greatest importance to them and have the biggest impact on their lives since the topics discussed are driven by patients and caregivers. A deeper understanding of the patient experience may lead to positive impacts on patient and physician discussions.

Limitations

Limitations to this exploratory study, including potential selection biases in relation to the user profiles of those posting on health-related social media, are not well understood, and there may be some bias in the information patients share in the public domain. It should be noted that insights derived from this study represent the population of patients with NSCLC or their caregivers who are using publicly available health-related social media and may not be representative of the whole NSCLC population and are therefore not generalizable. However, the nature of this study was hypothesis-generating and exploratory. While the study described experiences based on certain treatments of interest, the sample sizes in each treatment group were too small to draw comparisons, and no statistical tests were conducted to assess differences between treatment groups. Moreover, treatment groups were not mutually exclusive, and it is possible that there could be some misclassification in grouping users. Results by the treatment group should be interpreted with caution and should be used as hypothesis-generating qualitative insights. Furthermore, users posting on more than one included website were handled to the extent possible (using duplicate postings and usernames); however, there is the potential that some duplicate users remained in the analyses. Symptom rates should not be used as proxy calculations for symptom incidence, as these are limited to reports from health-related social media. While there are acknowledged limitations to the use of social media data, a study comparing the method to qualitative interviews and group concept mapping concluded that each method has stand-alone merit for specific research questions and that the use of multiple methods combined resulted in a deeper understanding of the patient experience.

Comparison With Prior Work

Fatigue and pain have been historically reported as the most common symptoms and side effects among patients with NSCLC at all stages, and effective treatment remains a challenge [15-17]. Our study suggests that pain and fatigue are not only the most common symptoms or side effects but also among the most bothersome to patients, as measured by social media posting activity. This underlines the importance of understanding how treatments are likely to impact pain and fatigue. Other recent studies have focused on the clinical outcomes of patients with advanced or metastatic disease treated with IO or TT [18]. A 2018 study assessed patient-reported symptoms and treatment impacts through administered PRO tools and questionnaires among patients with advanced NSCLC treated with chemotherapy or TT (osimertinib) in the AURA3 phase III trial. The study investigated improvements in prespecified symptoms and reported that almost 60% of patients on osimertinib noted an improvement in fatigue compared to approximately 40% of patients on chemotherapy (odds ratio 1.96, P=.008) [19].

Conclusions

This study used information from publicly available lung cancer-related social media to gain insights into the experiences of patients with NSCLC and their caregivers. Some of the key insights gained in this exploratory study were the important burden of pain and fatigue on patients across treatment groups, the high frequency of respiratory symptoms, and the impact of those symptoms on patients' daily functioning. Such insights shed light on the unmet needs of patients and their caregivers, allowing researchers to better understand the challenges they face in relation to the management of disease symptoms and their decision-making about treatment options.

Using this information, researchers can begin to address those needs that are of the greatest importance to patients and their caregivers and ensure data are collected on these concepts in the tools used to evaluate patient outcomes and experiences. Findings from health-related social media could be considered in the selection of PRO measures or domains to include by identifying symptoms that are prioritized by patients for discussion in the era of TT and IO. The findings of this study could be explored further and validated in future research and also help to understand the patient's needs for consideration in future NSCLC development programs.

Acknowledgments

Funding for this manuscript was provided by Novartis.

Data Availability

Due to concerns about being able to use web-based search engines to trace the original social media user based on the post text in the raw data sets, the authors will not be making the data set available.

Conflicts of Interest

SK is an employee of Novartis and owns shares of Novartis. SM maintains financial interests in the form of shareholdings within Novartis.

Multimedia Appendix 1
Treatments of Interest and Symptoms Rates.
[DOCX File , 69 KB - cancer_v9i1e45707_app1.docx]

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Abbreviations

IO: immuno-oncology
ML: machine learning
NLP: natural language processing
NSCLC: non–small cell lung cancer
QDA: qualitative data analysis
PRO: patient-reported outcome
RTx: radiation therapy

TT: targeted therapy

Edited by A Mavragani; submitted 23.01.23; peer-reviewed by D Carvalho, PP Zhao, P Dabas; comments to author 16.02.23; revised version received 24.03.23; accepted 27.03.23; published 12.07.23.

Please cite as:
Booth A, Manson S, Halhol S, Merinopoulou E, Raluy-Callado M, Hareendran A, Knoll S
Using Health-Related Social Media to Understand the Experiences of Adults With Lung Cancer in the Era of Immuno-Oncology and Targeted Therapies: Observational Study
JMIR Cancer 2023;9:e45707
URL: https://cancer.jmir.org/2023/1/e45707
doi:10.2196/45707
PMID:37436789

Original Paper

Advanced Messaging Intervention for Medication Adherence and Clinical Outcomes Among Patients With Cancer: Randomized Controlled Trial

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Abstract

Background: Medication adherence is crucial for improving clinical outcomes in the treatment of patients with cancer. The lack of adherence and adverse drug reactions can reduce the effectiveness of cancer therapy including the quality of life. The commonly used intervention methods for medication adherence continue to evolve, and the age of fifth-generation (5G) messaging has arrived.

Objective: In this study, we conducted a prospective, pilot randomized controlled trial to evaluate the effect of 5G messaging on medication adherence and clinical outcomes among patients with cancer in China.

Methods: The research population was patients with nonsmall cell lung cancer undergoing pemetrexed chemotherapy who require regular folic acid (FA) and vitamin B12 supplements. The intervention and control groups were assigned to 5G messaging and second-generation (2G) messaging, respectively. The patients’ medication adherence and quality of life were assessed at baseline and 1-month and 3-month time points. Moreover, the chemotherapy-related hematologic or nonhematologic toxicities, as well as the serum levels of FA and vitamin B12, were measured.

Results: Of the 567 patients assessed for eligibility between January and May 2021, a total of 154 (27.2%) patients were included. Overall, 80 were randomized to the control group and 74 to the intervention group. The odds of adherence in the 5G messaging intervention group were significantly higher than the control group at the 1-month (62/69, 90% vs 56/74, 76%; adjusted odds ratio 2.67, 95% CI 1.02-7.71) and 3-month (50/60, 83% vs 48/64, 75%; adjusted odds ratio 2.36, 95% CI 1.00-5.23) time points. Correspondingly, the FA and vitamin B12 serum levels of patients in the 5G messaging group were higher than those of the control group. Regarding hematologic toxicities, only the incidence of leukopenia in the intervention group was lower than that in the control group (25/80, 31% in the control group vs 12/74, 16% in the intervention group; P=.04). There were no differences in nonhematologic toxicities and quality of life between the 2 groups.

Conclusions: In summary, we conclude that compared with conventional 2G text-based messaging, a 5G messaging intervention can better improve medication adherence and clinical outcome among patients with cancer.

Trial Registration: Chinese Clinical Trial Registry ChiCTR2200058188; https://www.chictr.org.cn/showproj.html?proj=164489

(JMIR Cancer 2023;9:e44612) doi:10.2196/44612

KEYWORDS

5G messaging; fifth-generation; medication adherence; patients with cancer; clinical pharmacists; randomized controlled trial

Introduction

Medication adherence is crucial for improving clinical outcomes in the treatment of patients with cancer. Poor adherence is associated with disease progression and worse survival. Prolonged survival and symptom palliation are the main therapeutic goals. However, the lack of adherence can reduce the effectiveness of therapy including quality of life (QoL) [1] and increase health care costs [2]. Moderate enhancement or at least maintenance of QoL play a vital role among patients with cancer, but QoL may be affected by the severity and frequency of adverse drug reactions. These adverse effects can compromise QoL, increase financial costs, diminish adherence to treatment, and cause medical complications [3,4]. The toxicities of oral cancer therapy include fatigue, nausea, and diarrhea, and the lack of regular contact with an oncology team may impact adherence to oral regimens [5].

In addition to antitumor drugs, supplementation also plays an important role in the treatment and prevention of tumors: for example, the reduction of new skin cancer cases in recipients of lung transplants who take omega-3 fatty acid supplements [6]. In patients with nonsmall cell lung cancer (NSCLC), vitamin D supplementation may improve the survival of patients with early-stage lung adenocarcinoma with lower 25-hydroxy vitamin D levels [7]. However, the intervention management of antitumor drugs and supplementation adherence is challenging. Pemetrexed is the preferred drug for use as a component of platinum-based doublet chemotherapy for patients with NSCLC, because pemetrexed is an antifolate drug that acts primarily by disrupting folate-dependent metabolism and inhibiting multiple enzymes involved in pyrimidine and purine synthesis. Myelosuppression in hematotoxicity is the principal toxicity of pemetrexed. It has been demonstrated that the addition of vitamin B12 and folic acid (FA) to pemetrexed-containing chemotherapy regimens leads to a reduction of severe adverse events, especially hematologic toxicity, without diminishing antitumor efficacy [8]. However, FA supplement is regularly ignored by patients after discharge [9]. Patients who were nonadherent to FA supplement prescriptions had low FA intakes and serum folates, as well as high homocysteine levels and hematologic toxicities [10]. Thus, it is necessary to manage the medication adherence of patients with NSCLC undergoing pemetrexed chemotherapy who require FA and vitamin B12 supplements.

Currently, the commonly used intervention methods for medication adherence include a variety of medical-related text messaging interventions, apps, websites, etc. All of them have achieved good results in the intervention of tumor medication adherence [11-13]. Nevertheless, another study has found that text messaging failed to improve any outcomes in patients with breast cancer [14]. Smartphone apps require complex operations, such as downloading the app, and both apps and web-based education platforms possess spatial and temporal limitations—they depend on Wi-Fi or data networks to send high-definition videos to patients. With the development of information technology, second-generation (2G) text-based messaging has been raised to fifth-generation (5G) messaging. 5G messaging is constructed based on the latest standards of the Global System for Mobile Communications Association to achieve multimedia and interactive messages, which have the advantages of high speed, low delay, and greater connectivity.

5G messaging is superior in many ways to the commonly used intervention methods for medication adherence. Compared with the conventional 2G text-based messaging, advanced 5G messaging support multiple media formats, including high-definition pictures, audio, video, and emoticons; geographic location; contact card, etc. The video and audio can be delivered in many ways (including via email or websites). However, most patients with chronic conditions, including patients with cancer, are older adults, and using a mobile phone with 5G network connection is more convenient for the management of medication adherence among older adults.

More than 97% of county towns and 40% of urban areas in China have been covered by 5G networks. 5G applications are accelerating in areas such as education, health care, and information consumption. More than 600 tertiary hospitals in China have launched 5G+ emergency, remote diagnosis, and health management applications [15]. The application of 5G in distance education has gained attention, enabling patients in rural areas to obtain the same medical and pharmaceutical services as those in urban areas. By connecting a smartphone to the 5G messaging service of a communication company, the operators can supply personalized services and consultations to users through abundant media methods. Users can easily enjoy the closed-loop administration through click interaction and multimedia without complex operations and Wi-Fi–dependent limitations.

Therefore, we conducted this pilot study to assess whether a pharmacist-lead 5G messaging intervention can enhance medication adherence of regular FA supplementation and thus improve clinical outcomes among patients with NSCLC. This is the first study to apply 5G messaging to medication adherence among patients with cancer.

Methods

Research Setting

We conducted a randomized controlled trial with the concealment of allocation and single-blinded outcome assessment. The study was performed from January to May 2021 at Shanghai Tenth People's Hospital, which is the cancer center affiliated to Shanghai Tongji University. The study was registered in the Chinese Clinical Trial Registry (ChiCTR2200058188).

Participants Enrollment

We included patients who (1) were diagnosed with cytologically or histopathologically proven NSCLC and planned for upfront pemetrexed-platinum doublet chemotherapy; (2) owned a smartphone and were able to communicate in Mandarin Chinese; (3) had the capability to read messages and watch videos; and (4) had an Eastern Cooperative Oncology Group (ECOG) score of 0-3.

We excluded patients who (1) were diagnosed with other cancers; (2) did not speak Mandarin Chinese or were using a mobile phone that was unable to receive 5G messaging; (3) had reading or comprehensive impairments; and (4) were unwilling to participate in the trial.

FA and B12 Supplementation

Recommendations for supplementation included starting oral FA (350-1000 μg daily) 1 week before the first dose of pemetrexed and continuing the same for at least 2 weeks beyond the end of pemetrexed treatment. Along with FA, intramuscular vitamin B12 injection (1000 μg) should be administered and repeated every 9 weeks until the cessation of treatment [16].

5G Messaging Intervention

Randomization was performed in advance using a web-based random number generator [17] in a 1:1 ratio. The control group received 2G messaging (text only) twice a week. The text is as follows: "Dear <Patient Name>, please be reminded to take folic acid tablets as instructed by your doctor/pharmacist. Take tablets (350~1000 μg, usually 400 μg) daily starting one week before the dose of pemetrexed and continuing the same for at least 21 days beyond end of pemetrexed." This message was in Chinese.

The intervention group received 5G messaging twice a week. The contents of the 5G messaging intervention consisted of not only text but also video and audio messages of medication education: (1) the text content is the same as that from 2G messaging, with "For detailed explanation, please watching the following video or audio" added to the end; (2) the video content (Multimedia Appendix 1) was made according to the prescribing information of pemetrexed [16] and the guideline for FA supplementation in China [18]; (3) the video content has also been synchronized with the production of an audio version with only sound but no video (Multimedia Appendix 2). The video and audio messages were in Chinese (see Multimedia Appendix 3 for an English translation of the video content). The participants had the option to stop the messaging intervention at any time. The pharmacist followed up all patients by conducting surveys via phone calls every month.

Measurement and Outcomes

We collected data using the following instruments: (1) the Morisky Medication Adherence Scale 8 item (MMAS-8) [19-21]; (2) the EuroQol EQ-5D-3L; (3) the Beliefs about Medicines Questionnaire (BMQ)–Specific; and (4) a predefined data collection form. The MMAS-8 is an 8-item questionnaire designed to facilitate the identification of barriers and behaviors associated with adherence to medication. The possible answers to questions 1 to 7 are "Yes" (0 points) or "No" (1 point). Five of the questions are scored in reverse. The possible answers to question 8 are "Never," "Occasionally," "Sometimes," "Often," and "All the time," scoring 1, 0.75, 0.50, 0.25, and 0 points, respectively [19]. The EuroQol EQ-5D-3L comprises the following 5 dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each dimension has 3 levels: no problem, some problems, and extreme problems [22]. The BMQ-Specific assesses patients' beliefs about the particular medications prescribed for them, comprising 2 subscales: Specific Necessity and Specific Concerns. Each item of the BMQ subscales is scored on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree) [23]. In the data collection form, information regarding age, gender, other comorbidities, and concurrently used drugs was collected.

The primary outcomes were (1) the proportion of patients who adhered to medications at the 1-month time point and (2) incidence of any grade of hematologic toxicities (anemia, leukopenia, neutropenia, or thrombocytopenia) and nonhematologic toxicities (neuropathy, fatigue, fever, constipation, diarrhea, and vomiting) according to the National Cancer Institute Common Terminology Criteria for Adverse Events, version 3.0, during the study period. The secondary outcomes were (1) the proportion of patients who adhered to medications at the 3-month time point; (2) changes in serum levels of FA and vitamin B12; and (3) change in QoL from baseline to the 3-month time point.

Statistical Analysis

To detect a 20% difference in adherence between the control and intervention groups and to account for 20% loss to follow-up, we enrolled at least 152 patients (76 per group). Data were presented as absolute numbers, percentages, means with SDs, or medians with IQRs as appropriate. Characteristics and the QoL of patients randomized to the intervention and control groups were compared using chi-square test for all categorical variables and 2-tailed independent *t* test or Mann-Whitney *U* test for all continuous variables. Univariable logistic regression models were used to estimate the odds ratio (ORs) with 95% CIs of the intervention for adherence outcomes. The change in QoL was assessed using the McNemar test (categorical) and Wilcoxon signed rank test (continuous). All tests considered 2-sided P values of ≤.05 to be statistically significant. SPSS Statistics (version 25.0; IBM Corp) and GraphPad Prism (version 7.0; GraphPad Software, Inc) were used for statistical analyses. GraphPad Prism was also used to create graphs.

Ethics Approval

All study materials and procedures were approved by the institutional review board of Shanghai Tenth People's Hospital (protocol ID SHSY-IEC-4.1/21-248/01).

Informed Consent and Compensation

All enrolled participants have signed the informed consent forms before the trial started. They consented to primary data collection and allowed secondary analysis without additional consent. All the study data are anonymous or deidentified. The compensation type for all enrolled participants in human subjects research is cash.

Results

Baseline Characteristics

Of the 567 patients assessed for eligibility between January and May 2021, a total of 154 (27.2%) patients were included; 217 (38.3%) patients were excluded due to exclusion criteria, and 196 (34.6%) declined to participate. Of the 154 patients included, 80 were randomized to the control group and 74 to the intervention group. Three patients in the intervention group did not receive the intervention due to poor health, resulting in 71 patients in the intervention group. Out of the 154 patients, 143 (92.9%) and 124 (80.5%) completed the 1-month and 3-month follow-ups, respectively. The reasons for the loss of follow-up included being out of contact, death, discontinuing the intervention, etc (Figure 1).

The mean age of the patients was 64.3 (SD 8.1) years, and 43.5% (67/154) were male. The proportion of older patients (aged >65 years) was 39.6% (61/154). In addition to cancer, the majority of patients also had comorbidities, mainly hypertension (55/154, 35.7%), diabetes (25/154, 22.7%), and other comorbidities (35/154, 22.7%). Furthermore, 16.9% (26/154) of patients took more than 2 non-antitumor drugs. BMQ Specific Necessity and Concern scores were measured among the patients. No differences in the demographics and general characteristics, medical history, comorbidities, and BMQ-Specific scores were found among the control and intervention groups (Table 1).

Figure 1. Flowchart of the study population. 5G: fifth generation; ADR: adverse drug reactions.

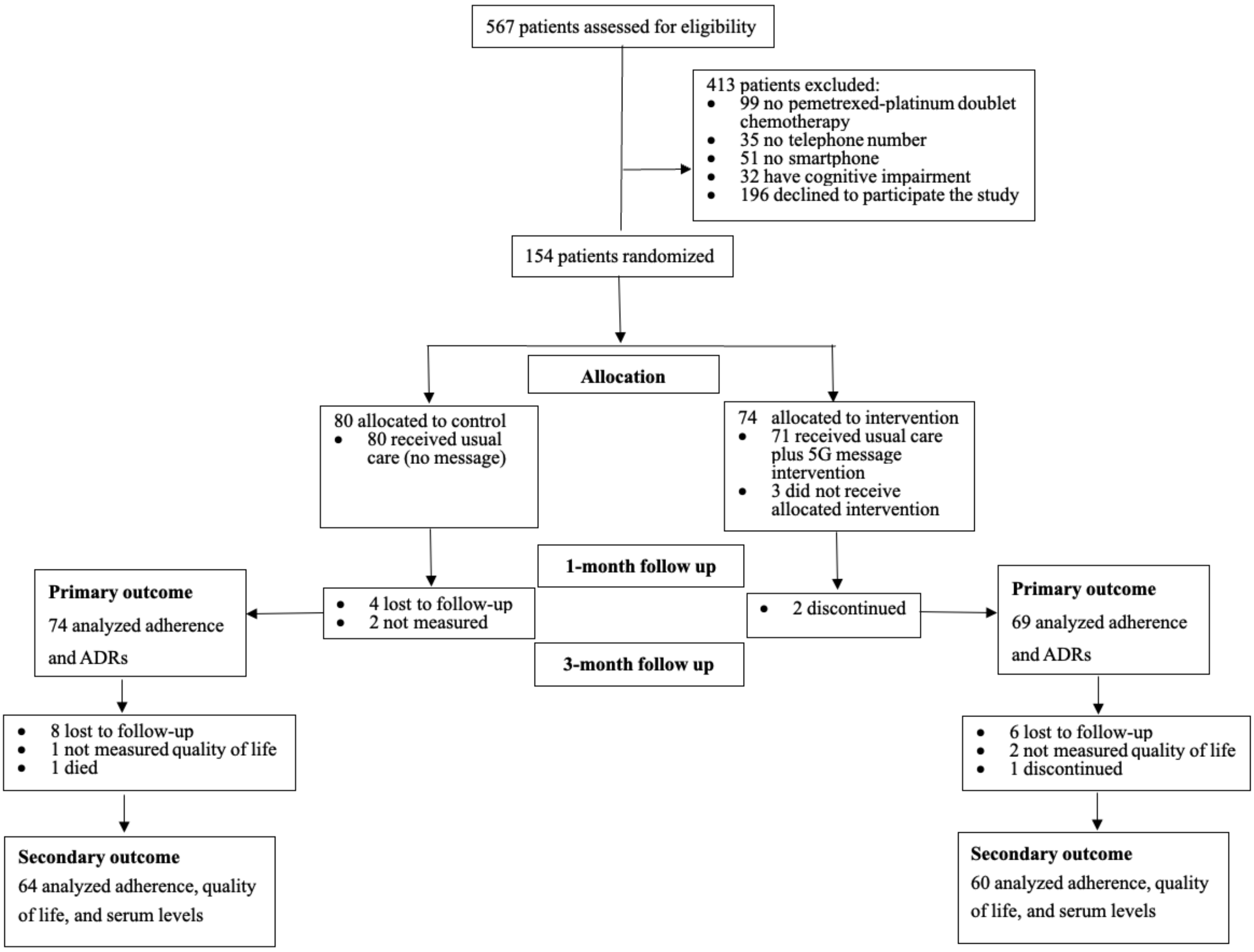


Table 1. Baseline characteristics of the study population.

Patient characteristic	All patients (n=154)	Control (n=80)	Intervention (n=74)	*P* value
Demographics and general characteristics				
Age (years), mean (SD)	64.3 (8.1)	62.4 (8.4)	66.5 (7.3)	.06[a]
Aged >65 years, n (%)	61 (39.6)	27 (33.8)	34 (45.9)	.12[b]
Male, n (%)	67 (43.5)	29 (36.3)	38 (51.4)	.06[b]
Medical history and comorbidities, n (%)				
Hypertension	55 (35.7)	23 (28.8)	32 (43.2)	.06[b]
Diabetes	35 (22.7)	19 (23.8)	16 (21.6)	.75[b]
Other comorbidities	35 (22.7)	15 (18.8)	20 (27)	.22[b]
>2 Non-antitumor drugs	26 (16.9)	12 (15)	14 (18.9)	.52[b]
BMQ[c] Specific score, median (IQR)				
BMQ Specific Necessity	23 (21-25)	20 (14-24)	21 (19-23)	.94[d]
BMQ Specific Concern	11 (9-15)	12 (9-15)	10 (9-13)	.29[d]

[a] Independent (2-tailed) *t* test.

[a] Chi-square test.

[c] BMQ: Beliefs about Medicines Questionnaire.

[d] Mann-Whitney *U* test.

Changes in Measures

The full score of the MMAS-8 is 8 points. A score of <6 represents poor adherence, a score of 6-8 represents moderate adherence, and a score of 8 represents good adherence. A greater proportion of patients were adherent in the intervention group than the control group at the 1-month (62/69, 90% vs 56/74, 76%; adjusted OR 2.67, 95% CI 1.02-7.71) and 3-month (50/60, 83% vs 48/64, 75%; adjusted OR 2.36, 95% CI 1.00-5.23) time points (Figure 2; Table 2).

There were significant increases in median EQ-5D-3L index value from baseline to the 3-month time point in both the control (0.68, IQR 0.54-1 vs 1, IQR 0.726-1; *P*<.001) and intervention (0.76, IQR 0.65-1 vs 1, IQR 0.73-1; *P*=.004) groups. The results indicated that both 2G and 5G messaging have the potential to ameliorate physical and mental health in the QoL. However, there was no significant difference in median change of EQ-5D-3L index values between the control and intervention groups at baseline or the 3-month time point (0.214, IQR 0.000-0.375 vs 0.000, IQR 0.000-0.279; *P*=.08; Table 3).

Figure 2. Patient's medication adherence at the 1-month and 3-month time points. The MMAS-8 Scale, content, name, and trademarks are protected by US copyright and trademark laws. Permission for use of the scale and its coding is required. A license agreement is available from MMAR, LLC., www.moriskyscale.com. MMAS-8: Morisky Medication Adherence Scale 8 item.

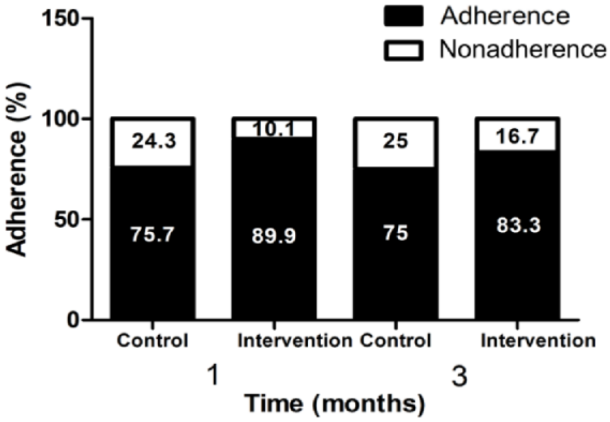


Table 2. Patient adherence at the 1-month and 3-month time points, measured using the MMAS-8[a,b]. Samples exclude patients who were not measured for adherence at the 1-month and 3-month time points.

Time point	Control, n (%)	Intervention, n (%)	Absolute difference in proportions (%; 95% CI)	Univariable analysis	
				OR[c] (95% CI)	*P* value
1 Month (control: n=74 and intervention: n=69)			14.3 (7-26.5)	2.67 (1.02-7.71)	.03[d]
Adherence	56 (76)	62 (90)			
Nonadherence	18 (24)	7 (10)			
3 Months (control: n=64 and intervention: n=60)			16 (1.5-28.4)	2.36 (1.00-5.23)	.049[d]
Adherence	48 (75)	50 (83)			
Nonadherence	16 (25)	10 (17)			

[a] MMAS-8: Morisky Medication Adherence Scale 8 item.

[b] The MMAS-8 Scale, content, name, and trademarks are protected by US copyright and trademark laws. Permission for use of the scale and its coding is required. A license agreement is available from MMAR, LLC., www.moriskyscale.com.

[c] OR: odds ratio.

[d] *P*<.05.

Table 3. Changes in quality of life from baseline to the 3-month time point.

EQ-5D-3L	Baseline[a]		3-month time point[a]		Comparison		
	Control[b] (n=80)	Intervention[b] (n=74)	Control[b] (n=64)	Intervention[b] (n=60)	P_1 value[c]	P_2 value[d]	P_3 value[e]
Mobility, n (%)					.34[f]	.58[f]	—[g]
No problems	50 (62)	57 (77)	43 (67)	50 (83)			
Problems	30 (38)	17 (23)	21 (33)	10 (17)			
Self-care, n (%)					.27[f]	.30[f]	—
No problems	66 (82)	65 (88)	58 (91)	57 (95)			
Problems	14 (18)	9 (12)	6 (9)	3 (5)			
Usual activities, n (%)					.05[f]	.18[f]	—
No problems	61 (76)	62 (84)	72 (90)	56 (93)			
Problems	19 (24)	12 (16)	8 (10)	4 (7)			
Pain/discomfort, n (%)					.81[f]	.83[f]	—
No problems	48 (60)	51 (69)	42 (66)	43 (72)			
Problems	32 (40)	23 (31)	22 (34)	17 (28)			
Anxiety/depression, n (%)					.052[f]	.12[f]	—
No problems	46 (58)	45 (61)	45 (70)	42 (70)			
Problems	34 (42)	29 (19)	19 (30)	18 (30)			
EQ-5D-3L index value, median (IQR)	0.68 (0.54-1)	0.76 (0.65-1)	1 (0.726-1)	1 (0.73-1)	<.001[h]	.004[h]	—
Change of EQ-5D-3L index value, median (IQR)	—	—	0.214 (0.000-0.375)	0.000 (0.000-0.279)	—	—	.08[f]

[a] No differences in each dimension and index value of the EQ-5D-3L between the control and intervention groups at baseline or the 3-month time point.

[b] Sample size of patients who reported EQ-5D-3L at both baseline and the 3-month time points.

[c] P_1: Comparison between baseline and 3-month EQ-5D-3L scores of the control group.

[d] P_2: Comparison between baseline and 3-month EQ-5D-3L scores of the intervention group.

[e] P_3: Comparison between changes from baseline of EQ-5D-3L index values of the control and intervention groups at the 3-month time point.

[f] McNemar test.

[g] Not applicable.

[h] Wilcoxon signed rank test.

In the aspect of hematologic toxicities, 66.5% (102/154) of patients developed anemia (any grade), 35.9% (55/154) developed neutropenia (any grade), 47.6% (73/154) developed leukopenia (any grade), and 30.5% (47/154) developed thrombocytopenia (any grade). There was not statistically less incidence in the intervention group compared with the control group except for leukopenia (25/80, 31% in the control group vs 12/74, 16% in the intervention group; $P=.04$; Table 4). There were not any significant differences in the incidence of nonhematologic toxicities (neuropathy, fatigue, fever, constipation, diarrhea, and vomiting) between the control and intervention groups (all $P>.05$; Table 4).

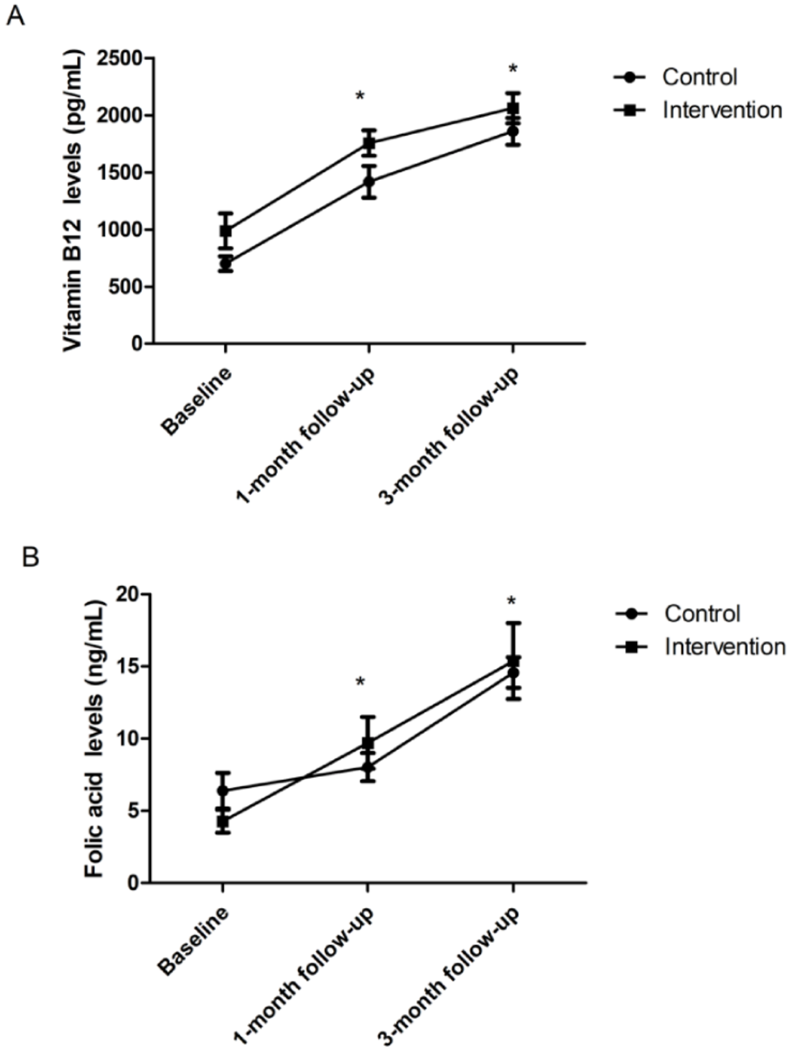
In total, 143 patients (74 control and 69 intervention) contributed to the analysis of the FA and vitamin B12 assays at the 1-month time point, and 124 patients (64 control and 60 intervention) contributed at the 3-month time point. FA and vitamin B12 levels at the 1-month and 3-month time points were significantly higher than the levels at baseline (all $P<.001$). FA and vitamin B12 levels were statistically greater in the intervention group than the control group at the 1-month and 3-month time points (all $P<.001$; Figure 3), which corresponds to the improvement of medication adherence.

Table 4. Hematologic and nonhematologic toxicity profiles of the patients.

Profile	Control (n=80), incidence (%; 95% CI)	Intervention (n=74), incidence (%; 95% CI)	*P* value
Hematologic toxicities			
Anemia			
Any grade	37.8 (26.4-49.9)	28.7 (18.6-40.8)	.25
Grade 3/4	7.7 (7.4-9.3)	7.0 (6.4-9.2)	.90
Leukopenia, any grade	31.4 (21.7-42.1)	16.2 (8.0-27.8)	.04[a]
Neutropenia, any grade	20.1 (12.5-31.4)	15.8 (7.4-25.8)	.36
Thrombocytopenia, any grade	18.3 (10.6-28.3)	12.2 (5.1-22.8)	.32
Nonhematologic toxicities			
Neuropathy, any grade	19 (10-31)	21 (12-32)	.84
Fatigue, any grade	40 (22-58)	38 (20-59)	.89
Fever, any grade	10 (3-19)	8 (5-17)	.78
Constipation, any grade	12 (6-23)	7 (3-17)	.43
Diarrhea			
Any grade	13 (6-22)	12 (6-23)	.99
Grade 3/4	5 (2-13)	6 (2-15)	.99
Vomiting			
Any grade	17 (9-27)	12 (6-22)	.36
Grade 3/4	5 (1-13)	4 (1-12)	.99

[a] $P<.05$.

Figure 3. Line and scatter plots illustrate serum levels of vitamin B12 (A) and folic acid (B) in the control and intervention treatment. Circles represent mean values, and error bars represent 95% CIs. *P<.001.



Discussion

Principal Findings

This pilot study was an attempt by a clinical pharmacist to use 5G technology to innovate and carry out intelligent pharmaceutical care in patients with cancer. Compared with 2G messaging, the 5G messaging intervention enhanced the proportion of adherent patients by over 14.2% at the 1-month time point and 8.3% at the 3-month time point. The levels of FA and vitamin B12 in patients with NSCLC in the 5G messaging group were higher than those in 2G messaging group, which corresponds to the improvement of medication adherence. In the aspect of hematologic toxicities, the incidence of leukopenia in the intervention group was lower than that in the control group. Compared with 2G messaging, the 5G messaging intervention enhanced medication adherence of FA and vitamin B12, which resulted in the partially reduced risk of myelosuppression in patients with NSCLC undergoing pemetrexed chemotherapy.

There were significant increases in median EQ-5D-3L index values from baseline to the 3-month time point in both the control and intervention groups. The results show that both 2G and 5G messaging have the potential to ameliorate physical and mental health in the QoL. Digital video interventions represent effective tools for enhancing mental health [24] and physical activity [25] in patients. The intervention of 5G messaging for physical and mental health needs further research. Recently, researchers have begun to present contents of medical education in videos. Information provided via video may better engage participants and improve their retention of content [26]. There is still debate about whether text or video is more effective as an intervention in health care. Vandelanotte et al [27] found that the personally tailored videos were not more effective than personally tailored text messages in increasing moderate-to-vigorous physical activity.

The increasing availability and ease of use of smartphone apps has allowed for substantial growth of apps that can be used for health behavior change. The mobile app can send text messages, check notifications, and open video channels. The telehealth program is feasible and enhance participants' and their families' access and motivation to engage in self-management [28]. However, the use of apps requires it to be downloaded, which would occupy a lot of the memory space of the smartphone. 5G technology, with low latency, high speed, enhanced high resolution, superior reliability, and less energy consumption, is bound to transform telemedicine and the health care industry as a whole [29]. This next-generation wireless networking of 5G technology has many far-reaching implications in both preventive and therapeutic care of the patients.

Huang et al [30] described that patients preferred to have reminders sent 30 minutes before their scheduled time for medication. A review of interventional trials to improve medication adherence stressed that personalized and interactive reminders are the most effective [31]. Our findings showed that 5G messaging played a good guiding role in the medication adherence of patients with cancer. 5G messaging possess interesting and unlimited potential. In the future, the frequency and timing of sending 5G messages shall be set by patients before sending. It is necessary to strengthen the timeliness and personalization of 5G messaging interventions to improve the long-term impact on patients' medication adherence. 5G technology will hopefully promote the innovation of intelligent pharmaceutical care and improve the efficiency and quality of clinical pharmaceutical care.

Limitations

Several issues in our study should be considered. First, this was a single-center study with a small sample size, and further studies with larger sample sizes in multiple centers, especially in rural areas, are needed to confirm these results. Second, this pilot study describes the effect of 5G messaging on adherence with supplementation medication for lung cancer. Further large-scale studies are needed to research the effect of 5G messaging on medication adherence to antitumor drugs. Third, the study focused on the Chinese population. As potential cultural differences could alter external validity for the use of 5G messaging, studies in other populations are planned.

Conclusions

Our randomized controlled trial showed a significant effect of 5G messaging in improving medication adherence among patients with cancer. Future studies could investigate the use of a tailored 5G messaging intervention on clinical outcomes according to the patients' preference.

Acknowledgments

This work was supported by the Program for Research-Oriented Physician of Shanghai Tenth People's Hospital (grant 2023LCYJFZRC002), the Shanghai Talent Development Fund (grant 2020091), and Shanghai Rising Stars of Medical Talent Development Program—Clinical Pharmacist Project [grant SHWSRS(2021)_099].

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Data Availability

The data sets generated during and/or analyzed during this study are available from the corresponding author on reasonable request.

Authors' Contributions

DJL (djli@tongji.edu.cn) and FMS (fumingshen@tongji.edu.cn) are co-corresponding authors. CXN and WJL contributed to data statistics and article writing. MN and FH contributed to data statistics and information gathering. DJL and FMS contributed to project design.

Conflicts of Interest

None declared.

Multimedia Appendix 1
The video of medication education in Chinese.
[MP4 File (MP4 Video), 9019 KB - cancer_v9i1e44612_app1.mp4]

Multimedia Appendix 2
The audio of medication education in Chinese.
[MP4 File (MP4 Video), 543 KB - cancer_v9i1e44612_app2.mp4]

Multimedia Appendix 3
English translation of the video content presented in Multimedia Appendix 1.
[DOCX File , 11 KB - cancer_v9i1e44612_app3.docx]

Multimedia Appendix 4
CONSORT-eHEALTH checklist (V 1.6.1).
[PDF File (Adobe PDF File), 8604 KB - cancer_v9i1e44612_app4.pdf]

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Abbreviations

2G: second-generation
5G: fifth-generation
BMQ: Beliefs about Medicines Questionnaire
ECOG: Eastern Cooperative Oncology Group
FA: folic acid
MMAS-8: Morisky Medication Adherence Scale 8 item
NSCLC: nonsmall cell lung cancer
QoL: quality of life

Edited by T de Azevedo Cardoso; submitted 26.11.22; peer-reviewed by L Schwartz, P Wang; comments to author 19.03.23; revised version received 25.03.23; accepted 20.07.23; published 31.08.23.

Please cite as:
Ni CX, Lu WJ, Ni M, Huang F, Li DJ, Shen FM
Advanced Messaging Intervention for Medication Adherence and Clinical Outcomes Among Patients With Cancer: Randomized Controlled Trial
JMIR Cancer 2023;9:e44612
URL: https://cancer.jmir.org/2023/1/e44612
doi:10.2196/44612
PMID:37651170

Original Paper

Telehealth Use Following COVID-19 Within Patient-Sharing Physician Networks at a Rural Comprehensive Cancer Center: Cross-sectional Analysis

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Abstract

Background: In response to the COVID-19 pandemic, cancer centers rapidly adopted telehealth to deliver care remotely. Telehealth will likely remain a model of care for years to come and may not only affect the way oncologists deliver care to their own patients but also the physicians with whom they share patients.

Objective: This study aimed to examine oncologist characteristics associated with telehealth use and compare patient-sharing networks before and after the COVID-19 pandemic in a rural catchment area with a particular focus on the ties between physicians at the comprehensive cancer center and regional facilities.

Methods: In this retrospective observational study, we obtained deidentified electronic health record data for individuals diagnosed with breast, colorectal, or lung cancer at Dartmouth Health in New Hampshire from 2018-2020. Hierarchical logistic regression was used to identify physician factors associated with telehealth encounters post COVID-19. Patient-sharing networks for each cancer type before and post COVID-19 were characterized with global network measures. Exponential-family random graph models were performed to estimate homophily terms for the likelihood of ties existing between physicians colocated at the hub comprehensive cancer center.

Results: Of the 12,559 encounters between patients and oncologists post COVID-19, 1228 (9.8%) were via telehealth. Patient encounters with breast oncologists who practiced at the hub hospital were over twice as likely to occur via telehealth compared to encounters with oncologists who practiced in regional facilities (odds ratio 2.2, 95% CI 1.17-4.15; *P*=.01). Patient encounters with oncologists who practiced in multiple locations were less likely to occur via telehealth, and this association was statistically significant for lung cancer care (odds ratio 0.26, 95% CI 0.09-0.76; *P*=.01). We observed an increase in ties between oncologists at the hub hospital and oncologists at regional facilities in the lung cancer network post COVID-19 compared to before COVID-19 (93/318, 29.3%, vs 79/370, 21.6%, respectively), which was also reflected in the lower homophily coefficients post COVID-19 compared to before COVID-19 for physicians being colocated at the hub hospital (*estimate:* 1.92, 95% CI 1.46-2.51, vs 2.45, 95% CI 1.98-3.02). There were no significant differences observed in breast cancer or colorectal cancer networks.

Conclusions: Telehealth use and associated changes to patient-sharing patterns associated with telehealth varied by cancer type, suggesting disparate approaches for integrating telehealth across clinical groups within this health system. The limited changes to the patient-sharing patterns between oncologists at the hub hospital and regional facilities suggest that telehealth was less likely to create new referral patterns between these types of facilities and rather replace care that would otherwise have been delivered in person. However, this study was limited to the 2 years immediately following the initial outbreak of COVID-19, and longer-term follow-up may uncover delayed effects that were not observed in this study period.

(JMIR Cancer 2023;9:e42334) doi:10.2196/42334

KEYWORDS

telehealth; rural cancer care; patient-sharing networks; network analysis; COVID-19; cancer care; telemedicine; oncology; oncologist; electronic health record data; health system; patient network

Introduction

The COVID-19 pandemic resulted in the rapid uptake of telehealth in cancer centers across the United States and around the world [1-3]. Since then, the advantages to sustained telehealth integration in cancer care have become more fully recognized, including increased access to specialists across greater distances, reduced travel burden for patients, and improved synchronous communication between regional specialists and community health care teams [4,5]. Telehealth in cancer care delivery, or tele-oncology, refers to the delivery of clinical oncology services through audio and video communication platforms to remote patients including chemotherapy monitoring, pain and symptom management, and palliative care [6]. In addition to the benefit of reducing infection risk during the COVID-19 pandemic, patients with cancer and treating physicians have reported general satisfaction with telehealth use in cancer care delivery [7-10]. However, challenges associated with telehealth remain, such as patient access to technology, quality of communication, establishing rapport between a physician and a new patient, and reimbursement policies [11-13]. Although survey results early in the pandemic found that the majority of oncologists were either highly likely or somewhat likely to continue using telehealth for established patients after the COVID-19 crisis [8], use-based data on telehealth visits in a post–COVID-19 era is needed to determine how and where telehealth may be having more persistent impacts on cancer care delivery.

The use of telehealth among oncologists may not only affect the way they deliver care to their own patients but also the physicians with whom they share patients. Patient-sharing networks built from administrative health care data, in which 2 physicians are connected if they have clinical encounters with common patients, provide a novel lens through which to study the impact of telehealth uptake. Patient-sharing relationships have been shown to capture self-reported professional relationships between physicians [14]. Patient-sharing networks have provided insight into informal integration between primary care and specialists, coordination among patient care teams, and locally unique linchpin physicians [15-17]. There is significant potential for patient-sharing networks to measure the impact of new policies and innovative care delivery models on the way in which physicians work together to deliver health care to their patients. For instance, the potential for telehealth to improve access to geographically distant providers may be reflected in changes to the patient-sharing patterns for cancer care within and between health systems. Within a health system spanning several hospitals, we hypothesized that telehealth might facilitate referrals between physicians at the hub hospital and physicians at regional facilities. This may in part occur due to an increase in web-based cancer multidisciplinary team meetings via web platforms, which allow specialized clinicians to join meetings they may not have had access to prior to COVID-19 [18]. However, if telehealth essentially replaces care that would otherwise have been delivered in person, we would expect to see minimal changes in the patient-sharing patterns with the uptake of telehealth.

The objective of this study was to examine telehealth encounters for patients diagnosed with breast, colorectal, and lung cancer within the Dartmouth Health system, home to a rural National Cancer Institute comprehensive cancer center. We first sought to identify characteristics of oncologists associated with telehealth encounters post COVID-19. Then, since we hypothesized that telehealth may lead to increased referrals between geographically distant providers, we examined whether there was an increase in the likelihood of patient-sharing ties between oncologists practicing at the Dartmouth Cancer Center in Lebanon, New Hampshire, and oncologists at regional hospitals. On March 15, 2020, Dartmouth Health implemented immediate social distancing policies due to the COVID-19 pandemic. Using this date to partition clinical encounters observed in the electronic health record data, we assembled pre- and post–COVID-19 patient-sharing networks for breast, colorectal, and lung cancer. We then assessed whether the structure of the patient-sharing networks changed between these time periods with the rapid uptake of telehealth.

Methods

Study Setting

Data were collected from electronic health records within the Dartmouth Health system in northern New England. The health system is comprised of a hub hospital in Lebanon, New Hampshire, where the Dartmouth Cancer Center resides, along with 5 sites and 15 regional affiliates across New Hampshire and Vermont.

Ethics Approval

This study was approved by the Dartmouth Health institutional review board (study 02001168). All analyses were performed according to institutional review board and data use agreements with Dartmouth Health regarding the use of electronic health record data for research.

Data Sources and Study Cohort

Retrospective data on adult patients diagnosed with incident breast, colorectal, and lung cancer between January 1, 2018, and December 31, 2020, were identified from the institutional tumor registry. Patients aged younger than 18 years or older than 99 years at the time of diagnosis were excluded. For those patients meeting our cohort criteria, we linked to the EPIC electronic health records at Dartmouth Health to identify their clinical encounters from 3 months prior to 12 months following their cancer diagnosis or through September 2021, whichever came first.

Assembly of Patient-Sharing Physician Networks

To assemble pre–COVID-19 and post–COVID-19 patient-sharing networks for breast, colorectal and lung cancers, clinical encounters were stratified by pre- or post–COVID-19 time periods depending on whether the visit took place prior to March 15, 2020. Patient-sharing networks for each cancer type were assembled where 2 physicians were connected in the network if they had clinical encounters in the same time period with the same cancer patient.

Study Variables

Physician characteristics of interest were specialty; patient volume; practicing in multiple locations; and practicing at the Dartmouth Health “hub” hospital in Lebanon, New Hampshire, home to the Dartmouth Cancer Center main campus. Physician specialty was obtained from electronic health record data. Cancer specialties included medical oncology, radiation oncology, general surgery, surgical oncology, plastic surgery for breast cancer, and thoracic surgery for lung cancer, where the latter 4 were collapsed into 1 category of surgery. Using encounters specific to either the pre- or post–COVID-19 time period, a physician was labeled as practicing at multiple sites if they had encounters in more than one ZIP code and as a “hub” hospital practitioner if they had clinical encounters with patients at the Dartmouth Health facility in Lebanon, New Hampshire. Patient characteristics included as covariates in the models included patient age in years at diagnosis and patient sex.

Outcome Variable

The encounter-level outcome variable of interest was whether an encounter with an oncologist occurred via telehealth, which was inclusive of video and audio-only encounters.

Statistical Analysis

Characteristics of patients and oncologists were summarized with descriptive statistics for each cancer type. Hierarchical logistic regression models were developed to study associations between the encounter-level variable of telehealth use and study variables. Random intercepts for patient and oncologist were specified to account for the nesting of encounters within patients and oncologists. To estimate the proportion of variance explained by patients and oncologists, intraclass correlation coefficients (ICC) for the patient and oncologist random effects were calculated. For example, the ICC for patient random effect is calculated by taking the ratio of between-patient variance and the total variance obtained from the mixed model. Hierarchical models were performed using the *lme4* package in R software (R Foundation for Statistical Computing) [19].

Network Analysis

Networks were analyzed using the *visNetwork* and *igraph* packages in R and visualized with the Frutcherman-Reingold layout [20]. Global network statistics evaluated for the pre- and post–COVID-19 networks include density (the number of observed ties divided by the total number of possible ties), transitivity (the tendency of sets of 3 physicians to form a connected triangle), average distance (the average number of steps along the network it takes to connect each pair of physicians), and degree centralization (the variation in the degree centrality across physicians). These global network measures were chosen because they reflect distinct aspects of the structure of connections within a network. Prior work has indicated that patient-sharing networks with greater density have been associated with higher costs and use of services [21], and greater transitivity has been associated with patient-reported measures of care coordination [22]. Average distance was included to capture whether network paths between pairs of physicians became shorter or longer with the uptake of telehealth. Centralization was chosen because we hypothesized that if telehealth led to more care being coordinated between the hub hospital and regional facilities, it may lead to less care being concentrated among highly connected hub-hospital physicians, resulting in lower centralization. Edges between oncologists were labeled based on whether both, one, or none of the oncologists in the nonnull dyad practiced at the hub hospital. The proportions of each type of edge were calculated for the pre- and post–COVID-19 time periods.

Exponential-family random graph models (ERGMs) are probability models in which the network as a whole is the dependent variable that offer a flexible approach for handling the complex dependence structure of network graphs [23]. ERGMs are based on exponential-family theory for specifying the probability distribution for a set of random graphs or networks to describe the local selection forces that shape the global structure of the network [24]. Homophily describes the tendency of nodes in the network to form ties with similar others, and we were particularly interested in estimating homophily based on physician practice location. We estimated separate ERGMs for each time period (before and post COVID-19) to estimate the homophily coefficient for practicing at the hub hospital, which represents the change in the log-odds of the tie if the oncologists have the trait in common (either both practice at the hub hospital or both practice at regional facilities) compared to if they do not have the trait in common (a tie spanning an oncologist at the hub hospital and an oncologist at a regional facility), conditioned on the rest of the network. We present results for the exponentiated homophily term adjusted for the “edges” term (ie, density), so that the homophily coefficients represent the differences in the likelihood of edges existing between oncologists with the concordant level of location compared to oncologists in different locations using the *ergm* package in R [25].

Results

Our study included patients with breast (n=1535), colorectal (n=601), and lung (n=1145) cancer (Table 1). The median age at diagnosis was 63, 66, and 68 years for patients with breast, colorectal, and lung cancer, respectively. Patients were 96.3% (3158/3281) White, which is reflective of the racial composition of northern New England. Of the total cohort of 3281 cancer patients, 951 (29%) patients had one or more telehealth encounters, and 939 of those patients were diagnosed post COVID-19.

The total number of oncologists across the 3 cancer types was relatively unchanged before and post COVID-19 (119 and 114, respectively), and 64.9% (74/114) of oncologists used telehealth post COVID-19 (Table S1 in Multimedia Appendix 1). Characteristics of oncologists by cancer type in the pre- and post–COVID-19 networks are summarized in Table 2. Telehealth use among oncologists before COVID-19 was rare (1%-3%), yet post–COVID-19 telehealth use was observed for 69% (53/77) of oncologists in the breast cancer network, 50% (33/66) of oncologists in the colorectal cancer network, and 61% (33/54) of oncologists in the lung cancer network. Of the 12,559 encounters between patient and oncologists post COVID-19, 1228 (9.8%) were via telehealth. The proportion of encounters with oncologists via telehealth and the number of oncologists using telehealth by month post COVID-19 peaks in April 2020 and then again around December 2020 (Figure S1 in Multimedia Appendix 1). Aside from telehealth use, none of the other characteristics of oncologists summarized in Table 2 were significantly different at *P*<.05 before and post COVID-19.

We found that the oncologist characteristics associated with telehealth encounters in the post–COVID-19 time period varied by cancer type (Table 3). Surgeons were less likely to have encounters via telehealth, and this association was statistically significant for breast cancer care (odds ratio [OR] 0.38, 95% CI 0.20-0.71; *P*=.003; reference=medical oncology). Additionally, for breast cancer care, patient encounters with oncologists with a medium patient volume were over 3 times as likely to occur via telehealth compared to patient encounters with low-volume oncologists (OR 3.84, 95% CI 1.09-13.62; *P*=.04), and patient encounters with hub hospital–based oncologists were over 2 times as likely to occur via telehealth compared with patient encounters with oncologists who practiced at regional facilities (OR 2.21, 95% CI 1.17-4.15; *P*=.01). For colorectal cancer care, we did not observe any significant associations between oncologist characteristics and telehealth encounters (*P*<.05); however, male patients with colorectal cancer were about half as likely to have telehealth encounters compared with female patients (OR 0.53, 95% CI 0.35-0.81; *P*=.003). For lung cancer care, patient encounters with radiation oncologists were more likely to occur via telehealth (OR 5.42, 95% CI 1.44-20.45; *P*=.01; reference=medical oncology), and patient encounters with physicians who practiced at more than 1 location were less likely to occur via telehealth (OR 0.26, 95% CI 0.09-0.76; *P*=.01). We assessed the variance in telehealth use explained by the random effects for patient and oncologist using the ICC (Table 3). The proportion of variance explained by the random effect for patient ranged from 0.14 for colorectal cancer to 0.17 for breast cancer. The proportion of variance explained by the random effect for oncologist ranged from 0.14 for colorectal cancer to 0.33 for lung cancer.

To gain insight into how telehealth use may have impacted relationships between oncologists, we assembled patient-sharing networks for cancer for the pre- and post–COVID-19 time periods. The post–COVID-19 patient-sharing networks for breast, colorectal, and lung cancer care are illustrated in Figure 1. Each node (circle) represents a physician, and a line connecting 2 nodes indicates that the 2 physicians shared patients with cancer. We assessed the overall structures of the pre–COVID-19 and post–COVID-19 networks based on 4 global network measures: density, the number of observed ties divided by the total number of possible ties; transitivity, the tendency of sets of 3 physicians to form a connected triangle; average distance, the average number of steps along the network it takes to connect each pair of physicians; and centralization, the variation in the degree centrality (number of ties) across physicians (Table 4). Network density, transitivity, and average distance were similar before and post COVID-19 for all 3 cancer networks. Centralization was lower in the post–COVID-19 network for all 3 cancer types, which may reflect less care being centralized among oncologists at the hub and more dispersed across providers in regional facilities.

We hypothesized that telehealth uptake in this health system may have led to more ties between pairs of oncologists that span the hub hospital and regional facilities in the post–COVID-19 network compared to the pre–COVID-19 network. Lung cancer care saw the most significant change in the distribution of edges across the 2 time periods, with 21.6% (79/370) of ties before COVID-19 and 29.3% (93/318) of ties post COVID-19 being between a hub hospital and non–hub hospital–based oncologist (*P*=.03; Table 4). For breast and colorectal cancer care, the distribution of ties was not statistically different between time periods. We next used *ergms* to examine the likelihood of ties forming between oncologists who are colocated at the hub hospital. In each cancer type, the homophily coefficient was positive in both time periods, reflecting the greater likelihood of a tie forming between pairs of physicians who both practice at the hub hospital (Table 4). If there is a greater likelihood of ties between pairs of oncologists that span the hub hospital and regional facilities post COVID-19 (conditional on the rest of the network), we would expect to see a lower homophily coefficient in the post–COVID-19 network compared with the pre–COVID-19 network. The most notable change before and post COVID-19 was observed in the lung cancer network. Ties between colocated oncologists were 2.45 (95% CI 1.98-3.03) times as likely to occur compared with those that were not colocated at the hub hospital in the pre–COVID-19 network, and the estimated likelihood in the post–COVID-19 network was reduced to 1.92 (95% CI 1.46-2.51).

Table 1. Characteristics of patients diagnosed with breast, colorectal, or lung cancer at Dartmouth Health.

Patient characteristic	Cancer type		
	Breast (n=1535)	Colorectal (n=601)	Lung (n=1145)
Year of diagnosis, n (%)			
2018	514 (33.5)	208 (34.6)	396 (34.6)
2019	531 (34.5)	199 (33.1)	411 (35.9)
2020	490 (31.9)	194 (32.3)	338 (29.5)
Age at diagnosis (years), median (IQR)	63 (54-71)	66 (55-75)	68 (62-75)
Male, n (%)	<11[a]	300 (49.9)	556 (48.6)
Race/ethnicity, n (%)			
Non-Hispanic White	1470 (95.8)	572 (95.2)	1116 (97.5)
Non-Hispanic Black	17 (1.1)	<11	<11
Hispanic/Latino	25 (1.6)	<11	<11
Unknown	23 (1.5)	14 (2.3)	15 (1.3)
Ever used telehealth, n (%)	456 (29.7)	178 (29.6)	317 (27.7)

[a] Values with fewer than 11 patients were suppressed to protect patient confidentiality.

Table 2. Characteristics of oncologists in the pre- and post–COVID-19 patient-sharing networks.

Characteristic	Patient-sharing network type								
	Breast cancer			Colorectal cancer			Lung cancer		
	Before COVID-19 (n=78)	Post COVID-19 (n=77)	*P* value	Before COVID-19 (n=72)	Post COVID-19 (n=66)	*P* value	Before COVID-19 (n=77)	Post COVID-19 (n=54)	*P* value
Specialty, n (%)									
Medical oncology	33 (42)	29 (38)	.83	35 (49)	33 (50)	.99	36 (47)	27 (50)	.50
Radiation oncology	10 (13)	10 (13)		9 (12)	8 (12)		10 (13)	10 (19)	
Surgery	35 (45)	38 (49)		28 (39)	25 (38)		31 (40)	17 (31)	
Patient volume, median (IQR)	16 (6-51)	10 (4-30)	.07	6 (3-14)	4 (2-11)	.10	6 (2-29)	9 (1-22)	.47
Multisite physician, n (%)	24 (31)	19 (25)	.40	17 (24)	16 (24)	.93	22 (29)	19 (35)	.42
Hub-hospital physician, n (%)	44 (56)	39 (51)	.47	45 (62)	41 (62)	.96	56 (73)	39 (72)	.95
Ever used telehealth, n (%)	2 (3)	53 (69)	<.001	1 (1)	33 (50)	<.001	2 (3)	33 (61)	<.001

Table 3. Multilevel models of the odds of an encounter being via telehealth by cancer type post COVID-19.

	Cancer type					
	Breast	*P* value	Colorectal	*P* value	Lung	*P* value
Patient characteristics, OR[a] (95% CI)						
Age at diagnosis (years)	1.01 (0.99-1.02)	.24	1.00 (0.99-1.02)	.59	1.01 (0.99-1.03)	.25
Male sex	N/A[b]		0.53 (0.35-0.81)[c]	.003	1.12 (0.80-1.57)	.51
Oncologist characteristics, OR (95% CI)						
Cancer specialty						
Medical oncology	Ref[d]		Ref		Ref	
Radiation oncology	0.81 (0.30-2.21)	.69	0.73 (0.25-2.15)	.57	5.42 (1.44-20.45)[c]	.01
Surgery	0.38 (0.20-0.71)[c]	.003	0.49 (0.21-1.15)	.10	0.68 (0.18-2.58)	.57
Patient volume						
Low	Ref		Ref		Ref	
Medium	3.84 (1.09-13.62)[c]	.04	1.24 (0.38-4.07)	.74	1.98 (0.32-12.14)	.46
High	1.09 (0.40-2.96)	.87	0.92 (0.37-2.28)	.84	0.34 (0.09-1.28)	.11
Multisite physician	0.58 (0.28-1.22)	.15	0.70 (0.30-1.63)	.40	0.26 (0.09-0.76)[c]	.01
Hub-hospital physician	2.21 (1.17-4.15)[c]	.01	1.10 (0.51-2.38)	.82	1.46 (0.45-4.72)	.53
Intraclass correlation coefficient						
Oncologist	0.163	N/A	0.144	N/A	0.333	N/A
Patient	0.171	N/A	0.135	N/A	0.142	N/A
Overall	0.334	N/A	0.286	N/A	0.475	N/A

[a] OR: odds ratio.

[b] N/A: not applicable.

[c] Significant, *P*<.05.

[d] Ref: reference.

Figure 1. Post–COVID-19 patient sharing networks for (A) breast cancer, (B) colorectal cancer, and (C) lung cancer. TH: telehealth.

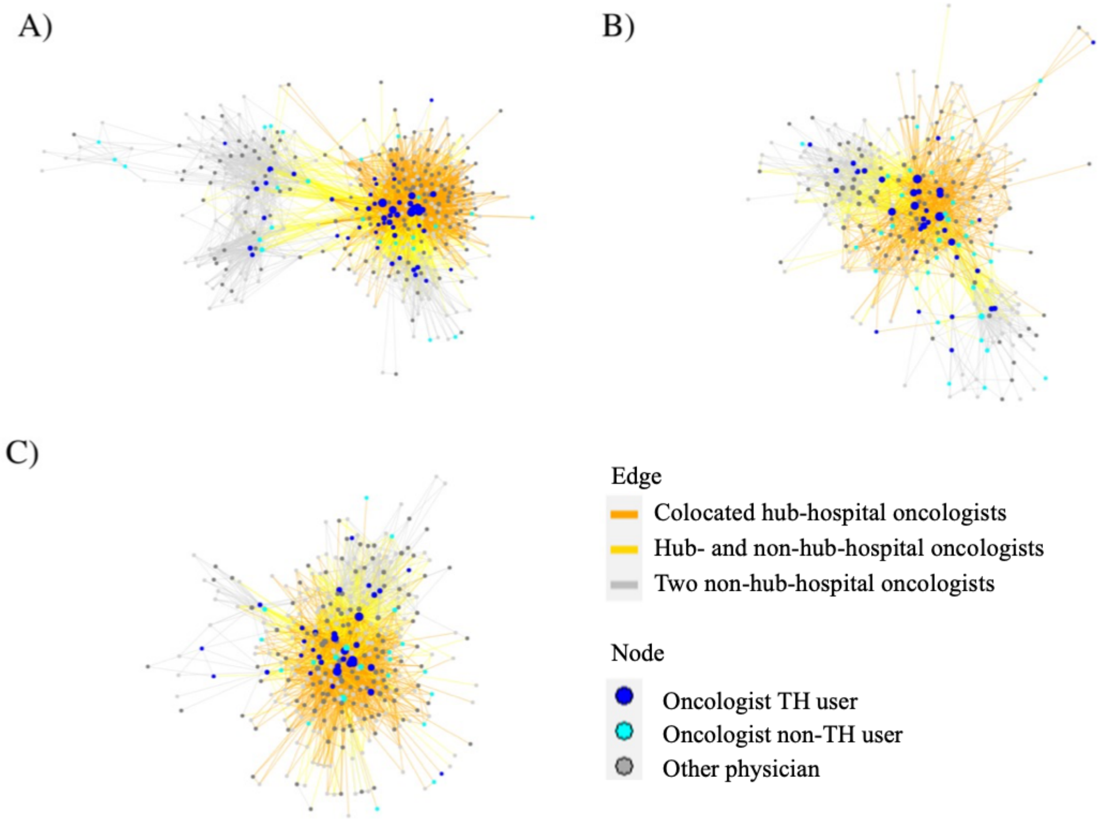

Table 4. Patient-sharing networks before and post COVID-19. Only nonnull dyads were considered when characterizing edges based on hub-hospital physicians.

	Before COVID-19	Post COVID-19	*P* value
Breast cancer			
Global network statistics			
Density	0.057	0.044	N/A[a]
Transitivity	0.252	0.266	N/A
Average distance	2.229	2.478	N/A
Centralization	0.612	0.442	N/A
Hub-hospital oncologists in dyad (before COVID-19: n=651; post COVID-19: n=635), n (%)			
2	369 (56.7)	353 (55.6)	.09
1	223 (34.3)	201 (31.7)	
0	59 (9.1)	81 (12.8)	
Homophily coefficient for practicing at the hub hospital (95% CI)	2.46 (2.08-2.9)[b]	2.74 (2.27-3.3)[b]	N/A
Colorectal cancer			
Global network statistics			
Density	0.049	0.042	N/A
Transitivity	0.260	0.290	N/A
Average distance	2.330	2.602	N/A
Centralization	0.450	0.320	N/A
Hub-hospital oncologists in dyad (before COVID-19: n=340; post COVID-19: n=339), n (%)			
2	215 (63.2)	190 (56.1)	.09
1	91 (26.8)	99 (29.2)	
0	34 (10.0)	50 (14.8)	
Homophily coefficient for practicing at the hub hospital (95% CI)	2.67 (2.14-3.33)[b]	2.55 (1.98-3.28)[b]	N/A
Lung cancer			
Global network statistics			
Density	0.050	0.041	N/A
Transitivity	0.246	0.279	N/A
Average distance	2.198	2.424	N/A
Centralization	0.564	0.363	N/A
Hub-hospital oncologists in dyad (before COVID-19: n=370; post COVID-19: n=318), n (%)			
2	277 (74.9)	208 (65.4)	.03
1	79 (21.6)	93 (29.3)	
0	14 (3.8)	17 (5.4)	
Homophily coefficient for practicing at the hub hospital (95% CI)	2.45 (1.98-3.03)[b]	1.92 (1.46-2.51)[b]	N/A

[a] N/A: not applicable.

[b] Exponential-family random graph model.

Discussion

This study assessed telehealth use within the Dartmouth Health system in rural northern New England. We found that physician specialty, patient volume, practicing at multiple locations, and practicing at the hub hospital were associated with telehealth use, but the strength of these associations differed across cancer types. Our study also corroborates recent work that found that variation across practices and clinicians explains a substantial amount of the variance in telehealth use [25,26]. Interestingly, we observed that patient encounters with oncologists who practice at more than 1 location were less likely to occur via telehealth. Considering telehealth and traveling oncologists are both potential levers that health systems can pull to increase access to care for otherwise underserved patient populations, examining how these resources complement each other and their impact on care quality and patient experience may inform strategies on equitable resource allocation to optimize access to care.

In addition to assessing characteristics of oncologists, our study examined how the uptake of telehealth post COVID-19 may have impacted the structure of relationships between physicians. Whether telehealth in oncology provides avenues for new referral paths and in what context will inform how this technology may be leveraged to address barriers in access to care in areas with limited oncologist supply. Patient-sharing networks showing significant changes, such as those we observed in the lung cancer network, may reflect new referral patterns between geographically distant providers that were established with the uptake of telehealth, whereas no changes may indicate that telehealth was primarily used in place of care that would have been delivered in person prior to the pandemic. This hypothesis could be explored in interviews with cancer providers and patients and tested further in larger claims-based data sets.

Our study has several limitations that may limit generalizability of our findings. First, all clinical encounters were limited to a single health care system. Dartmouth Cancer Center is the only National Cancer Institute–designated cancer center in northern New England, and its catchment area spans New Hampshire, Vermont, and some portions of Maine and northern New York. However, we are unable to observe clinical encounters that occurred outside of Dartmouth Health and its affiliated sites. Second, our study cohort only includes patients who were diagnosed through December 2020, and the data analyzed include their encounters 12 months following their diagnosis or through September 2021. The decline in telehealth use among oncologists observed for the last months of our study is likely exaggerated due to not including data from patients diagnosed with cancer in 2021. Efforts to track telehealth use among oncologists early versus late in the pandemic, and beyond 2021 as the data become available, may uncover associations and trends that were not evident in the time period analyzed in this study. Third, patient-level unmeasured confounders, such as insurance type and travel distance to physicians, may have contributed to telehealth use and the presence of ties in the patient-sharing network. Fourth, we are unable to control for other secular trends in the pre- and post–COVID-19 time periods that may have contributed to changes in the patient-sharing networks. Finally, this was a retrospective observational study so causality cannot be determined.

After the rapid uptake of telehealth in response to the COVID-19 pandemic, we are now starting to observe how and where telehealth may persist in the delivery of cancer care. Ongoing research on patient preferences and access to telehealth, in addition to physician and care team preferences, will be critical to mitigate disparate access to telehealth services [27-31]. Our study finds that the characteristics of oncologists who used telehealth differed across cancer types, indicating that efforts to standardize use across cancer care providers may be needed to reduce unwarranted variation in its implementation. Alternatively, our findings may indicate that the acceptability and appropriateness of telehealth varies across cancer types. The dissemination of guidelines for telehealth use during cancer care will support efforts aiming to reduce unwarranted variation in telehealth use among patients diagnosed with cancer and their care teams [32,33]. The extent to which telehealth changes access to cancer care and coordination of care among all providers and individuals in a patient's care team is an area of active study [34]. Analyzing patient-sharing networks from administrative data as more current data sets become available can continue to shed light on whether telehealth is having an impact on cancer referral pathways and the organization of relationships between providers involved in cancer care.

Acknowledgments

Research reported in this publication was supported by the National Cancer Institute of the National Institutes of Health under Award Number R37CA263936 (to ELM) and the National Cancer Institute of the National Institutes of Health under Award Number R01CA267990 (to TO). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Data Availability

The data sets generated and analyzed for the current study are not publicly available to due data use agreements with Dartmouth Health because they contain protected health information. Researchers interested in obtaining these data would need to submit their own requests with Dartmouth Health Human Research Protection Program institutional review board.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary material.
[DOCX File , 1438 KB - cancer_v9i1e42334_app1.docx]

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Abbreviations

ERGM: exponential-family random graph modeling
ICC: intraclass correlation coefficient
OR: odds ratio

Edited by A Mavragani; submitted 31.08.22; peer-reviewed by B Wolfe-Piggott, A Saha; comments to author 11.11.22; revised version received 02.12.22; accepted 19.12.22; published 17.01.23.

Please cite as:
Yu L, Liu YC, Cornelius SL, Scodari BT, Brooks GA, O'Malley AJ, Onega T, Moen EL
Telehealth Use Following COVID-19 Within Patient-Sharing Physician Networks at a Rural Comprehensive Cancer Center: Cross-sectional Analysis
JMIR Cancer 2023;9:e42334
URL: https://cancer.jmir.org/2023/1/e42334
doi:10.2196/42334
PMID:36595737

Original Paper

Moving Forward With Telehealth in Cancer Rehabilitation: Patient Perspectives From a Mixed Methods Study

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Abstract

Background: The COVID-19 pandemic accelerated the use of telehealth in cancer care and highlighted the potential of telehealth as a means of delivering the much-needed rehabilitation services for patients living with the side effects of cancer and its treatments.

Objective: This mixed methods study aims to explore patients' experiences of telehealth and their preferences regarding the use of telehealth for cancer rehabilitation to inform service development.

Methods: The study was completed in 2 phases from October 2020 to November 2021. In phase 1, an anonymous survey (web- and paper-based) exploring the need, benefits, barriers, facilitators, and preferences for telehealth cancer rehabilitation was distributed to survivors of cancer in Ireland. In phase 2, survivors of cancer were invited to participate in semistructured interviews exploring their experiences of telehealth and its role in cancer rehabilitation. Interviews were conducted via telephone or video call following an interview guide informed by the results of the survey and transcribed verbatim, and reflexive thematic analysis was performed using a qualitative descriptive approach.

Results: A total of 48 valid responses were received. The respondents were at a median of 26 (range 3-256) months after diagnosis, and 23 (48%) of the 48 participants had completed treatment. Of the 48 respondents, 31 (65%) reported using telehealth since the start of the pandemic, 15 (31%) reported having experience with web-based cancer rehabilitation, and 43 (90%) reported a willingness for web-based cancer rehabilitation. A total of 26 (54%) of the 48 respondents reported that their views on telehealth had changed positively since the start of the pandemic. Semistructured interviews were held with 18 survivors of cancer. The mean age of the participants was 58.9 (SD 8.24) years, 56% (10/18) of the participants were female, and 44% (8/18) of the participants were male. Reflexive thematic analysis identified 5 key themes: telehealth improves accessibility to cancer rehabilitation for some but is a barrier for others, lived experiences of the benefits of telehealth in survivorship, the value of in-person health care, telehealth in cancer care and COVID-19 (from novelty to normality), and the future of telehealth in cancer rehabilitation.

Conclusions: Telehealth is broadly welcomed as a mode of cancer rehabilitation for patients living with and beyond cancer in Ireland. However, issues regarding accessibility and the importance of in-person care must be acknowledged. Factors of convenience, time savings, and cost savings indicate that telehealth interventions are a desirable patient-centered method of delivering care when performed in suitable clinical contexts and with appropriate populations.

(JMIR Cancer 2023;9:e46077) doi:10.2196/46077

KEYWORDS

telehealth; telemedicine; cancer rehabilitation; oncology; qualitative; mixed methods; mobile phone

Introduction

Background

Telehealth has been widely adopted as an effective way to provide health care and continue access to a vast range of clinical specialties since the beginning of the COVID-19 pandemic [1-4]. Before this, telehealth, that is, the provision of health care at a distance using information and communication technology [5], was not widely used, despite being in existence for several decades [4,6]. Although the sudden and widespread adoption of telehealth in 2020 enabled the continued provision of health care, it also fueled an investment in digital infrastructure, regulatory changes, and innovations in care, creating an ideal environment for its continued growth [7-9]. Emerging literature suggests that there is a role for telehealth beyond the pandemic to enhance patient outcomes and improve convenience, efficiency, and access to care [8,10,11].

Cancer rehabilitation aims to reduce the physical, psychosocial, and cognitive effects of cancer and its treatment on patients through specialist input from health care professionals, including physiotherapists, psycho-oncologists, exercise physiologists, dietitians, and occupational therapists [12]. Many cancer rehabilitation services that were previously delivered in person swiftly pivoted to telehealth models of delivery at the beginning of the pandemic. Telehealth was found to be acceptable and feasible in cancer rehabilitation [1], and it offers several advantages to patients, including reduced travel time, improved access to those where geographical distance previously precluded participation, reduced costs, and greater convenience, indicating that telehealth can be a valuable, patient-centered mode of service delivery once it is appropriately implemented [13,14].

However, there are challenges associated with telehealth in cancer rehabilitation. Some patients require, or have a strong preference for, in-person care; equally, certain rehabilitation interventions can be unsuitable for, or compromised through, web-based delivery [13,15,16]. In addition, there are important issues regarding equality and inclusion to address. Although telehealth facilitates access in some cases, there are many groups for whom telehealth would impair access, such as those with poor internet connectivity or lower IT skills [17-19]. Many factors influence telehealth access and use, and throughout the pandemic, telehealth was found to be better adopted by those of a younger age, those with higher levels of education, and those living in urban areas [20,21].

As we emerge from the COVID-19 pandemic and health care services return to in-person models of delivery, we have a new awareness of the capability of telehealth to transform health care. Using this new information, we can harness the benefits of telehealth to develop and improve cancer rehabilitation services on national and international levels. The focus of service improvements should always be on providing high-quality care, which is accessible and safe, and be built around the needs and preferences of patients [6,22,23]. This can be achieved by first understanding patient experiences and preferences of telehealth in cancer rehabilitation and then applying this knowledge to co-design suitable services [24]. In early 2020, when many cancer rehabilitation services urgently changed from in-person to telehealth, there was no time to discuss with stakeholders how best to make this change. We now have the opportunity to consult with people living with and beyond cancer and gather recommendations for telehealth in cancer rehabilitation; this process has been commenced across other rehabilitation specialties, including cardiac and stroke rehabilitation [20,25].

Objectives

The aim of this study is to understand patient experiences of and preferences for telehealth for cancer rehabilitation, with a view to making recommendations for the development of cancer rehabilitation services in a postpandemic health care system.

Methods

Overview

A mixed methods approach was implemented across 2 methodological phases to enable an in-depth exploration of the patients' experiences of and preferences for telehealth delivery of cancer rehabilitation. In phase 1, a national survey was conducted to investigate the need, benefits, barriers, facilitators, and preferences for telehealth cancer rehabilitation. In phase 2, using a qualitative methodology, semistructured interviews were conducted to explore patients' experiences of and preferences for cancer rehabilitation via telehealth in greater depth.

Phase 1: Survey

Study Design and Participants

In phase 1, people living with and beyond cancer from across Ireland were invited to complete an anonymous survey (eg, web- and paper-based). The exclusion criterion was no history of cancer diagnosis.

Survey Instrument

The survey instrument was developed by a team of 4 researchers (LON, GS, EG, and DC) with expertise in cancer rehabilitation in partnership with 3 patient representatives who advised on the content and usability and piloted and approved the finalized survey. The final survey consisted of 25 questions, including 24 closed questions (including dropdown questions, a rating scale, and dichotomous questions [yes or no options]) and 1 open-ended question (ie, qualitative data), which were split across 3 sections. Section 1 gathered demographic information including age group, gender cancer diagnosis, and treatment. Section 2 asked participants to identify the side effects associated with their cancer and its treatments and their needs for rehabilitation. Section 3 explored (1) previous use of telehealth; (2) willingness to use telehealth for cancer rehabilitation; (3) barriers, benefits, and facilitators of telehealth; (4) preferences for the format of cancer rehabilitation via telehealth; and (5) how the COVID-19 pandemic has influenced their views on telehealth.

Data Collection and Analysis

Data were collected over a 2-month period between October and November 2020 using a voluntary sampling process. The survey was administered on the web through the XM survey software tool (Qualtrics) and circulated through the social media platforms of the Trinity St James's Cancer Institute (TSJCI) and associated clinical and academic partners, by charity partners (eg, the Oesophageal Cancer Fund and Irish Cancer Society), and through our national cancer agency the National Cancer Control Program. Paper versions of the survey were provided to patients attending physiotherapy outpatient appointments at the TSJCI, Ireland's largest cancer center.

Categorical data analysis was performed using Microsoft Excel, and the results were presented as counts and percentage frequency of responses. The responses to the open-ended question regarding the impact of COVID-19 on telehealth views were evaluated using content analysis by 2 researchers (LON and LB), who coded the responses and then grouped the responses into key findings.

Phase 2: Semistructured Interviews

Study Design and Participants

Phase 2 used qualitative methodology (ie, semistructured interviews) to gain deeper insights and understanding of the role of telehealth in the delivery of cancer rehabilitation. The inclusion criteria stated that adults with a confirmed diagnosis of cancer living in Ireland were eligible to participate. A voluntary sampling method was applied, in which participants in phase 1 were invited upon completion of the survey to express an interest in participation in phase 2. In addition, an advertisement seeking participants was circulated through the social media platforms of the TSJCI and associated clinical and academic partners, charity partners, and the National Cancer Control Program. Recruitment persisted until researchers determined that the data had reached a level of depth where no new themes or codes were emerging and the study could be reproduced [26,27]. The interviews were conducted and reported according to the Consolidated Criteria for Reporting Qualitative Research checklist for qualitative studies [28].

Data Collection and Analysis

Sociodemographic information and details pertaining to the current use of technology were reported by the participants. A total of 3 female specialist cancer rehabilitation physiotherapists (LON, LB, and GS [all recipients of PhD in the field of cancer rehabilitation]) who were experienced in qualitative research with patients living with and beyond cancer conducted the one-on-one interviews. Most participants (16/18, 89%) had no previous engagement with the research team, and 11% (2/18) of the participants had participated in previous research projects at this center. Semistructured interviews followed a flexible interview guide (Textbox 1), which was developed by a team of 4 researchers (LON, GS, EG, and DC) in partnership with our patient representatives. After completion of the survey, the interview guide was refined to address the findings and topics of interest from the survey. The interview guide explored the participants' previous experiences of telehealth and their perspectives on its role in cancer rehabilitation. Interviews were conducted remotely via telephone or video call, were audio recorded, and transcribed verbatim. The participants were not given the transcripts for their input or feedback.

Textbox 1. Phase 2 semistructured interview guide.

Phase 2 semistructured interview guide questions

1. What is your overall impression of telehealth?
2. What do you think are the advantages and disadvantages of delivering health care in this way?
3. Can you describe your experience of receiving health care through telehealth?
4. What role can telehealth play in providing cancer rehabilitation services?
5. Do you have any suggestions for how telehealth could be used to help support people during and after cancer treatment?
6. Do you think the COVID-19 pandemic has changed patients' view of telehealth? Can you describe how?

Phase 2 transcripts were imported into the NVivo (Lumivero) qualitative data analysis management software. Reflexive thematic analysis was performed using a qualitative descriptive approach [29] by 2 researchers (LON and LB) following the standardized process described by Braun and Clarke [30,31]. After a period of data familiarization, codes were generated across the data set and grouped into themes. The 2 researchers compared their codes and themes generated, and any differences in coding were resolved through consensus to determine the final themes and codes.

Ethical Considerations

Ethics approval for human participant research was granted by the Tallaght University Hospital and St James's Hospital Research Ethics Committee, Dublin, Ireland (REC:2020-07 List 25-Amendment 23). The study was conducted in accordance with the Declaration of Helsinki, and all participants provided informed consent (written or via electronic form) before undertaking the survey and the semistructured interview. To protect the privacy and confidentiality of the participants, phase 1 data were anonymous, and phase 2 data were pseudonymized. Participants received no compensation monetary or otherwise for their participation.

Results

Phase 1: Survey

A total of 48 valid responses to the survey were obtained, 44 (92%) of which were submitted on the web. Demographics and cancer-related characteristics are presented in Table 1.

Table 1. Survey participant demographics and cancer-related characteristics (N=48).

Characteristic	Values
Age (years), n (%)	
18-24	1 (2)
25-34	3 (6)
35-44	11 (23)
45-54	24 (50)
55-64	4 (8)
65-74	5 (10)
>75	0 (0)
Gender, n (%)	
Female	36 (75)
Male	11 (23)
Nonbinary	1 (2)
Time since cancer diagnosis (months), median (range)	26 (3-256)
Cancer type, n (%)	
Breast	26 (54)
Esophageal	6 (13)
Bladder	2 (4)
Lung	2 (4)
Ovarian	2 (4)
Prostate	2 (4)
Other	8 (17)
Diagnosis of metastatic cancer, n (%)	11 (23)
Cancer treatment received, n (%)	
Surgery	41 (85)
Chemotherapy	32 (67)
Radiation therapy	33 (69)
Immunotherapy	5 (10)
Stem cell therapy	1 (2)
Hormone therapy	18 (38)
Targeted therapy	3 (6)
Alternative therapy	1 (2)
Treatment status, n (%)	
Treatment completed	23 (48)
Treatment ongoing	25 (52)
Cancer and treatment side effects, n (%)	
Participants reporting side effects	41 (85)
Participants reporting ≥3 side effects	34 (71)
Participants who would like help with side effects	37 (77)

The participants were mostly female (36/48, 75%) and aged <55 years (39/48, 81%), and breast cancer was the most common diagnosis (26/48, 54%). Most of the participants (41/48, 85%) reported experiencing ongoing side effects of their cancer and treatment, and 71% (34/48) of the participants reported experiencing ≥3 side effects. The most frequent side effects were fatigue (33/48, 69%), pain (24/48, 50%), menopausal issues (19/48, 40%), anxiety (18/48, 38%), and nerve problems such as numbness and tingling (18/48, 38%). In total, 77% (37/48) of the participants reported feeling that they could benefit from seeing a health care professional regarding their side effects.

The respondents' perceptions of telehealth including ease of use, benefits, and barriers are presented in Table 2.

In total, 31 (65%) of the 48 respondents had experienced telehealth since the onset of the COVID-19 pandemic, and most of the respondents (43/48, 90%) were open to using it specifically for cancer rehabilitation. Furthermore, 26 (54%) of the 48 respondents reported that the COVID-19 pandemic had changed their views on telehealth. Content analysis of open-ended responses revealed that the pandemic required people to become more familiar with videocalls (in multiple aspects of life). Participants felt that telehealth was a safe way to access health care services during this time. Some participants were now more likely to engage in telehealth, even those who had not used it before. A small proportion of respondents (5/48, 10%) reported frustrations because of the lack of in-person contact during the pandemic. Respondents outlined preferences for future delivery of cancer rehabilitation via telehealth, and these findings have been synthesized with preferences noted in the phase 2 semistructured interviews.

Table 2. Survey participants’ experiences and perceptions of telehealth (N=48).

Telehealth-related question	Values
Used telehealth for medical or rehabilitation purposes during the COVID-19 pandemic, n (%)	
Yes	31 (65)
No	17 (35)
Type of medical, rehabilitation, or support service accessed via telehealth, n (%)	
Hospital consultant	22 (46)
GP[a] appointment	16 (33)
1:1 health care professional appointment	8 (17)
Exercise class	16 (33)
Mindfulness session	11 (23)
Relaxation session	4 (8)
Other	8 (17)
Reported ease of access to telehealth, median (range)	
Ease of use rated on a scale ranging from 0=difficult to 10=very easy	8 (0-10)
Accessed telehealth cancer rehabilitation services, n (%)	
Yes	15 (31)
No	33 (68)
Willing to access telehealth cancer rehabilitation services, n (%)	
Yes	43 (90)
No	5 (10)
Has COVID-19 changed your views on telehealth? n (%)	
Yes	26 (54)
No	22 (46)
Perceived benefits of telehealth, n (%)	
Time saved	38 (79)
Cost saved	31 (65)
Reduced waiting time	33 (69)
Reduced face-to-face interaction	25 (50)
Other	4 (8)
Perceived barriers to patients’ use of telehealth, n (%)	
Difficulty with internet access	7 (15)
Poor IT skills	2 (4)
Web-based security concerns	5 (10)
Do not like using digital technology for health	5 (10)
Other	6 (13)
Perceived facilitators to patients’ use of telehealth, n (%)	
Device provision	6 (13)
Internet provision	4 (8)
Introductory telehealth call	15 (31)
Introductory in-person session	27 (56)
Telehealth hotline	18 (38)
Other	4 (8)

[a] GP: general practitioner.

Phase 2: Semistructured Interviews

Overview

A total of 18 people with a history of cancer participated in phase 2 interviews. The median interview duration was 21 (range 7-46) minutes. Participant sociodemographic data are presented in Table 3.

Table 3. Semistructured interviews—sociodemographic characteristics (N=18).

Participant number	Gender	Age (years), range	Cancer type	Highest level of education completed	Employment status	Completed treatment
1	Male	65-74	Prostate	Master’s degree	Retired	Yes
2	Female	55-64	Breast	Secondary school	Unable to work	No
3	Male	65-74	Esophageal, kidney, and liver	Secondary school	Employed	Yes
4	Male	35-44	Esophageal	Diploma	Unable to work	Yes
5	Female	45-54	Esophageal	Trade, technical, or vocational training	Employed	Yes
6	Female	45-54	Esophageal	Master’s degree	Unable to work	Yes
7	Male	65-74	Esophageal	Bachelor’s degree	Other	Yes
8	Male	65-74	Esophageal and CLL[a]	Master’s degree	Retired	Yes
9	Male	65-74	Hodgkin lymphoma	Bachelor’s degree	Retired	Yes
10	Female	55-64	Breast	Diploma	Employed	No
11	Female	55-64	Breast	Secondary school	Unable to work	No
12	Female	55-64	Breast	Bachelor’s degree	Self-employed	No
13	Female	55-64	Breast	Doctorate degree	Retired	No
14	Male	55-64	Prostate	Diploma	Retired	Yes
15	Male	55-64	RCC[b] and lung metastases	Diploma	Employed	No
16	Female	35-44	Breast	Master’s degree	Employed	No
17	Female	55-64	Esophageal	Bachelor’s degree	Employed	Yes
18	Female	55-64	Breast	Trade, technical or vocational training	Employed	No

[a] CLL: chronic lymphocytic leukemia.

[b] RCC: renal cell carcinoma.

The mean age of the participants was 58.9 (SD 8.24) years, 56% (10/18) of the participants were female, and 44% (8/18) of the participants were male. A total of 11 (61%) of the 18 participants had completed cancer treatment. All participants reported owning a smartphone and at least 1 other digital device (eg, tablet, laptop, or desktop). In total, 10 (56%) of the 18 participants used activity monitor watches (eg, Fitbit, Garmin, and Apple watch). All participants reported daily use of digital devices, and 33% (6/18) of the respondents expressed a high level of comfort with technology gained through work or leisure activities. The findings of the reflexive thematic analysis were grouped into 5 key themes and 13 subthemes (Textbox 2).

Preferences for specific aspects of telehealth cancer rehabilitation, as reported by participants at any point in the interviews, are presented along with the survey results in Table 4.

Textbox 2. Reflexive thematic analysis themes and subthemes.

Themes and subthemes

1. Telehealth improves accessibility to cancer rehabilitation but is a barrier for others
    - Telehealth removes geographical barriers to cancer rehabilitation
    - Internet connectivity issues in rural areas
    - IT skills
2. Lived experiences of the benefits of telehealth in cancer survivorship
    - A more comfortable mode of health care delivery
    - Safe and secure care during the pandemic
3. The value of in-person health care delivery
    - The desire for personal connection
    - Limitations of telehealth
4. Telehealth in cancer care and COVID-19—from novelty to normality
    - An enforced and dramatic change
    - Now an accepted mode of health care delivery for survivors of cancer
5. The future of telehealth in cancer rehabilitation
    - Willingness exists
    - Acknowledged need for rehabilitative support
    - Amenability of cancer rehabilitation services to telehealth delivery
    - Preferences and recommendations for future services

Table 4. Preferences for cancer rehabilitation via telehealth (phase 1, survey, and phase 2, semistructured interviews)[a].

Preference	Survey, n (%)	Semistructured interview, participants reporting
Delivery of telehealth		
Individual consultation	34 (71)	P[b]5, P8, and P12
Group sessions	N/A[c]	P5, P6, P7, P11, P12, P13, P17, and P18
Small group sessions	30 (63)	Nil
Larger sessions	25 (52)	Nil
Type of telehealth cancer rehabilitation services		
Exercise class	30 (63)	P1, P2, P5, P6, P7, P9, P11, P12, P13, and P15
Educational session on		
Nutrition	29 (60)	P11
Medication management	20 (42)	Nil
Fatigue	29 (60)	Nil
Sexual well-being	17 (35)	Nil
Coping with cancer	23 (48)	P5, P6, P7, P11, P12, P13, P17, and P18
Mental health	27 (56)	P1, P2, P4, P6, P8, P11, and P15
Lymphoedema	7 (15)	Nil
Other	5 (10)	Nil
Timing for telehealth cancer rehabilitation		
Before treatment	18 (38)	P11 and P12
During treatment	23 (48)	Nil
Early stage of recovery	36 (75)	P10
Survivorship	30 (63)	P1, P5, P6, P11, and P12
Palliative care	12 (25)	Nil

[a] Phase 2 preferences were included if mentioned by respondent at any point in the semistructured interview.

[b] P: participant.

[c] N/A: not applicable.

Theme 1: Telehealth Improves Access to Cancer Rehabilitation for Some But Is a Barrier for Others

Participants described that telehealth could improve the equality of access to cancer rehabilitation through its ability to eliminate geographic limitations:

> *I think accessibility, you don't have to live in the capital city, to access the right professional, you know, that you can access from anywhere in the country.* [Participant 13]
>
> *People would have travelled across the country to be in the group...but now, the fact that we are online, we have it [all across the country].* [Participant 11]

However, they also felt that there was a risk of escalating health care inequalities in those who had poor internet connection or poor IT skills. Adequate internet connectivity was deemed an essential facilitator for the delivery of cancer rehabilitation via telehealth. Although connectivity was not an issue for most participants, 2 of them noted poor connections in rural Ireland:

> *If you're living in a rural area you're screwed, because broadband isn't really up to speed.* [Participant 4]

Although all participants who completed the semistructured interviews were comfortable with technology, they were concerned that other people, particularly older generations, may not have sufficient confidence, interest, or IT skills to engage with telehealth, highlighting that it may not be suitable for all:

> *I imagine there is people there who don't have a clue as to connecting with any of these things.* [Participant 2]
>
> *a lot of people are terrified of technology of an older age...my aunt...she certainly wouldn't be able to set up an iPad.* [Participant 10]

Theme 2: Lived Experiences of the Benefits of Telehealth in Cancer Survivorship

Most participants reported experiencing ongoing negative sequelae arising from their cancer and its treatments. Participants with ongoing fatigue or pain valued the improved efficiency of health care generated by telehealth because it reduced the time and travel demands of hospital visits:

> *When I was going through treatment, what I found probably the most exhausting was probably the commuting, so, in and out to appointments and being in queues for appointments.* [Participant 10]

Engaging in health care appointments from home via telehealth was more comfortable and less physically and mentally tiring:

> *A huge benefit was that I didn't have to leave home. I didn't have to take my break-through meds to travel.* [Participant 11]
>
> *Sometimes people physically, mentally and emotionally would prefer to stay at home.* [Participant 17]

Participants especially valued that telehealth enabled care to continue without infection risk during COVID-19 and allowed for invaluable group rehabilitative activities to continue even during the strictest periods of lockdown:

> *Especially these days where you don't want to be mixing with people, mingling, picking up bugs whatever so it definitely has a place.* [Participant 15]
>
> *Even last year in the heights and the depths of the lockdown a group of us, one of the people was trained or is training in yoga so she started doing zoom yoga.* [Participant 17]

Theme 3: The Value of In-Person Health Care Delivery

Although participants were clearly enthused by the potential of telehealth in cancer rehabilitation, most still highly valued in-person care. There was a strong desire for in-person contact, which facilitated sharing of personal information:

> *I'd be definitely more inclined to speak intimate things to the doctor in person, rather than over the phone or over Zoom.* [Participant 7]

Participants discussed how in-person care was still at the core of comprehensive health care. They valued when health care professionals could see their entire body, how they moved, their body language, and emotions:

> *With the psychotherapy, that (Zoom) really didn't work...it was all, "Oh yes, everything is fine." It wasn't all fine. I only see this lady from the shoulders up, she is not reading my body language.* [Participant 12]
>
> *I don't think anything can replicate the face to face, the personal...you can read I believe a lot more when you are present with the person.* [Participant 17]

There was a sense of loss of a less-tangible, but deeply impactful, aspect of in-person care, "the personal touch":

> *You are losing the personal touch, seeing the whites of somebody's eyes.* [Participant 15]

Participants identified aspects of health care that are not amenable to telehealth delivery:

> *I do appreciate that certain things can only be done by physical examination.* [Participant 10]
>
> *The downside of seeing the physiotherapist online was that he couldn't get his hand on (palpate) the spot.* [Participant 12]

Theme 4: Telehealth and COVID-19 (From Novelty to Normality in Cancer Survivorship)

Participants discussed how they were forced to change their mindset about telehealth because of COVID-19, and that for some, support was required to enable the transition in the model of care:

> *We have been pushed into a situation where people are being forced to use [telehealth].* [Participant 18]
>
> *I think now everything has changed because of COVID. Everything now is about your safety, isn't it?* [Participant 11]

The changes in health care delivery using telehealth were acknowledged. Some participants felt that there is a strong willingness in the general public to continue with telehealth service:

> *On the [telehealth] side of things I think people would grab it with both hands.* [Participant 9]
>
> *I want to avoid queues, I want to avoid commuting, so I personally for me, I think it has been very, very progressive.* [Participant 10]

Others identified how, with the passing of the emergency phase of the COVID-19 pandemic, there was a returning focus on in-person care and that telehealth options may not be as available:

> *Actually, what has been talked about with some cancer people I know, regret at how the world is reverting to face to face, closing off the online options.* [Participant 13]

Theme 5: The Future of Telehealth in Cancer Rehabilitation

The participants were clearly enthusiastic about the continued delivery of cancer rehabilitation via telehealth. Participants discussed that any lessons from the recent escalation in telehealth delivery during the pandemic should be brought forward to enhance rehabilitative options for patients living with and beyond cancer:

> *I may be too enthusiastic about it but I don't really see any downsides to it. I really just see it as an enormous positive.* [Participant 13]
>
> *There's an old saying in business, never waste a crisis so whatever you guys have learned about what has worked in the pandemic hold onto it for dear life and don't roll back on it.* [Participant 9]

There was acknowledgment that telehealth delivery of cancer rehabilitation is a developing practice, and there is considerable need for further evaluation and implementation of these types of services for survivors of cancer:

> *I was shocked to see that in the current Slainte Care programme (Irish health care policy document) that has been released that there is not a big focus around*

> *cancer and telehealth for cancer patients or cancer society.* [Participant 14]

Participants highlighted that across the cancer survivorship trajectory, even long into survivorship, individuals may struggle to cope with the physical and psychosocial impairments that occur because of their cancer and its treatments and expressed frustration regarding the lack of rehabilitative support available:

> *With the COVID thing where you're not to go out, not to go to crowds, all this thing that you're at home a lot, just trying to cope with all that at the minute is quite hard.* [Participant 2]
>
> *What I found was very lacking, the mental health end of things.* [Participant 11]
>
> *I think the level of care I was given was excellent, but, what I would say was that aftercare, physically, emotionally, was really lacking.* [Participant 16]

Participants discussed that many forms of cancer rehabilitation of physical and psychosocial nature could be easily implemented via telehealth:

> *The other element of the physio would be the exercises to do, post-surgery...I don't see why they couldn't be delivered online.* [Participant 10]
>
> *I already do meditation...it's really, really, good on telehealth (I don't really want to be in a room with a group of other people when I am closing my eyes).* [Participant 2]

Despite the overwhelming positive attitude of participants toward telehealth, they highlighted that it is not suitable for all and that some will need support to access telehealth-based health care:

> *People might need to be eased into it rather than driven into it.* [Participant 9]

It was important to participants that telehealth technologies be user-friendly and connected across health services:

> *I think some of it is out there and the problem is it has become a bit fragmented.* [Participant 13]
>
> *Technology, now, mind you, sometimes I would like to throw it in the bin, I know what I need to know and the extra stuff I don't want to know.* [Participant 12]

There was a strong desire for reputable and trustworthy information. Participant 10 reported that despite having multiple spinal metastases, "proper medical supervised good information" from a web-based source allowed her to feel protected while doing exercise via telehealth. Some suggested that a hybrid model of rehabilitation would be of benefit to survivors of cancer:

> *I think we need to move to a hybrid model...People I talk to online, former cancer patients, don't really want to go back to only face to face.* [Participant 13]

Discussion

Principal Findings

This mixed methods study shows evidence that telehealth-based cancer rehabilitation is broadly acceptable and welcomed by people living with and beyond cancer in Ireland. Participants in both phases of this study deemed telehealth to be highly acceptable for both physical and psychosocial cancer rehabilitation and acknowledged its convenience for this population. Nonetheless, there were some concerns about the limitations of telehealth, particularly regarding accessibility issues, and there was a strong preference among participants to maintain some aspect of in-person care.

A key finding of this study is that there is an important potential role for telehealth in the delivery of cancer rehabilitation. Participants in both phases identified that a wide range of cancer rehabilitation services are amenable to delivery via telehealth, for example, exercise classes, dietetic support, and counseling. Moreover, most phase 1 participants (41/48, 85%) reported experiencing side effects from their cancer and its treatments, which would benefit from rehabilitative input. Up to 40% of survivors of cancer live with long-term posttreatment sequelae including pain, fatigue, and psychosocial issues, and many more individuals experience debilitating short-term side effects, all of which can negatively affect physical function, social engagement, and ultimately quality of life and well-being [32,33]. The impact of these side effects is disproportionally placed on those of lower financial means, experiencing isolation and comorbidities [34]. There is evidently a high requirement for cancer rehabilitation services, especially those that are low cost and easily accessible to people living in isolated circumstances, for example, living in rural areas or without access to transport. However, cancer rehabilitation programs are not the standard of care in many jurisdictions, and existing cancer rehabilitation services are often underresourced and in need of significant investment and expansion to meet demands [35]. Accordingly, new models of care are required to meet these significant demands. Telehealth has the capability to help address these service demands and is widely cited in the literature as a patient-centered means of rehabilitative support that may positively affect functional outcomes [36-38].

The results of the national survey revealed that time and cost savings were popular benefits of telehealth, and during the semistructured interview, respondents elaborated further on this to reveal that the reduction in travel burden was specifically a main benefit of telehealth. Cancer rehabilitation services in Ireland are typically located in major teaching hospitals in urban centers, and the ability to access health care from one's own home using telehealth was particularly welcomed by phase 2 participants who reported that they were living in rural communities. Globally, there are considerable inequities reported between urban and rural dwelling survivors of cancer [39]. Although the incidence of cancer is typically higher in urban areas, those from more rural communities have an elevated risk of poor health outcomes, with higher levels of cancer-related morbidity and mortality consistently reported [40,41]. These findings may be attributed to the limited availability of clinical care and supportive care services in rural areas, the acknowledged transportation barriers, and the significantly higher financial burden (eg, increased transport costs and increased time away from employment) experienced by rural survivors of cancer. Telehealth provides a unique opportunity to help reduce this health care inequality. Efforts to implement rehabilitative services via telehealth for rural-dwelling survivors of cancer have been warmly received to date. Doorenbos et al [42] previously highlighted how an online support group for rural American Indian and Alaska Native communities survivors of cancer was a viable method of supporting these rurally isolated groups and helped generate a feeling of no longer being alone on the cancer journey. Previous work by our research group [13] also flagged the benefits of telehealth delivery for those from rural communities; in a feasibility study of 12 survivors of esophagogastric cancer who undertook a 12-week multidisciplinary telehealth rehabilitation program, the ability to join sessions from any location with an internet connection was considered very positive and facilitated the participation of patients who lived far away from the urban hospital with minimal disruption to their daily lives. Similarly, Waterland et al [43] recently reported that telehealth was a well-received method of rehabilitation delivery to those in rural and regional areas of Australia about to embark on major cancer surgery. These findings complement the views of our rural participants who welcomed the opportunity to avail cancer rehabilitation without the need to travel to an urban center and highlight the importance of continuing to maintain and develop telehealth cancer rehabilitation services in the postemergency phase of the pandemic.

There was a consensus among participants in both phases of this study that maintaining some level of in-person contact is very important for cancer survivorship care. Concerns remain that telehealth delivery may lead to diminishment of the much-valued patient–health care provider relationship, and a strong recommendation from the semistructured interviews conducted as part of this study was that before commencing cancer rehabilitation via telehealth, patients should have an opportunity to meet in-person with the health care professional to establish their relationship. Similar concerns have been reported in previous work in this field. Recently, Dennett et al [44] reported on the rapid implementation of an exercise-based telehealth rehabilitation program for survivors of cancer. Despite high satisfaction with the rapid care delivery achieved through telehealth, participants felt a sense of loss of meaningful personal connections through this mode of delivery. Indeed, evaluations of telehealth cancer rehabilitation programs consistently report a desire for an element of in-person care to accompany telehealth delivery [45,46]. To this end, the option of a hybrid approach to delivery (ie, a mix of in-person and telehealth delivery) may be an attractive compromise for those survivors of cancer who seek both the benefits of telehealth delivery and in-person care. There is limited literature available on the efficacy of a hybrid approach to cancer rehabilitation, indicating that this topic has been relatively understudied to date. Considerable research is required on how best to deliver cancer rehabilitation in a hybrid mode. Building on our findings from the ReStOre@Home study [13], we will investigate a hybrid approach to cancer rehabilitation in the ReStOre II trial, a randomized controlled trial investigating the efficacy of a 12-week multidisciplinary program of rehabilitation for survivors of upper gastrointestinal and hepatopancreaticobiliary cancers [47].

The results of the survey strongly indicated that telehealth is a welcomed method of delivering a wide variety of cancer rehabilitation services (eg, exercise rehabilitation, fatigue management, and psychological support) in a variety of formats (eg, one-to-one and group-based rehabilitation) across the cancer trajectory from diagnosis to palliative care. When explored more deeply in the semistructured interviews, there was a strong desire for future telehealth cancer rehabilitation services to be delivered in a more effective, inclusive, and patient-centered manner. Moreover, given the unprecedented acceleration of the use of telehealth throughout the COVID-19 pandemic, it is incumbent that any advances in care achieved are maintained, optimized, and used to further improve the equality of access to cancer rehabilitation. The main barriers to the widespread implementation of cancer rehabilitation via telehealth are often because of disparities in internet connectivity, access to devices, and IT knowledge and skills. There is a clear need to minimize these disparities to improve accessibility and maximize inclusion in telehealth-based rehabilitation [48]. Access to high-speed internet is a persistent and prevalent issue, particularly for those living in more rural areas. For example, 2021 figures from the Central Statistics Office in Ireland reported a lower rate of household internet access in the more rural western and northern border areas of Ireland (78% and 75%, respectively), compared with a rate of 93% of households nationally [49]. Lack of access to suitable digital devices can also be a barrier to engaging in telehealth; however, the provision of an IT device by health care or research professionals has been demonstrated as an effective and comparatively affordable method to support inclusion in telehealth interventions [13,50]. Finally, given that only 63% of the world's population uses the internet, poor digital health literacy is the largest challenge to telehealth engagement [51]. Various educational approaches have been used in the literature to improve digital health knowledge and self-efficacy. These include didactic training, workshops, collaborative learning, and peer tutor models to impart knowledge and improve self-efficacy [52]. Further investigation of these strategies is required to help improve accessibility to telehealth as a means of delivering cancer rehabilitation to a wider cohort of the world's survivors of cancer.

Drawing on the findings from this study and the related literature described in the discussion above, we compiled a list of recommendations for the design and development of telehealth cancer rehabilitation services. These recommendations are presented in Textbox 3.

Textbox 3. Recommendations for the design and development of telehealth cancer rehabilitation services.

Recommendations for the design and development of telehealth cancer rehabilitation services

1. Providers of cancer rehabilitation services should be supported to develop a telehealth arm to their services, if they are not already doing so.
2. A wide range of cancer rehabilitation specialties and disciplines should consider delivering services via telehealth.
3. Appraise patients' suitability for telehealth carefully before commencing the intervention. Assess their level of digital skills, internet connectivity, and access to a suitable device.
4. Offer an in-person session for the patient's first appointment to optimally establish an interpersonal relationship. Encourage and facilitate take-up of this option.
5. Examine how elements of in-person care can be most effectively offered throughout the treatment pathway, for example, develop a hybrid model and provide occasional in-person sessions.
6. Provide an equivalent in-person service for those unable to, or who decline to, use telehealth services.

Study Strengths and Limitations

The primary strength of this study is its focus on the patients' voices, which was largely unheard during the rapid change to telehealth services in 2020. Another key strength lies in the robust mixed methods approach. It leveraged the survey findings to shape the interview guide, enabling researchers to delve into important issues with greater depth when engaging with survivors of cancer.

The proportionally low number of in-person surveys completed is because of the restrictions on in-person services during the COVID-19 pandemic. Fewer patients were available in the hospital to be approached for completing the survey, and there were restrictions on interactions with those who were present in person. This limitation has resulted in a high number of responses being gathered on the web, which may be biased toward those who are more comfortable with digital technologies and, therefore, more interested in telehealth. We also acknowledge that all participants in phase 2 were familiar with IT, reporting daily IT use; therefore, there is a need for future research to focus on the viewpoints of those who are less frequent users of IT or those who have difficulty accessing IT and therefore may have differing viewpoints on telehealth. We also note that 10% (5/48) of those surveyed were aged >65 years and that people with breast cancer were disproportionately overrepresented. Future work should focus more on *offline* data collection and specifically seek the opinions of older adults and those with a wider range of cancer diagnoses. We also acknowledge that future studies regarding the development of telehealth services should be inclusive of all stakeholders, especially health care professionals; however, this was beyond the scope of this study, which focused on the patients' voices.

Conclusions

Telehealth was widely adopted during the COVID-19 pandemic, and there is now an important opportunity for cancer rehabilitation to develop patient-focused telehealth services. Telehealth is widely accepted and welcomed in cancer rehabilitation, as patients are much more familiar with it now, finding it generally convenient and capable of improving accessibility to rehabilitation services. There is also a strong desire to maintain in-person care for specific circumstances, such as initial assessments or more personal survivorship issues. Those with poor digital skills and poor internet connection must be supported to access telehealth or equivalent in-person care. People living with and beyond cancer will benefit from cancer rehabilitation services that can most appropriately draw from both the "personal touch" of in-person care and the convenience and efficiency of telehealth.

Acknowledgments

The authors would like to thank the patient representatives, Mr P Browne, Ms B Conway, and Mr T O'Neill for their contributions to the survey design process. The authors would also like to acknowledge the Irish Cancer Society, Oesophageal Cancer Fund, and National Cancer Control Programme for their support in advertising the study through their social media networks. During this project, the authors LON and LB were funded by the Health Research Board (HRB-DIFA-2018-009), and GS was funded by a joint Health Research Board and Irish Cancer Society Award (MRCG-2018-17).

Authors' Contributions

LON, GS, EG, DC, and JH conceived and designed the study. LON, LB, and GS collected the data. LON and LB performed the analysis. LON and LB wrote the manuscript with the help of GS, EG, DC, and JH.

Conflicts of Interest

None declared.

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Abbreviations

TSJCI: Trinity St James's Cancer Institute

Edited by T de Azevedo Cardoso; submitted 29.01.23; peer-reviewed by F Medina, A Mahnke; comments to author 17.07.23; revised version received 03.09.23; accepted 18.09.23; published 09.11.23.

Please cite as:
O'Neill L, Brennan L, Sheill G, Connolly D, Guinan E, Hussey J
Moving Forward With Telehealth in Cancer Rehabilitation: Patient Perspectives From a Mixed Methods Study
JMIR Cancer 2023;9:e46077
URL: https://cancer.jmir.org/2023/1/e46077
doi:10.2196/46077
PMID:37943595

Corrigenda and Addenda

Correction: The Patient Experience of Acute Lymphoblastic Leukemia and Its Treatment: Social Media Review

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Related Article:

Correction of: https://cancer.jmir.org/2023/1/e39852

(JMIR Cancer 2023;9:e54665) doi:10.2196/54665

In “The Patient Experience of Acute Lymphoblastic Leukemia and Its Treatment: Social Media Review” (JMIR Cancer 2023;9:e39852), the authors made two updates.

A plain language summary was included as Multimedia Appendix 2.

The following sentence was added to the *Conclusion*, referring to the plain language summary:

> *Information about this study in a plain language format is available in Multimedia Appendix 2.*

The correction will appear in the online version of the paper on the JMIR Publications website on December 20, 2023, together with the publication of this correction notice. Because this was made after submission to PubMed, PubMed Central, and other full-text repositories, the corrected article has also been resubmitted to those repositories.

Multimedia Appendix 1
Plain language summary.
[PDF File (Adobe PDF File), 263 KB - cancer_v9i1e54665_app2.pdf]

Submitted 17.11.23; this is a non–peer-reviewed article;accepted 21.11.23; published 20.12.23.

Please cite as:
Crawford R, Sikirica S, Morrison R, Cappelleri JC, Russell-Smith A, Shah R, Chadwick H, Doward L
Correction: The Patient Experience of Acute Lymphoblastic Leukemia and Its Treatment: Social Media Review
JMIR Cancer 2023;9:e54665
URL: https://cancer.jmir.org/2023/1/e54665
doi:10.2196/54665
PMID:38118141

Commentary

Behavior Change Techniques for the Maintenance of Physical Activity in Cancer

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Related Article:

Comment on: http://www.jmir.org/2023/1/e47187/

Abstract

Ester et al report the findings from a 2-arm cluster randomized controlled trial nested within a hybrid effectiveness-implementation study, which involved a 12-week exercise and behavior change program for rural and remote Canadians (Exercise for Cancer to Enhance Living Well [EXCEL]). The addition of 23 weeks of app-based physical activity monitoring to the EXCEL program did not result in significant between-group differences in physical activity at 6 months. While several behavior change techniques were included in the initial 12-week intervention, additional techniques were embedded within the mobile app. However, there is currently a lack of evidence regarding how many and which behavior change techniques are the most effective for people with cancer and if these differ based on individual characteristics. Potentially, the use of the mobile app was not required in addition to the behavior change support delivered to both groups as part of the EXCEL program. Further research should involve participants who may be in most need of behavioral support, for example, those with lower levels of self-efficacy. Suggestions for future research to tailor behavior change support for people with cancer are discussed.

(JMIR Cancer 2023;9:e53602) doi:10.2196/53602

KEYWORDS

cancer; physical activity; behavior change

Introduction

Ester et al [1] recently report findings from a 2-arm cluster randomized controlled trial (RCT) nested within a hybrid effectiveness-implementation study providing rural and remote Canadians access to a 12-week exercise and behavior change program (Exercise for Cancer to Enhance Living Well [EXCEL]). Maintenance of physical activity (PA) behaviors beyond the completion of an exercise program is challenging for both healthy individuals and those with chronic health conditions including cancer. This is a critical issue, given the aging population and the known health benefits of increased PA, including management of common comorbidities such as type 2 diabetes and cardiac disease, prevention of secondary cancers, reduced risk of cancer recurrence, and improvements in survival [2]. Nonetheless, <25% of RCTs of exercise in cancer report significant between-group differences in PA when measured a minimum of 6 months following program completion [3]. The findings of this cluster RCT are similar [1]. Furthermore, in the intervention group, the addition of 23 weeks of app-based PA monitoring to the program did not cause significant between-group differences in self-reported moderate to vigorous physical activity at 6 months. Notably, each group reported PA levels below the recommended guidelines at baseline. Both groups reported significant increases in PA, with weekly increases in moderate to vigorous physical activity minutes (intervention vs control groups: baseline, 60.0, IQR 0.0-180.0 vs 40.0, IQR 0.0-135.0; week 12, 240.0, IQR 117.5-387.75 vs 225.0, IQR 102.5-352.5; week 24, 205.0, IQR 87.5-330.0 vs 160.0, IQR 55.0-180.0). The authors should be commended for their focus on recruiting rural and remote participants and longer-term follow-up, which are elements that are often lacking in evaluations of exercise program effectiveness [4].

What Is Required to Change PA Behaviors?

In the initial 12-week component, both groups received the EXCEL "exercise and educate" program, which involved 5 educational topics delivered on the web and targeted the following behavior change techniques (BCTs): instruction on how to perform the behavior, goal setting, action planning, information about health consequences, and social support [5]. These BCTs appeared sufficient to support significant improvements in PA levels upon completing the 12-week intervention compared to baseline and to maintain PA behavior at the 24-week follow-up. Although additional BCTs were embedded within the mobile app (accessible to the intervention group during both the initial 12-week intervention and maintenance period), these apparently did not further improve PA levels. Evidence supporting the safety and efficacy of exercise for people with cancer is now well established [6], and as such, there is increasing focus on incorporating BCTs to support the maintenance of beneficial health behaviors post intervention. However, BCTs are not consistently embedded in PA programs for people with cancer, and reporting commonly lacks transparency, making replication difficult. In a Cochrane systematic review including 24 RCTs (comparing exercise intervention to usual care in sedentary adults), only 6 were based on a theoretical behavior change model [7]. BCT number and type in all included interventions were inconsistent, with the most common being prompting practice, providing instruction on performing the behavior, setting graded tasks, and self-monitoring (behavior and outcome). This contributed to a lack of evidence regarding the most effective BCTs for people with cancer, how many BCTs are sufficient, and whether these differ based on individual characteristics.

Engagement With Mobile Health Apps

Over three-quarters (32/42) of participants who withdrew from the EXCEL trial within the first 12 weeks were in the intervention group; however, no withdrawals occurred between 12 and 24 weeks. This raises the question of whether the participants' burden of using the mobile app along with participating in the EXCEL program was too high or whether participants simply felt it was not required. Findings from participant interviews will provide valuable insights into their app usage experiences and preferences. The app included several features that facilitate mobile health app use in the posttreatment setting, including having a cointervention alongside the app (telemonitoring and personalized feedback), easy navigation, being a single app housing all required information, visual graphs, and information on energy levels. Barriers to uptake associated with technical problems were addressed by troubleshooting support provided by EXCEL staff. Additional factors that may have improved uptake include app integration with PA trackers and the inclusion of relevant educational videos [8]. Time since treatment completion, as people learn to live with the consequences of their disease, has also been reported to be a barrier to the uptake of mobile health apps [9]. Almost half of the participants were within 3 years post treatment; however, the average posttreatment duration was not reported.

Conclusions and Future Directions

In their conclusion, Ester et al [1] highlight the need for future research assessing PA maintenance beyond 6 months post program. The generalizability of these findings also needs consideration. Despite residing in rural and remote areas and not meeting PA guidelines at baseline, the EXCEL sample may not be representative of cancer survivors most in need of behavior change support. Participants were mainly female (n=174, 87%), had incomes>US $100,000 (n=72, 36%), and were well educated (n=146, 73% completed university or college or graduate school). This raises the question of how to best target our interventions and often limited resources to those who may require more PA behavior change support. Baseline screening assessments may be necessary to identify those with lower self-efficacy or perceived behavioral control [10] or a greater number of comorbidities for inclusion in future trials. As the field progresses and the focus continues shifting to support PA maintenance, researchers should aim to investigate different approaches to delivering BCTs (eg, number of BCTs, app vs incorporated into program sessions) and how this impacts PA levels—specifically with the EXCEL trial, directly comparing the app's impact to the "exercise and educate" program. BCTs introduced in the app and the "exercise and educate" program might have been sufficient individually to support PA maintenance. The effectiveness of these approaches may also differ between participants and future research investigating characteristics of "responders" versus "nonresponders" may further guide tailored behavior change support to understand who requires what level of behavior change support and how this should be delivered.

Data Availability

Data sharing is not applicable to this article as no data sets were generated or analyzed during this study.

Authors' Contributions

LE and TJ were involved in the conceptualization, writing, review, and editing of the paper.

Conflicts of Interest

None declared.

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Abbreviations

BCT: behavior change technique
EXCEL: Exercise for Cancer to Enhance Living Well
PA: physical activity
RCT: randomized controlled trial

Edited by T de Azevedo Cardoso; submitted 18.10.23; this is a non–peer-reviewed article;accepted 09.11.23; published 28.11.23.

Please cite as:
Edbrooke L, Jones TL
Behavior Change Techniques for the Maintenance of Physical Activity in Cancer
JMIR Cancer 2023;9:e53602
URL: https://cancer.jmir.org/2023/1/e53602
doi:10.2196/53602
PMID:38015601

Publisher:
JMIR Publications
130 Queens Quay East.
Toronto, ON, M5A 3Y5
Phone: (+1) 416-583-2040
Email: support@jmir.org