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Contents

Reviews

Investigation of Intervention Solutions to Enhance Adherence to Oral Anticancer Medicines in Adults: Overview of Reviews (e34833)
Thu Dang, Abdur Forkan, Nilmini Wickramasinghe, Prem Jayaraman, Marliese Alexander, Kate Burbury, Penelope Schofield. 4

eHealth Interventions for Dutch Cancer Care: Systematic Review Using the Triple Aim Lens (e37093)
Liza van Deursen, Anke Versluis, Rosalie van der Vaart, Lucille Standaar, Jeroen Struijs, Niels Chavannes, Jiska Aardoom. 18

Viewpoints

Physicians' Perceptions of and Satisfaction With Artificial Intelligence in Cancer Treatment: A Clinical Decision Support System Experience and Implications for Low-Middle–Income Countries (e31461)
Srinivas Emani, Angela Rui, Hermano Rocha, Rubina Rizvi, Sergio Juaçaba, Gretchen Jackson, David Bates. 41

Optimizing Social Support in Oncology with Digital Platforms (e36258)
Dimos Katsaros, James Hawthorne, Jay Patel, Kaitlin Pothier, Timothy Aungst, Chris Franzese. 50

Original Papers

Making National Cancer Institute–Designated Comprehensive Cancer Center Knowledge Accessible to Community Oncologists via an Online Tumor Board: Longitudinal Observational Study (e33859)
Maitri Kalra, Elizabeth Henry, Kelly McCann, Meghan Karuturi, Jean Bustamante Alvarez, Amanda Parkes, Robert Wesolowski, Mei Wei, Sarah Mougalian, Gregory Durm, Angel Qin, Caitlin Schonewolf, Meghna Trivedi, Avan Armaghani, Frederick Wilson, Wade Iams, Anita Turk, Praveen Vikas, Michael Cecchini, Sam Lubner, Priyadarshini Pathak, Kristen Spencer, Vadim Koshkin, Matthew Labriola, Catherine Marshall, Katy Beckermann, theMednet.org NCI-CCC Tumor Board Program Collaborative Group, Marina Sharifi, Anthony Bejjani, Varsha Hotchandani, Samir Housri, Nadine Housri. 58

Identifying Themes for Assessing Cancer-Related Cognitive Impairment: Topic Modeling and Qualitative Content Analysis of Public Online Comments (e34828)
Shelli Kesler, Ashley Henneghan, Whitney Thurman, Vikram Rao. 68

Timing and Motivations for Alternative Cancer Therapy With Insights From a Crowdfunding Platform: Cross-sectional Mixed Methods Study (e34183)
John Peterson, Trevor Wilson, Joshua Gruhl, Sydney Davis, Jaxon Olsen, Matthew Parsons, Benjamin Kann, Angela Fagerlin, Melissa Watt, Skyler Johnson. 75

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Convenient Access to Expert-Reviewed Health Information via an Alexa Voice Assistant Skill for Patients With Multiple Myeloma: Development Study (e35500)
Marc-Andrea Baertsch, Sarah Decker, Leona Probst, Stefan Joneleit, Hans Salwender, Franziska Frommann, Hartwig Buettner. 84

Self-monitoring of Physical Activity After Hospital Discharge in Patients Who Have Undergone Gastrointestinal or Lung Cancer Surgery: Mixed Methods Feasibility Study (e35694)
Marijke de Leeuwerk, Martine Botjes, Vincent van Vliet, Edwin Geleijn, Vincent de Groot, Erwin van Wegen, Marike van der Schaaf, Jurriaan Tuynman, Chris Dickhoff, Marike van der Leeden. 92

Exploring Resource-Sharing Behaviors for Finding Relevant Health Resources: Analysis of an Online Ovarian Cancer Community (e33110)
Khushboo Thaker, Yu Chi, Susan Birkhoff, Daqing He, Heidi Donovan, Leah Rosenblum, Peter Brusilovsky, Vivian Hui, Young Lee. 107

Development of a Web-Based Decision Aid and Planning Tool for Family Building After Cancer (Roadmap to Parenthood): Usability Testing (e33304)
Catherine Benedict, Katherine Dauber-Decker, Jennifer Ford, D'Arcy King, David Spiegel, Lidia Schapira, Pamela Simon, Michael Diefenbach.
1 2 4

An Examination of Patients and Caregivers on Reddit Navigating Brain Cancer: Content Analysis of the Brain Tumor Subreddit (e35324)
Sanidhya Tripathi, Pearman Parker, Arpan Prabhu, Kevin Thomas, Analiz Rodriguez. 138

Implementing a Health Care Professional–Supported Digital Intervention for Survivors of Cancer in Primary Care: Qualitative Process Evaluation of the Renewed Intervention (e36364)
Jazzine Smith, Rosie Essery, Lucy Yardley, Alison Richardson, Joanna Slodkowska-Barabasz, Claire Foster, Eila Watson, Chloe Grimmett, Adam Geraghty, Paul Little, Katherine Bradbury. 147

The Acceptability of an Electronically Delivered Acceptance- and Mindfulness-Based Physical Activity Intervention for Survivors of Breast Cancer: One-Group Pretest-Posttest Design (e31815)
Michael Robertson, Emily Cox-Martin, Ross Shegog, Christine Markham, Kayo Fujimoto, Casey Durand, Abenaa Brewster, Elizabeth Lyons, Yue Liao, Sara Flores, Karen Basen-Engquist. 160

Barriers to Clinical Trial Participation: Comparative Study Between Rural and Urban Participants (e33240)
Dinesh Mudaranthakam, Byron Gajewski, Hope Krebill, James Coulter, Michelle Springer, Elizabeth Calhoun, Dorothy Hughes, Matthew Mayo, Gary Doolittle. 181

Patient and Provider Perspectives on Enrollment in Precision Oncology Research: Qualitative Ethical Analysis (e35033)
Kayte Spector-Bagdady, Madison Kent, Chris Krenz, Collin Brummel, Paul Swiecicki, J Brenner, Andrew Shuman. 189

The Cancer Research Database (CRDB): Integrated Platform to Gain Statistical Insight Into the Correlation Between Cancer and COVID-19 (e35020)
Shahid Ullah, Farhan Ullah, Wajeeha Rahman, Dimitrios Karras, Anees Ullah, Gulzar Ahmad, Muhammad Ijaz, Tianshun Gao. 195

A Cancer Exercise Toolkit Developed Using Co-Design: Mixed Methods Study (e34903)
Amy Dennett, Clarice Tang, April Chiu, Christian Osadnik, Catherine Granger, Nicholas Taylor, Kristin Campbell, Christian Barton. 209

Mobile-Based Self-management Application Requirements for Patients With Gastric Cancer: Quantitative Descriptive Study of Specialist and Patient Perspectives (e36788)
Azade Yazdanian, Hamed Mehdizadeh, Azita Balaghafari, Mahdi Kahouei, Maede Masoudinezhad. 223

Evaluation of a Mobile Health App Offering Fertility Information to Male Patients With Cancer: Usability Study (e33594)
Eden Gelgoot, Katya Kruglova, Peter Chan, Kirk Lo, Zeev Rosberger, Philippa Chown, Jordana Kazdan, Siobhan O'Connell, Phyllis Zelkowitz.
2 3 2

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Extracting Multiple Worries From Breast Cancer Patient Blogs Using Multilabel Classification With the Natural Language Processing Model Bidirectional Encoder Representations From Transformers: Infodemiology Study of Blogs (e37840)
Tomomi Watanabe, Shuntaro Yada, Eiji Aramaki, Hiroshi Yajima, Hayato Kizaki, Satoko Hori. 244

The Experiences of Patients With Adjuvant and Metastatic Melanoma Using Disease-Specific Social Media Communities in the Advent of Novel Therapies (Excite Project): Social Media Listening Study (e34073)
Guy Faust, Alison Booth, Evie Merinopoulou, Sonia Halhol, Heena Tosar, Amir Nawaz, Magdalena Szlachetka, Gavin Chiu. 253

Understanding the Lived Experiences of Patients With Melanoma: Real-World Evidence Generated Through a European Social Media Listening Analysis (e35930)
Jyoti Chauhan, Sathyaraj Aasaithambi, Iván Márquez-Rodas, Luigi Formisano, Sophie Papa, Nicolas Meyer, Andrea Forschner, Guy Faust, Mike Lau, Alexandros Sagkriotis. 264

Communicating Treatment-Related Symptoms Using Passively Collected Data and Satisfaction/Loyalty Ratings: Exploratory Study (e29292)
Ian Kudel, Toni Perry. 275

Short Paper

News Coverage of Colorectal Cancer on Google News: Descriptive Study (e39180)
Corey Basch, Grace Hillyer, Erin Jacques. 285

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Review

Investigation of Intervention Solutions to Enhance Adherence to Oral Anticancer Medicines in Adults: Overview of Reviews

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Abstract

Background: Adherence to anticancer medicines is critical for the success of cancer treatments; however, nonadherence remains challenging, and there is limited evidence of interventions to improve adherence to medicines in patients with cancer.

Objective: This overview of reviews aimed to identify and summarize available reviews of interventions to improve adherence to oral anticancer medicines in adult cancer survivors.

Methods: A comprehensive search of 7 electronic databases was conducted by 2 reviewers who independently conducted the study selection, quality assessment using the A Measurement Tool to Assess Systematic Reviews 2, and data extraction. The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2020 checklist was adapted to report the results.

Results: A total of 29 reviews were included in the narrative synthesis. The overall quality of the systematic reviews was low. The 4 main strategies to promote adherence were focused on education, reminders, behavior and monitoring, and multicomponent approaches. Digital technology–based interventions were reported in most reviews (27/29, 93%). A few interventions applied theories (10/29, 34%), design frameworks (2/29, 7%), or engaged stakeholders (1/29, 3%) in the development processes. The effectiveness of interventions was inconsistent between and within reviews. However, interventions using multiple strategies to promote adherence were more likely to be effective than single-strategy interventions (12/29, 41% reviews). Unidirectional communication (7/29, 24% reviews) and technology alone (11/29, 38% reviews) were not sufficient to demonstrate improvement in adherence outcomes. Nurses and pharmacists played a critical role in promoting patient adherence to oral cancer therapies, especially with the support of digital technologies (7/29, 24% reviews).

Conclusions: Multicomponent interventions are potentially effective in promoting patient adherence to oral anticancer medicines. The seamless integration of digital solutions with direct clinical contacts is likely to be effective in promoting adherence. Future

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research for developing comprehensive digital adherence interventions should be evidence-based, theory-based, and rigorously evaluated.

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KEYWORDS

digital; intervention; medication adherence; oncology; oral anticancer; systematic review

Introduction

With the advent of oral anticancer medicines (OACMs) more than 2 decades ago [1], there has been a gradual shift for cancer treatments to be increasingly administered at home [2]. Oncology care teams and their patients face new challenges in ensuring optimal adherence to therapy. Studies have revealed that the rate of adherence to OACMs varies widely across cancers, but it can be as low as 16% [3] and often worsens over time [4]. Medication adherence (MA) is defined as "the extent to which patients take their medication as recommended by their health care provider" [5]. Adherence is an important predictive factor for the success of OACMs [1,6], particularly when these therapies require patients to take medications correctly over a long period.

Given the high priority of adherence to OACMs in cancer care, there have been an increasing number of interventions to address MA issues, particularly in oral endocrine therapy for breast cancer [7] and oral medications for hematologic malignancies [8]. However, published reviews have disclosed that the evidence for these interventions is limited in both quantity [9] and quality [2].

In recent years, in an effort to provide more evidence in this area, there have been quite a few published reviews of adherence interventions in oncology, especially digital solutions [10-13]. However, these reviews varied in scope, methodology, and outcome of interest, which could overwhelm decision makers. This overview of reviews aimed to identify and summarize the available reviews of interventions to improve adherence to OACMs in adults with cancer. Overviews are new methodological approaches that have been used where multiple reviews already exist on the topic of interest to filter the plethora of information and provide a framework for clinical decision makers [14,15].

Methods

Overview

The study protocol was registered in the PROSPERO (International Prospective Register of Systematic Reviews) database (CRD42021240578) [16]. The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2020 statement was adapted to report this systematic review of reviews [17] and is presented in Multimedia Appendix 1 [17].

Search Strategy

A systematic literature search was performed on 7 databases for all publications up to March 2021: Ovid MEDLINE, Ovid Embase, CINAHL, PsycINFO, Web of Science, the Cochrane Database of Systematic Reviews, and the Database of Abstracts of Reviews of Effects. The Peer Review of Electronic Search Strategies checklist [18] was used to guide the development of the search strategy. The electronic search strategy was initially developed in MEDLINE by a reviewer (THD) and was then peer-reviewed by a group of experts in relevant fields (KB, MA, NW, PPJ, and PS) and a librarian to ensure its comprehensiveness. The search strategy combined controlled vocabulary and keywords, including synonyms, antonyms, and acronyms related to adherence, intervention, and cancer, and was adapted for each database. We did not limit the publication date but limited the search to the English language, human studies, and reviews only (refer to Multimedia Appendix 2 for full search strategies).

In addition to the database search, bibliographies of selected studies were also hand-searched to identify relevant studies not detected by the electronic search.

Criteria for Considering Studies for This Review

The studies had to meet all the following criteria to be eligible for inclusion:

- Population: adults (≥18 years) diagnosed with any type of cancer undergoing OACMs. Studies on children were excluded because of the specificity of treatment issues in this group. Studies in a group of the population that separately reported results for adults with cancer were also included;
- Intervention: any type of intervention that included a component to enhance patient adherence to oncology treatment;
- Comparator: usual care or active control intervention;
- Outcome: MA compliance or persistence, clinical outcomes, and quality of life of people with cancer;
- Study type: reviews, including literature review or narrative review, scoping review, and systematic review.

Study Selection

One reviewer (THD) conducted the searching, deduplication, and initial screening of titles and abstracts of all studies found. A second reviewer (ARMF) conducted a random independent assessment of the identified papers and reviewed the screening results of the first reviewer. Two reviewers independently screened all full texts of potentially eligible papers. When necessary, any differences between the 2 reviewers were discussed until consensus was reached or resolved by a third reviewer. Covidence site, operated by Veritas Health Innovation Ltd [19], was used for data screening, selection, and management.

Assessment of Methodological Study Quality

The methodological quality of the included systematic reviews was independently assessed by 2 reviewers (THD and ARMF),

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adapting the A Measurement Tool to Assess Systematic Reviews (AMSTAR) 2, which has demonstrated satisfactory reliability and construct validity [20]. AMSTAR 2 is a tool used to evaluate the methodological quality of systematic reviews, which includes randomized and nonrandomized studies of interventions, including 10 domains and 16 items or questions. The answering options were *yes*, partial *yes*, or *no/no* information (corresponding to low or high risk of bias). We used the findings from the AMSTAR 2 critical appraisal to understand the certainty of the evidence base of the systematic reviews. Disagreements were resolved by discussion.

As AMSTAR 2 does not combine individual item ratings to create an overall score, the scheme for interpreting weaknesses detected in critical (7) and noncritical (9) items, proposed by Shea et al [20], was applied. The overall confidence in the results of the review was classified as *high*, *moderate*, *low*, or *critically low*, according to the number of critical and noncritical weaknesses identified in the systematic review under appraisal.

Data Extraction and Synthesis

Data were independently extracted by 2 reviewers (THD and ARMF) in a standardized table (Multimedia Appendix 3), which was pilot-tested, for 7 random eligible studies, and then, results were compared and agreed upon. THD extracted data for the remaining eligible studies, which were then reviewed by ARMF, with discrepancies resolved through consensus. The corresponding authors of the included studies were contacted for further information or clarification, if necessary. The extracted data included the type of review, research questions, type of interventions, search strategies, search period limits, characteristics of included studies, quality assessments, methods of analyses, and findings. The included reviews were expected to have high heterogeneity in terms of interventions, comparators, outcome measures, study populations, and methodologies. Therefore, statistical pooling through meta-analysis was not appropriate.

Results

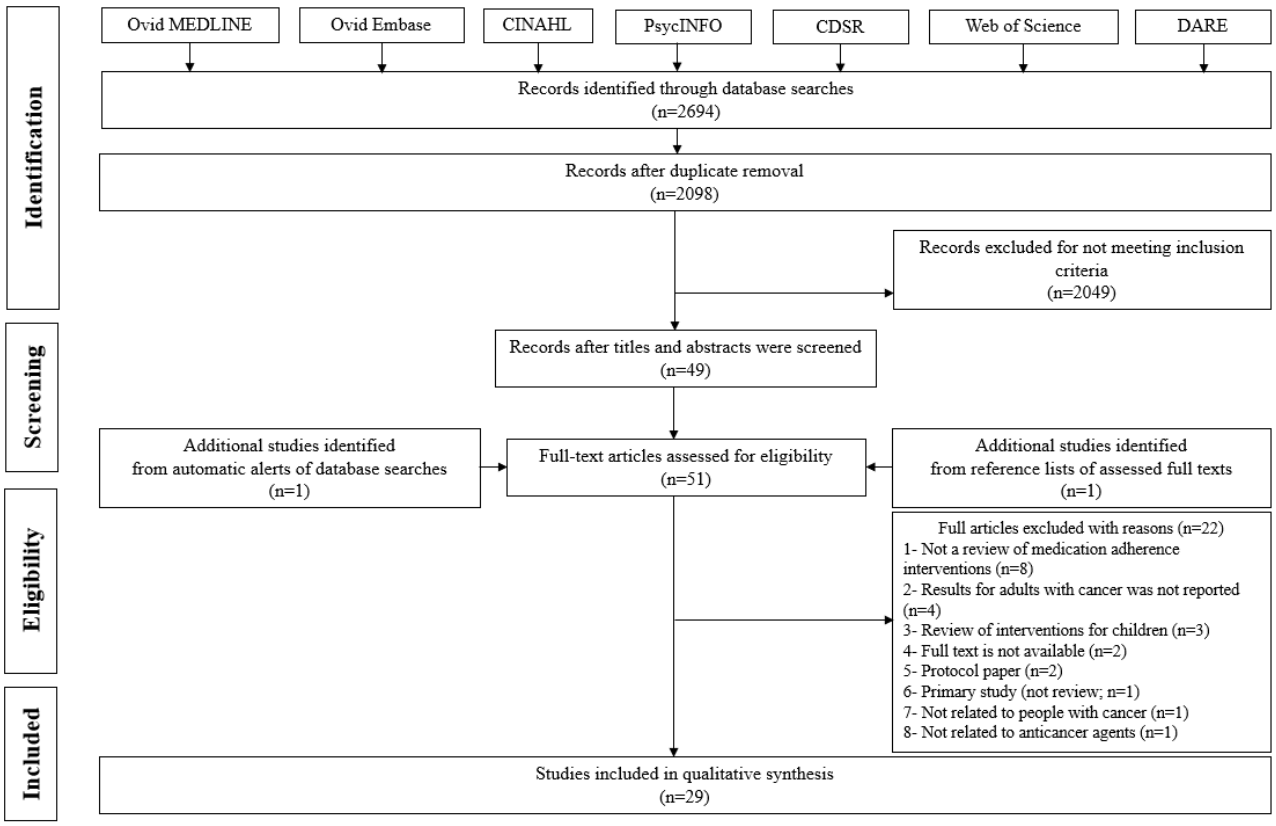
Overview

The results of this review are presented in the following order: search results, characteristics of included reviews, quality of systematic reviews, description of interventions, and outcomes of included reviews by group—scoping, systematic, and literature reviews. Owing to the heterogeneity of the included reviews, the findings are presented in a narrative format and refer to meta-analyses performed by the authors of the included reviews whenever available.

Search Results

The search strategy identified 2098 unique results from 7 databases, 1 from the reference lists of the included studies, and 1 from the automatic alerts of the databases. Title and abstract screening identified 51 studies for full-text screening, of which 29 (57%) met the inclusion criteria. Details of the excluded studies and reasons for exclusion are provided in Multimedia Appendix 4 [2,7-9,12,21-46]. A high level of concordance was achieved between the 2 reviewers in the screening process, with disagreement in only 10% (5/51) of cases. These 5 papers were discussed by the 2 reviewers, and consensus was achieved. The selection process is illustrated in the flowchart (Figure 1).

Figure 1. Flow diagram of study selection. CDSR: Cochrane Database of Systematic Reviews; DARE: Database of Abstracts and Reviews of Effects.



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Characteristics of the Included Reviews

Study Design and Publication Time

Among the 29 included reviews, 12 (41%) were systematic reviews [2,7-9,12,21-27], 5 (17%) were scoping reviews [11,13,47-49], and the remaining 12 (41%) were literature reviews [10,28,29,50-58]. All 29 reviews were descriptive, with only 1 (3%) including meta-analyses [25]. All the studies were published in English. Of these 29 reviews, 25 (86%) were published between 2014 and 2021 and the remaining 4 (14%) were published before 2014 [28,50-52]. Although literature reviews were published throughout the period from 2009 to 2021, the results of all systematic reviews were publicly reported between 2014 and 2019, and the publication of 5 scoping reviews began in 2018.

Participants

Most reviews included studies on all types of cancer (22/29, 76%) [2,9-11,13,21,22,24,26-29,47-55,58], followed by breast cancer (6/29, 21%) [7,12,23,25,56,57], and hematological cancer (1/29, 3%) [8]. A total of 90% (26/29) reviews [2,7-13,21,23-29,48-57] examined adherence interventions for disease-modifying therapies, and 10% (3/29) reviews [22,47,58] reported adherence interventions for all types of cancer treatments. In total, 17% (5/29) reviews specifically focused on women [7,12,23,25,56], 7% (2/29) on adolescents and young adults [22,58], and 3% (1/29) on socially disadvantaged people with cancer [26]. The characteristics of the 29 studies included in this overview are presented in Multimedia Appendix 5.

Aims of the Reviews

Although all 29 reviews aimed to synthesize evidence of interventions used to promote MA among people with cancer, 6 (21%) narrative reviews also included available literature on adherence to oral anticancer regimens [2,28,50,52,53,58]. Of the 5 scoping reviews, 4 (80%) targeted digital adherence solutions, such as mobile apps [47,49], mobile phone–delivered interventions [48], and digital interventions in general [11]. Of the 12 systematic reviews, 6 (50%) focused on examining either the efficacy [22] or the effectiveness of adherence interventions [9,12,21,24,25]. Some of the reviews specifically focused on the type of interventions (eg, nurse-led [51], pharmacist-led [24], educational [21], and technology-mediated [10,11,47-49,54,55,57]), specific settings (eg, ambulatory care setting [21]), and socially disadvantaged groups in the Organization for Economic Co-operation and Development countries [26].

Quality of Systematic Reviews

Among the 29 reviews, 12 (41%) were systematic reviews, of which only 1 (3%) conducted meta-analyses (Multimedia Appendix 5). Methodological quality was low or critically low overall, with at least 2 out of 16 AMSTAR 2 appraisal items [20] not met in all systematic reviews. The quality assessment of the 7 critical AMSTAR 2 domains is presented in Multimedia Appendix 6. Only 8% (1/12) systematic reviews from the study by Arthurs et al [21] received moderate overall confidence ratings in the reported results, which meant that this systematic review may provide an accurate summary of the results of the included studies to address the questions of interest. Moreover, 33% (4/12) and 59% (7/12) of systematic reviews received low and critically low overall confidence ratings, respectively, meaning that the summarized results of these studies may be inaccurate and that the conclusions need to be interpreted carefully. The best adherence was found for using the components of the PICO (population, intervention, comparison, and outcome) framework when describing the search question and inclusion criteria (item 1) and describing the included studies in adequate detail (item 8). The item that most reviews (9/12, 75%) failed to meet was providing a justification for excluding individual studies (item 7). For the critical domains, 42% (5/12) reviews referred to a review protocol (item 2), and 25% (3/12) reviews provided a list of excluded studies and justified their exclusion (item 7). Nearly all reviews (11/12, 92%) accounted for risk of bias when interpreting the results (item 13). Most of the reviews (10/12, 83%) used a satisfactory technique for assessing the risk of bias in individual studies (item 9), and 75% (9/12) of reviews conducted a comprehensive literature search (item 4). The only review with meta-analyses adhered to the item of using appropriate methods for statistical combination of the results (item 11) and investigated publication bias (item 15). More details on the bias assessments of all 16 AMSTAR 2 items are provided in Multimedia Appendix 7 [2,7-9,12,21-27].

Description of Interventions

Overview

Given the wide range of aims mentioned above, interventions were categorized differently across and within reviews. Most reviews (21/29, 72%) reported diverse and multimodal interventions [2,7-9,12,13,21-29,50-54,56,58]; however, 28% (8/29) of reviews provided detailed technology-mediated interventions [10,11,22,47-49,55,57].

Modes of Delivery

Owing to the heterogeneity and lack of a common approach to categorizing the interventions in the reviews, we describe the modes of delivery for each one in Multimedia Appendix 8. Although interventions could be broadly classified as face-to-face or remote, these categories should only be considered as a guide because they were not always exclusive, owing to the complexity of interventions. For example, the same educational elements could be delivered via direct contact and web-based channels.

Face-to-face Interventions Only

The only 2 reviews in this group of interventions [50,51] were published the earliest among the reviews included in this study. One review [51] focused particularly on nurse-delivered interventions.

Remote Interventions Only

A total of 28% (8/29) of reviews reported only on nonface-to-face interventions with the assistance of technologies [10,11,22,47-49,55,57]. All these reviews were published in the last 6 years. Most were directed at individuals through various delivery modes, including phone, SMS text messages, and mobile apps.

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Combined Face-to-face and Remote Interventions

A total of 66% (19/29) of reviews were concerned with either face-to-face or remote modes of delivery or complex multimodal interventions [2,7-9,12,13,21,23-29,52-54,56,58]. Interventions in these reviews were either single or multicomponent, often including education; reminders; and affective components, such as patient navigators, emotional and self-management support, and problem solving.

More details about interventions in each review are presented in Multimedia Appendix 9 [2,7-13,21-29,47-58].

Theoretical Frameworks

Only 34% (10/29) of reviews reported on theoretical frameworks. The most common theories were the Health Belief Model [59] and its subsequent versions, Social Learning Theory, and Social Cognitive Theory [60], which were mentioned in 21% (6/29) of reviews [12,13,22,23,28,48]. The Self-Regulation Model [61] was the second most common framework, featured in 10% (3/29) of reviews [13,22,49]. One review [48] mentioned self-determination theory [62]. None of the face-to-face intervention reviews discussed theoretical frameworks.

Intervention Providers

As interventions are diverse, their providers include a range of professionals in the health care field: clinicians, nurses, pharmacists, and health providers. The interventions in most reviews were delivered by a multidisciplinary team. However, one review specifically focused on nurse-led interventions [28] and another on pharmacist-led interventions [24]. A total of 10% (3/29) of reviews reported on interventions delivered by nurses or pharmacists [21,27,51].

Intervention Development

Most reviews did not discuss the development of interventions. Using design frameworks and engaging stakeholders were rarely mentioned. One review [48] reported that stakeholders were engaged in the design of all included interventions, for example, patients and oncology clinicians were engaged in the early design phases to explore end users' perceptions of the acceptability and usefulness of the interventions. Stakeholders were patients, caregivers, clinicians, administrators, care providers, the community, and society, depending on the type of intervention. Two design frameworks [63,64] were applied in the development of interventions in 2 reviews [48,49].

Dose and Duration

Although the doses and durations were mentioned in 31% (9/29) of reviews [7,10,13,21,24,29,48,53,57], they were brief and varied for different types of interventions and modes of delivery. For example, the frequency of SMS text messages was daily, bidaily, or weekly [7,10,29,48,57]. Automated voice responses could be set up on a daily, weekly, or monthly basis [10,29]. The duration of multicomponent interventions varied from 9 to 18 months [29]. The follow-up period of interventions could be as short as 2 months or as long as 45 months [24].

Outcomes of Included Reviews by Group

Overview

All reviews, except 3 [47,49,51], reported MA improvement as a primary outcome. Some also reported medication persistence [23]; clinical outcomes, such as symptoms and adverse events [24]; hospital admission rates [9]; subclinical responses; survival time [8]; cancer-related knowledge and self-management skills [22,26]; and some quality-of-life indicators [26]. A total of 10% (3/29) studies [24,26,49] mentioned patient satisfaction and economic impact outcomes [24]. For this review, we focused on MA outcomes and discussed some of the secondary outcomes. The results from the 5 scoping reviews are described first, followed by 12 systematic reviews, and finally, the findings from the 12 narrative reviews.

MA (Primary Outcome)

Overview

Not all reviews specified how MA was measured. In reviews that specified how MA was measured, the methods were diverse: subjective, objective, or biomedical. Subjective measurements, such as patient self-reports and clinician reports, were the easiest reporting methods. However, perhaps because of its potential inaccuracy, it was only used to measure adherence in 12 reviews [2,7,8,10,12,13,21,23,25,52,53,56]. Half (14/29, 48%) of the reviews reported objective measurements, such as pill diaries, pill counts, and medication event monitoring systems [2,7-10,12,13,21,23,25,28,51-53], whereas some (7/29, 24%) mentioned biomedical measurements, such as drug metabolites in urine [2,7-10,52,56].

Scoping Reviews

MA was reported as a primary outcome in 60% (3/5) of scoping reviews [11,13,48] (Multimedia Appendix 10). Skrabal Ross et al [48] explored the evidence of mobile-delivered interventions, mainly SMS text messages and mobile apps (5 studies). Gambalunga et al [11] focused on mobile apps (7 studies). Both reviews concluded that despite the use of digital means in facilitating the adherence of patients with cancer to oral treatments being strongly recognized in the literature, its effectiveness was either underexamined [48] or poorly supported [11]. The engagement of stakeholders and the use of design frameworks in developing digital interventions were very important [48]. In a scoping review of 56 studies evaluating adherence to oral antineoplastic agents [13], less than half (n=25, 45%) reported statistically significant improvements in adherence or persistence. Of these 56 studies, 8 (14%) used a mobile health tool and SMS text messages as the mode of delivery. The results revealed that drug-reminder SMS text messaging, either alone or in combination with a mobile app targeting intentional nonadherence, appeared to be effective among people with a single diagnosis but not among those with different diagnoses. The review also emphasized that theory-based and evidence-based interventions tailored to the needs of patients were more likely to be effective.

In the other 2 scoping reviews [47,49], mobile apps were reported as useful tools in facilitating the delivery of behavioral guidance, real-time capture of patients' symptoms, monitoring

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of adherence, and supporting the self-management of side effects [49]. Nevertheless, the efficacy of mobile apps in improving symptom management and MA requires further exploration [48].

Systematic Reviews

MA was the primary outcome of all 12 systematic reviews. Findings from the meta-analytic results are presented first, followed by narrative syntheses.

Only 1 systematic review by Finitsis and Vose [25] contained meta-analyses to quantify the aggregate effect of interventions to improve adjuvant endocrine therapy adherence among women with breast cancer and meta-analyzed these effects across studies. A total of 7 studies that reported 8 interventions were included in this review [30-35,65]. Nearly half (3/7, 43%) of the included studies used one-way communication to deliver information and education to patients. Two studies used bidirectional communication between oncology nurses and patients. One study used a multicomponent intervention, including a mobile app and phone call follow-up from the care team. The results showed that interventions using bidirectional communication (ie, eliciting information from patients and sending information to patients) had statistically significant effects compared with the control groups within each study (k=4; Cohen d=0.59; 95% CI 0.23-0.95), whereas those using only one-way communication (ie, purely providing information to patients) did not (k=4; Cohen d=−0.03; 95% CI −0.27 to 0.20). The authors concluded that the interventions failed when one-way flow communication was used. Interventions to improve adjuvant endocrine therapy adherence should enhance patient engagement via bidirectional platforms. The additional details are presented in Multimedia Appendix 11 [13-19].

MA was reported as a primary outcome in all 11 narrative systematic reviews [2,7-9,12,21-24,26,27]. Four main strategies to promote adherence emerged from these reviews: education, reminders, behavior and monitoring, and multicomponent interventions. The reported results varied between and within reviews, even for the same types of intervention (Multimedia Appendix 12).

The educational strategy was reported in all reviews, either as a stand-alone intervention or as an element of multicomponent interventions. Educational materials often included information about diseases and medications (eg, dosage, side effects, storage, disposal, and ways to remember to take the medication). Studies revealed that education alone, regardless of delivery (eg, face-to-face, leaflets, or mailouts), was insufficient to promote adherence to anticancer regimens [2,7,8,12,23,27].

There are many mechanisms that can be used to remind patients to take their medication. These could be as simple as calendars, diaries, dosing sheets, pillboxes, and charts or more advanced, with the help of technology, such as SMS text messages and mobile apps. Although reminders could be effective in reinforcing the behavior of taking the medication in some chronic conditions, such as HIV or AIDS [52,53], their effectiveness in oncology has not been demonstrated [7,9,26].

The behavioral and monitoring strategies have been broadly used in MA interventions in various forms and modes of delivery: delivered either in a single form or mode (monitoring pill-taking, autopharmacy refills, electronic prescribing, and individual coaching) [2,7,23,24] or an intervention package (monitoring and feedback, side effect management, and positive self-care behavior) [2,7,22,23]. Similar to the diversity of interventions within this group of strategies, their effectiveness in enhancing adherence to oral antineoplastic medicines varied widely within and between reviews [2,7,9,22,26,27].

Multicomponent interventions were reported in 82% (9/11) of systematic reviews [2,7-9,12,21,23,24,26], often including a combination of education; reminders; and behavioral, cognitive, or affective components. Tailored education in combination with drug reminders and counseling delivered by nurses or pharmacists to promote symptom management and adherence behavior was likely to be effective in improving adherence [2,8,9,12,24]. Nevertheless, in a few (4/29, 14%) reviews, nurse-led tailored patient education [21], pharmacist-led intensive care programs [21], and education combined with reminder interventions were not effective [7,23]. The effect of education, pill shaping, and home restructuring was uncertain in the systematic review by Mathes and Antoine [9]. This uncertainty was also observed in multicomponent interventions including education, reminders, and motivational interviewing [23]; or interventions including education and monitoring [27].

There were some overlaps across systematic reviews at the individual-study level. The results of 18 primary studies, including 7 randomized controlled trials [30,34-37,66,67], were reported in more than 1 systematic review [30,33-44,65-69]. For example, 2 randomized controlled trials on the compliance of patients to anastrozole in a therapy program, published by Hadji et al [66], and the influence of a patient information program on adherence and persistence to an aromatase inhibitor in breast cancer treatment, published by Ziller et al [35], were reported in the same 5 systematic reviews [2,7,12,23,25]. More details on the overlap of primary studies across systematic reviews are presented in Multimedia Appendix 13 [13,15-27,47-50].

Literature Reviews

Among the 12 included literature reviews, 4 (33%) focused on technology-based interventions; 1 (8%) examined nursing interventions [51]; and 2 (17%) expanded the scope of research to areas such as adherence or persistence rates [50] and its impacts [53], challenges to adherence in oncology [28,52,53], and adherence measurements [52]. MA was reported as a primary outcome in all literature reviews except 2 [51,57] (Multimedia Appendix 14).

The results from these literature reviews were consistent with findings from included scoping and systematic reviews: education alone was insufficient to promote adherence to oral medication regimens [29,53,54,58], and multicomponent interventions were more likely to be effective in improving adherence [10,28,29,50,52-55,58]. Behavioral and monitoring strategies did not consistently improve adherence rates when used alone [29,50,53], although some studies have reported positive results [28,29,56].

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However, the effectiveness of reminders was controversial. Reminder tools, such as calendars, diaries, and dosing sheets, likely improved patient adherence [28,53], whereas daily pillboxes were unlikely to do so [28,50]. Electronic reminders, such as SMS text messages and mobile apps, were reported to be effective in the review of Accordino and Hershman [52] but ineffective in another review conducted by Cazeau [10].

Narrative reviews also revealed that oncology nurses and pharmacists, as part of a multidisciplinary team, can have a significant influence on patient adherence via education, increased access to medicines, early identification of symptoms, and side effect self-management skills [28,29,51,53].

Secondary Outcomes

In addition to MA rates, clinical outcomes, such as decreased symptoms [24], cytogenetic response, and survival time [8], were evaluated. The effects of education on clinical outcomes were uncertain [8]. However, some multicomponent interventions, including education, tailored counseling, and affective components (eg, home visit support), showed possible positive effects [8,24]. In 2 reviews [22,26], interventions combining side effect management, positive self-care behavioral promotion, education, counseling, or organizational change elements improved cancer-related knowledge and self-efficacy among people with cancer. Two reviews [9,24] listed hospital admission rate as a secondary outcome, but it was not statistically significant in all included interventions.

Discussion

Principal Findings

This overview of reviews aimed to synthesize evidence from available reviews on interventions to improve MA to OACMs in adults with cancer. To the best of our knowledge, this is the first study to achieve this goal. Among the 29 included reviews, only 1 (3%) conducted meta-analyses and 17 (59%) did not follow systematic methodologies in identifying, analyzing, and reporting literature. Consequently, it was impossible to perform quantitative analyses. Nevertheless, including literature reviews in the narrative synthesis is useful for understanding the breadth of the study field. The only systematic reviews of moderate quality focused on therapeutic patient education interventions in ambulatory care settings [21]. The other 11 systematic reviews on the topic of interest had low or critically low confidence rating. Therefore, the results of the included reviews should be interpreted with caution.

The comparability of the study results is limited because of the high heterogeneity of the included reviews (Multimedia Appendix 5) and studies within each review [9,13]. The content of adherence-enhancing interventions is varied [29]. In addition, there are differences in the characteristics of patients whose adherence has been influenced [9]. Furthermore, comparability is constrained owing to different adherence measurements [2,7,8,52]. Accordingly, this review summarizes the main themes of the included reviews rather than comparing them.

This review suggests that single strategies to promote adherence (eg, education, reminders, or monitoring) are not sufficient to improve adherence. Multidimensional interventions that used collective strategies to promote adherence (education, reminder, cognitive, behavioral, and affective) were potentially more effective. Our findings are in line with earlier reviews of interventions to improve adherence in various chronic conditions [45,46] and those focusing on cancer [9,50,54,58]. These findings also resonate with the report of the World Health Organization that MA is a multidimensional phenomenon determined by 5 dimensions (social and economic, health system, condition-related, therapy-related, and patient-related) [70]. Thus, multicomponent interventions applying different strategies are needed to address the multifaceted adherence phenomenon [70].

The described theoretical frameworks were neither clear nor validated. One-third of reviews reported on the scattered use of cognitive and behavioral theories in only a few studies [12]. Although the authors [12,48] emphasized the importance of using theoretical grounding in planning, designing, and evaluating outcomes of multilevel interventions, a few [13,23] argued that the effect of this was quite modest. This uncertainty is in line with a meta-analysis of 683 studies that quantified the impact of theory-driven interventions on adherence [71]. The limited use of theory to design interventions means that no conclusions can be drawn regarding the importance and effectiveness of theoretically derived interventions. Furthermore, the complex and multifaceted factors contributing to nonadherence represent another challenge in the selection of an appropriate conceptual model to design interventions. Perhaps, a combination of theories may better explain the diverse barriers and facilitators of MA and provide a stronger direction to formulate interventions. Future research should pay more attention to this aspect of adherence interventions.

The use of digital solutions to enhance adherence to cancer treatment has been increasing in the past decade [47,55]. The literature has emphasized the potential of digital platforms to facilitate oral antineoplastic adherence among people with cancer [11]. Medication nonadherence can be intentional or unintentional. Intentional nonadherence is a patient's conscious decision not to take a drug, for example, because of unpleasant side effects [72]. Unintentional nonadherence is unplanned by a patient, for example, because of forgetfulness [73]. Therefore, the interventions require different modes of action. A variety of measures, such as patient education and good patient-provider communication, can enable patients to better report and manage therapeutic side effects [55]. Technologies can enhance these measures by providing patients with rapid, continuous, and easy access to both educational resources and symptom self-management strategies, also facilitating communication between patients and their care teams [11,55]. Personal lifestyle and electronic triggers (eg, SMS text messages) remind and motivate patients to take their medication, so that it becomes an integral part of their daily activities [11,52]. In both cases, digital platforms (eg, mobile apps) can enable real-time monitoring of patient self-management [11]. However, this is an emerging field, and most studies have focused only on evaluating the acceptability, usability, and feasibility of interventions. The effectiveness of digital MA interventions in clinical oncology practice is poorly supported [47,48]. Future research should not only focus on determining the effect of

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digital interventions on adherence but also on identifying barriers to delivering high-quality personalized care to end users [11].

Using frameworks and engaging stakeholders in the design and development of digital interventions is crucial. Design frameworks help in planning the resources needed for each stage of the design and to mobilize them effectively and efficiently [48]. The involvement of stakeholders is central in ensuring that the intervention meets the needs of the target audience and in increasing its sustainability [49]. Nevertheless, strategies involving stakeholders (eg, patients, caregivers, oncology clinicians, nurses, pharmacists, and the community) have rarely been reported [48]. The involvement of professionals in the intervention development processes was very limited [49,55]; only 2 studies [74,75] mentioned patients' and clinicians' participation. Most interventions did not use or, at least, did not report the use of design frameworks in the development processes [48]. Given the rapid increase of technology applications in MA and the importance of this aspect in intervention development, it is worthy of future research into the involvement of stakeholders and the design framework used in the development of adherence interventions.

The findings from this review show that the use of digital solutions alone may be insufficient and may require cultural adaptive change [57]. Health care professionals' interaction with patients is pivotal to augmenting the effect of these interventions [51]. Nurses and pharmacists are uniquely positioned to promote adherence to oral cancer therapies [10,51,53]. Findings suggest that clinical support (eg, tailoring education to meet patients' needs) and symptom assessment and management provided by nurses empowered patients' ability to adhere to treatments [8,28,55]. Future interventions in cancer should maximize the advantage that health professionals can contribute to patients' MA with the support of digital technology.

Finally, this review suggests that to consolidate evidence on the effects of MA interventions in cancer, further work is needed using rigorous methods, such as prospective randomized designs in large samples of patients. Study outcomes should not only be limited to adherence rates but also the long-term effects of interventions and meaningful clinical outcomes, such as decreased symptoms and adverse effects of therapy, inhibited disease progression, and increased patient survival and quality of life. These suggestions are consistent with the results of some other systematic reviews of interventions to promote adherence to OACMs that have been published to date [2,9].

Limitations

This review has inevitable limitations owing to the limited existing high-quality quantitative analytic evidence, which also demonstrates a high risk of bias. Similarly, the significant heterogeneity across and within reviews and studies did not allow statistical analyses beyond reporting of results from the only meta-analysis and narrative analyses performed by the authors of the included reviews. Throughout the process, we relied on published evidence rather than aggregated data from individual studies. Therefore, a definitive assessment of the overall strength of evidence and the effectiveness of current interventions to enhance adherence to anticancer medicines among adults with cancer is not possible. Finally, only the reviews published in English were included. Thus, there is a risk of missing the relevant literature published in other languages. However, comprehensive searches were conducted using different databases to minimize this limitation as much as possible.

Conclusions

Despite these challenges, this review suggests the potential effectiveness of multicomponent interventions to promote adherence to OACMs in adults. This review highlights the role of digital health in enabling and enhancing multicomponent adherence interventions. Nurses and pharmacists are in unique positions and play an important role in facilitating and motivating patient adherence behavior in oncology treatments. These processes can be facilitated without creating a burden if they are integrated into the current routine practices with the support of technology. The findings from this review support the need for future research in developing evidence-based digital multicomponent interventions to assist people with cancer in adhering to their oral therapies. This review also underscores the importance of stakeholders' involvement and the use of a design framework in the development of interventions to increase translatability and sustainability in real oncology practices. Given the rapidly increasing use of oral antineoplastic medicines and the dramatic availability of digital tools worldwide, research in this field is expected to increase rapidly.

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Authors' Contributions

All authors made substantial contributions and approved the conception, drafting, and final version of the manuscript. THD analyzed and interpreted the data. THD drafted the paper with contributions from ARMF, NW, PPJ, MA, KB, and PS.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2020 checklist.
[DOCX File , 32 KB - cancer_v8i2e34833_app1.docx]

Multimedia Appendix 2
Search strategy.
[DOCX File , 17 KB - cancer_v8i2e34833_app2.docx]

Multimedia Appendix 3
Data extraction table.
[XLSX File (Microsoft Excel File), 11 KB - cancer_v8i2e34833_app3.xlsx]

Multimedia Appendix 4
Table of excluded studies.
[DOCX File , 57 KB - cancer_v8i2e34833_app4.docx]

Multimedia Appendix 5
Characteristics of included reviews.
[XLSX File (Microsoft Excel File), 15 KB - cancer_v8i2e34833_app5.xlsx]

Multimedia Appendix 6
Methodological quality of included systematic reviews (A Measurement Tool to Assess Systematic Reviews 2 critical domains, adapted from Shea et al [20]).
[DOCX File , 41 KB - cancer_v8i2e34833_app6.docx]

Multimedia Appendix 7
Methodological quality of included systematic reviews.
[DOCX File , 20 KB - cancer_v8i2e34833_app7.docx]

Multimedia Appendix 8
Interventions grouped according to modes of delivery.
[XLSX File (Microsoft Excel File), 11 KB - cancer_v8i2e34833_app8.xlsx]

Multimedia Appendix 9
Intervention details of included reviews.
[XLSX File (Microsoft Excel File), 13 KB - cancer_v8i2e34833_app9.xlsx]

Multimedia Appendix 10
Outcome of included scoping reviews.
[XLSX File (Microsoft Excel File), 12 KB - cancer_v8i2e34833_app10.xlsx]

Multimedia Appendix 11
Outcomes of included systematic reviews with meta-analyses.
[XLSX File (Microsoft Excel File), 11 KB - cancer_v8i2e34833_app11.xlsx]

Multimedia Appendix 12
Outcomes of included systematic reviews—narrative reviews.
[XLSX File (Microsoft Excel File), 14 KB - cancer_v8i2e34833_app12.xlsx]

Multimedia Appendix 13
Primary studies overlap across systematic reviews.
[XLSX File (Microsoft Excel File), 11 KB - cancer_v8i2e34833_app13.xlsx]

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Multimedia Appendix 14
Outcome of included literature reviews.
[XLSX File (Microsoft Excel File), 14 KB - cancer_v8i2e34833_app14.xlsx]

References

1. Geynisman DM, Wickersham KE. Adherence to targeted oral anticancer medications. Discov Med 2013 Apr;15(83):231-241 [FREE Full text] [Medline: 23636140]
2. Greer JA, Amoyal N, Nisotel L, Fishbein JN, MacDonald J, Stagl J, et al. A systematic review of adherence to oral antineoplastic therapies. Oncologist 2016 Mar;21(3):354-376 [FREE Full text] [doi: 10.1634/theoncologist.2015-0405] [Medline: 26921292]
3. Bouwman L, Eeltink CM, Visser O, Janssen JJ, Maaskant JM. Prevalence and associated factors of medication non-adherence in hematological-oncological patients in their home situation. BMC Cancer 2017 Nov 09;17(1):739 [FREE Full text] [doi: 10.1186/s12885-017-3735-1] [Medline: 29121889]
4. Hershman DL, Unger JM, Barlow WE, Hutchins LF, Martino S, Osborne CK, et al. Treatment quality and outcomes of African American versus white breast cancer patients: retrospective analysis of Southwest Oncology studies S8814/S8897. J Clin Oncol 2009 May 01;27(13):2157-2162 [FREE Full text] [doi: 10.1200/JCO.2008.19.1163] [Medline: 19307504]
5. Konstantinou P, Kassianos AP, Georgiou G, Panayides A, Papageorgiou A, Almas I, et al. Barriers, facilitators, and interventions for medication adherence across chronic conditions with the highest non-adherence rates: a scoping review with recommendations for intervention development. Transl Behav Med 2020 Dec 31;10(6):1390-1398. [doi: 10.1093/tbm/ibaa118] [Medline: 33231691]
6. Xu S, Yang Y, Tao W, Song Y, Chen Y, Ren Y, et al. Tamoxifen adherence and its relationship to mortality in 116 men with breast cancer. Breast Cancer Res Treat 2012 Nov;136(2):495-502. [doi: 10.1007/s10549-012-2286-z] [Medline: 23065002]
7. Ekinci E, Nathoo S, Korattyil T, Vadhariya A, Zaghloul HA, Niravath PA, et al. Interventions to improve endocrine therapy adherence in breast cancer survivors: what is the evidence? J Cancer Surviv 2018 Jun;12(3):348-356. [doi: 10.1007/s11764-017-0674-4] [Medline: 29396760]
8. Kavookjian J, Wittayanukorn S. Interventions for adherence with oral chemotherapy in hematological malignancies: a systematic review. Res Social Adm Pharm 2015;11(3):303-314. [doi: 10.1016/j.sapharm.2014.08.006] [Medline: 25262600]
9. Mathes T, Antoine SL, Pieper D, Eikermann M. Adherence enhancing interventions for oral anticancer agents: a systematic review. Cancer Treat Rev 2014 Feb;40(1):102-108. [doi: 10.1016/j.ctrv.2013.07.004] [Medline: 23910455]
10. Cazeau N. Mobile health interventions: examining medication adherence outcomes among patients with cancer. Clin J Oncol Nurs 2021 Aug 01;25(4):431-438 [FREE Full text] [doi: 10.1188/21.CJON.431-438] [Medline: 34269338]
11. Gambalunga F, Iacorossi L, Notarnicola I, Serra V, Piredda M, De Marinis MG. Mobile health in adherence to oral anticancer drugs: a scoping review. Comput Inform Nurs 2020 Jun 19;39(1):17-23. [doi: 10.1097/CIN.0000000000000643] [Medline: 32568900]
12. Heiney SP, Parker PD, Felder TM, Adams SA, Omofuma OO, Hulett JM. A systematic review of interventions to improve adherence to endocrine therapy. Breast Cancer Res Treat 2019 Feb;173(3):499-510 [FREE Full text] [doi: 10.1007/s10549-018-5012-7] [Medline: 30387003]
13. Rosenberg SM, Petrie KJ, Stanton AL, Ngo L, Finnerty E, Partridge AH. Interventions to enhance adherence to oral antineoplastic agents: a scoping review. J Natl Cancer Inst 2020 May 01;112(5):443-465 [FREE Full text] [doi: 10.1093/jnci/djz244] [Medline: 31899790]
14. Smith V, Devane D, Begley CM, Clarke M. Methodology in conducting a systematic review of systematic reviews of healthcare interventions. BMC Med Res Methodol 2011 Feb 03;11(1):15 [FREE Full text] [doi: 10.1186/1471-2288-11-15] [Medline: 21291558]
15. Hunt H, Pollock A, Campbell P, Estcourt L, Brunton G. An introduction to overviews of reviews: planning a relevant research question and objective for an overview. Syst Rev 2018 Mar 01;7(1):39 [FREE Full text] [doi: 10.1186/s13643-018-0695-8] [Medline: 29490699]
16. Dang TH, Wickramasinghe N, Jayaraman PP, Burbury K, Forkan AR, Alexander M, et al. Interventions to improve medication adherence in adults with cancer: a systematic review. PROSPERO International prospective register of systematic reviews. 2021. URL: https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=240578 [accessed 2022-04-03]
17. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021 Mar 29;372:n71 [FREE Full text] [doi: 10.1136/bmj.n71] [Medline: 33782057]
18. McGowan J, Sampson M, Lefebvre C. An evidence based checklist for the peer review of electronic search strategies (PRESS EBC). Evid Based Libr Inf Pract 2010 Mar 17;5(1):149-154 [FREE Full text] [doi: 10.18438/b8sg8r]
19. Better systematic review management. Covidence. 2021. URL: https://www.covidence.org/ [accessed 2021-01-10]
20. Shea BJ, Reeves BC, Wells G, Thuku M, Hamel C, Moran J, et al. AMSTAR 2: a critical appraisal tool for systematic reviews that include randomised or non-randomised studies of healthcare interventions, or both. BMJ 2017 Sep 21;358:j4008 [FREE Full text] [doi: 10.1136/bmj.j4008] [Medline: 28935701]

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21. Arthurs G, Simpson J, Brown A, Kyaw O, Shyrier S, Concert CM. The effectiveness of therapeutic patient education on adherence to oral anti-cancer medicines in adult cancer patients in ambulatory care settings: a systematic review. JBI Database System Rev Implement Rep 2015 Jun 12;13(5):244-292. [doi: 10.11124/jbisrir-2015-2057] [Medline: 26455611]
22. Robertson E, Wakefield C, Marshall K, Sansom-Daly U. Strategies to improve adherence to treatment in adolescents and young adults with cancer: a systematic review. Clin Oncol Adolesc Young Adults 2015 May 10;2015(5):35-49 [FREE Full text] [doi: 10.2147/coaya.s85988]
23. Hurtado-de-Mendoza A, Cabling ML, Lobo T, Dash C, Sheppard VB. Behavioral interventions to enhance adherence to hormone therapy in breast cancer survivors: a systematic literature review. Clin Breast Cancer 2016 Aug;16(4):247-55.e3 [FREE Full text] [doi: 10.1016/j.clbc.2016.03.006] [Medline: 27133733]
24. Colombo LR, Aguiar PM, Lima TM, Storpirtis S. The effects of pharmacist interventions on adult outpatients with cancer: a systematic review. J Clin Pharm Ther 2017 Aug;42(4):414-424 [FREE Full text] [doi: 10.1111/jcpt.12562] [Medline: 28556392]
25. Finitsis DJ, Vose BA, Mahalak JG, Salner AL. Interventions to promote adherence to endocrine therapy among breast cancer survivors: a meta-analysis. Psychooncology 2019 Feb;28(2):255-263. [doi: 10.1002/pon.4959] [Medline: 30511789]
26. Ruiz-Pérez I, Rodríguez-Gómez M, Pastor-Moreno G, Escribá-Agüir V, Petrova D. Effectiveness of interventions to improve cancer treatment and follow-up care in socially disadvantaged groups. Psychooncology 2019 Apr;28(4):665-674. [doi: 10.1002/pon.5011] [Medline: 30695816]
27. Zerillo JA, Goldenberg BA, Kotecha RR, Tewari AK, Jacobson JO, Krzyzanowska MM. Interventions to improve oral chemotherapy safety and quality: a systematic review. JAMA Oncol 2018 Jan 01;4(1):105-117 [FREE Full text] [doi: 10.1001/jamaoncol.2017.0625] [Medline: 28570732]
28. Schneider SM, Hess K, Gosselin T. Interventions to promote adherence with oral agents. Semin Oncol Nurs 2011 May;27(2):133-141 [FREE Full text] [doi: 10.1016/j.soncn.2011.02.005] [Medline: 21514482]
29. Spoelstra SL, Sansoucie H. Putting evidence into practice: evidence-based interventions for oral agents for cancer. Clin J Oncol Nurs 2015 Jun;19(3 Suppl):60-72. [doi: 10.1188/15.S1.CJON.60-72] [Medline: 26030394]
30. Ell K, Vourlekis B, Xie B, Nedjat-Haiem FR, Lee PJ, Muderspach L, et al. Cancer treatment adherence among low-income women with breast or gynecologic cancer: a randomized controlled trial of patient navigation. Cancer 2009 Oct 01;115(19):4606-4615 [FREE Full text] [doi: 10.1002/cncr.24500] [Medline: 19551881]
31. Graetz I, McKillop CN, Stepanski E, Vidal GA, Anderson JN, Schwartzberg LS. Use of a web-based app to improve breast cancer symptom management and adherence for aromatase inhibitors: a randomized controlled feasibility trial. J Cancer Surviv 2018 Aug;12(4):431-440 [FREE Full text] [doi: 10.1007/s11764-018-0682-z] [Medline: 29492753]
32. Hadji P, Ziller V, Kyvernitakis J, Bauer M, Haas G, Schmidt N, et al. Persistence in patients with breast cancer treated with tamoxifen or aromatase inhibitors: a retrospective database analysis. Breast Cancer Res Treat 2013 Feb;138(1):185-191. [doi: 10.1007/s10549-013-2417-1] [Medline: 23334803]
33. Heisig SR, Shedden-Mora MC, von Blanckenburg P, Schuricht F, Rief W, Albert US, et al. Informing women with breast cancer about endocrine therapy: effects on knowledge and adherence. Psychooncology 2015 Feb;24(2):130-137. [doi: 10.1002/pon.3611] [Medline: 24953538]
34. Neven P, Markopoulos C, Tanner M, Marty M, Kreienberg R, Atkins L, et al. The impact of educational materials on compliance and persistence rates with adjuvant aromatase inhibitor treatment: first-year results from the compliance of aromatase inhibitors assessment in daily practice through educational approach (CARIATIDE) study. Breast 2014 Aug;23(4):393-399 [FREE Full text] [doi: 10.1016/j.breast.2014.02.009] [Medline: 24675394]
35. Ziller V, Kyvernitakis I, Knöll D, Storch A, Hars O, Hadji P. Influence of a patient information program on adherence and persistence with an aromatase inhibitor in breast cancer treatment--the COMPAS study. BMC Cancer 2013 Sep 04;13:407 [FREE Full text] [doi: 10.1186/1471-2407-13-407] [Medline: 24006873]
36. Macintosh PW, Pond GR, Pond BJ, Leung V, Siu LL. A comparison of patient adherence and preference of packaging method for oral anticancer agents using conventional pill bottles versus daily pill boxes. Eur J Cancer Care (Engl) 2007 Jul;16(4):380-386. [doi: 10.1111/j.1365-2354.2006.00758.x] [Medline: 17587364]
37. Markopoulos C, Neven P, Tanner M, Marty M, Kreienberg R, Atkins L, et al. Does patient education work in breast cancer? Final results from the global CARIATIDE study. Future Oncol 2015;11(2):205-217. [doi: 10.2217/fon.14.179] [Medline: 25591836]
38. Levine AM, Richardson JL, Marks G, Chan K, Graham J, Selser JN, et al. Compliance with oral drug therapy in patients with hematologic malignancy. J Clin Oncol 1987 Sep;5(9):1469-1476. [doi: 10.1200/JCO.1987.5.9.1469] [Medline: 3625261]
39. Simons S, Ringsdorf S, Braun M, Mey UJ, Schwindt PF, Ko YD, et al. Enhancing adherence to capecitabine chemotherapy by means of multidisciplinary pharmaceutical care. Support Care Cancer 2011 Jul;19(7):1009-1018 [FREE Full text] [doi: 10.1007/s00520-010-0927-5] [Medline: 20552377]
40. Khandelwal N, Duncan I, Ahmed T, Rubinstein E, Pegus C. Oral chemotherapy program improves adherence and reduces medication wastage and hospital admissions. J Natl Compr Canc Netw 2012 May;10(5):618-625. [doi: 10.6004/jnccn.2012.0063] [Medline: 22570292]

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41. Moon JH, Sohn SK, Kim SN, Park SY, Yoon SS, Kim IH, et al. Patient counseling program to improve the compliance to imatinib in chronic myeloid leukemia patients. Med Oncol 2012 Jun;29(2):1179-1185. [doi: 10.1007/s12032-011-9926-8] [Medline: 21472487]
42. Krolop L, Ko YD, Schwindt PF, Schumacher C, Fimmers R, Jaehde U. Adherence management for patients with cancer taking capecitabine: a prospective two-arm cohort study. BMJ Open 2013 Jul 19;3(7):e003139 [FREE Full text] [doi: 10.1136/bmjopen-2013-003139] [Medline: 23872296]
43. Spoelstra SL, Given BA, Given CW, Grant M, Sikorskii A, You M, et al. An intervention to improve adherence and management of symptoms for patients prescribed oral chemotherapy agents: an exploratory study. Cancer Nurs 2013;36(1):18-28. [doi: 10.1097/NCC.0b013e3182551587] [Medline: 23235499]
44. Neuner JM, Kamaraju S, Charlson JA, Wozniak EM, Smith EC, Biggers A, et al. The introduction of generic aromatase inhibitors and treatment adherence among Medicare D enrollees. J Natl Cancer Inst 2015 May 12;107(8):djv130 [FREE Full text] [doi: 10.1093/jnci/djv130] [Medline: 25971298]
45. Nieuwlaat R, Wilczynski N, Navarro T, Hobson N, Jeffery R, Keepanasseril A, et al. Interventions for enhancing medication adherence. Cochrane Database Syst Rev 2014 Nov 20;2014(11):CD000011 [FREE Full text] [doi: 10.1002/14651858.CD000011.pub4] [Medline: 25412402]
46. Roter DL, Hall JA, Merisca R, Nordstrom B, Cretin D, Svarstad B. Effectiveness of interventions to improve patient compliance: a meta-analysis. Med Care 1998 Aug;36(8):1138-1161. [doi: 10.1097/00005650-199808000-00004] [Medline: 9708588]
47. Jupp JC, Sultani H, Cooper CA, Peterson KA, Truong TH. Evaluation of mobile phone applications to support medication adherence and symptom management in oncology patients. Pediatr Blood Cancer 2018 Nov;65(11):e27278. [doi: 10.1002/pbc.27278] [Medline: 29943893]
48. Skrabal Ross X, Gunn KM, Patterson P, Olver I. Mobile-based oral chemotherapy adherence-enhancing interventions: scoping review. JMIR Mhealth Uhealth 2018 Dec 21;6(12):e11724 [FREE Full text] [doi: 10.2196/11724] [Medline: 30578182]
49. Magalhães B, Fernandes C, Martinez-Galiano JM, Santos C. Exploring the use of mobile applications by cancer patients undergoing chemotherapy: a scoping review. Int J Med Inform 2020 Dec;144:104293. [doi: 10.1016/j.ijmedinf.2020.104293] [Medline: 33091832]
50. Ruddy K, Mayer E, Partridge A. Patient adherence and persistence with oral anticancer treatment. CA Cancer J Clin 2009;59(1):56-66 [FREE Full text] [doi: 10.3322/caac.20004] [Medline: 19147869]
51. Winkeljohn D. Adherence to oral cancer therapies: nursing interventions. Clin J Oncol Nurs 2010 Aug;14(4):461-466. [doi: 10.1188/10.CJON.461-466] [Medline: 20682501]
52. Accordino MK, Hershman DL. Disparities and challenges in adherence to oral antineoplastic agents. Am Soc Clin Oncol Educ Book 2013:271-276 [FREE Full text] [doi: 10.14694/EdBook_AM.2013.33.271] [Medline: 23714520]
53. McCue DA, Lohr LK, Pick AM. Improving adherence to oral cancer therapy in clinical practice. Pharmacotherapy 2014 May;34(5):481-494. [doi: 10.1002/phar.1399] [Medline: 24877187]
54. Burhenn PS, Smudde J. Using tools and technology to promote education and adherence to oral agents for cancer. Clin J Oncol Nurs 2015 Jun;19(3 Suppl):53-59. [doi: 10.1188/15.S1.CJON.53-59] [Medline: 26030395]
55. Odeh B, Kayyali R, Nabhani-Gebara S, Philip N. Optimizing cancer care through mobile health. Support Care Cancer 2015 Jul;23(7):2183-2188. [doi: 10.1007/s00520-015-2627-7] [Medline: 25649121]
56. Wassermann J, Rosenberg SM. Treatment decisions and adherence to adjuvant endocrine therapy in breast cancer. Curr Breast Cancer Rep 2017 Apr 27;9(2):100-110. [doi: 10.1007/s12609-017-0248-5]
57. Mougalian SS, Gross CP, Hall EK. Text messaging in oncology: a review of the landscape. JCO Clin Cancer Inform 2018 Dec;2:1-9 [FREE Full text] [doi: 10.1200/CCI.17.00162] [Medline: 30652579]
58. Vandermorris A, Sampson L, Korenblum C. Promoting adherence in adolescents and young adults with cancer to optimize outcomes: a developmentally oriented narrative review. Pediatr Blood Cancer 2020 Apr;67(4):e28128. [doi: 10.1002/pbc.28128] [Medline: 31886630]
59. Rosenstock IM. Historical origins of the health belief model. Health Educ Monogr 1974 Dec 01;2(4):328-335. [doi: 10.1177/109019817400200403]
60. Bandura A, National Institute of Mental Health. Social foundations of thought and action: a social cognitive theory. Englewood Cliffs, NJ, USA: Prentice Hall; 1986.
61. Leventhal H, Leventhal EA, Contrada RJ. Self-regulation, health, and behavior: a perceptual-cognitive approach. Psychol Health 1998 Jul;13(4):717-733 [FREE Full text] [doi: 10.1080/08870449808407425]
62. Ryan RM, Deci EL. Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. Am Psychol 2000 Jan;55(1):68-78. [doi: 10.1037//0003-066x.55.1.68] [Medline: 11392867]
63. Whittaker R, Merry S, Dorey E, Maddison R. A development and evaluation process for mHealth interventions: examples from New Zealand. J Health Commun 2012;17 Suppl 1:11-21. [doi: 10.1080/10810730.2011.649103] [Medline: 22548594]
64. Schofield P, Chambers S. Effective, clinically feasible and sustainable: key design features of psycho-educational and supportive care interventions to promote individualised self-management in cancer care. Acta Oncol 2015 May;54(5):805-812. [doi: 10.3109/0284186X.2015.1010016] [Medline: 25813474]

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65. Yu KD, Zhou Y, Liu GY, Li B, He PQ, Zhang HW, et al. A prospective, multicenter, controlled, observational study to evaluate the efficacy of a patient support program in improving patients' persistence to adjuvant aromatase inhibitor medication for postmenopausal, early stage breast cancer. Breast Cancer Res Treat 2012 Jul;134(1):307-313. [doi: 10.1007/s10549-012-2059-8] [Medline: 22527106]
66. Hadji P, Blettner M, Harbeck N, Jackisch C, Lück HJ, Windemuth-Kieselbach C, et al. The Patient's Anastrozole Compliance to Therapy (PACT) Program: a randomized, in-practice study on the impact of a standardized information program on persistence and compliance to adjuvant endocrine therapy in postmenopausal women with early breast cancer. Ann Oncol 2013 Jun;24(6):1505-1512 [FREE Full text] [doi: 10.1093/annonc/mds653] [Medline: 23378537]
67. Schneider SM, Adams DB, Gosselin T. A tailored nurse coaching intervention for oral chemotherapy adherence. J Adv Pract Oncol 2014 May;5(3):163-172 [FREE Full text] [doi: 10.6004/jadpro.2014.5.3.2] [Medline: 25089216]
68. Neugut AI, Subar M, Wilde ET, Stratton S, Brouse CH, Hillyer GC, et al. Association between prescription co-payment amount and compliance with adjuvant hormonal therapy in women with early-stage breast cancer. J Clin Oncol 2011 Jun 20;29(18):2534-2542 [FREE Full text] [doi: 10.1200/JCO.2010.33.3179] [Medline: 21606426]
69. Ribed A, Romero-Jiménez RM, Escudero-Vilaplana V, Iglesias-Peinado I, Herranz-Alonso A, Codina C, et al. Pharmaceutical care program for onco-hematologic outpatients: safety, efficiency and patient satisfaction. Int J Clin Pharm 2016 Apr;38(2):280-288. [doi: 10.1007/s11096-015-0235-8] [Medline: 26715547]
70. Sabate E. Adherence to long-term therapies: evidence for action. World Health Organization. 2003. URL: http://apps.who.int/iris/bitstream/handle/10665/42682/9241545992.pdf;jsessionid=124EC26242112F95748308104B9745F9?sequence=1 [accessed 2022-04-04]
71. Conn VS, Enriquez M, Ruppar TM, Chan KC. Meta-analyses of theory use in medication adherence intervention research. Am J Health Behav 2016 Mar;40(2):155-171 [FREE Full text] [doi: 10.5993/AJHB.40.2.1] [Medline: 26931748]
72. Jackevicius CA, Mamdani M, Tu JV. Adherence with statin therapy in elderly patients with and without acute coronary syndromes. JAMA 2002 Jul;288(4):462-467. [doi: 10.1001/jama.288.4.462] [Medline: 12132976]
73. Usherwood T. Encouraging adherence to long-term medication. Aust Prescr 2017 Aug;40(4):147-150 [FREE Full text] [doi: 10.18773/austprescr.2017.050] [Medline: 28947853]
74. Pereira-Salgado A, Westwood JA, Russell L, Ugalde A, Ortlepp B, Seymour JF, et al. Mobile health intervention to increase oral cancer therapy adherence in patients with chronic myeloid leukemia (the REMIND system): clinical feasibility and acceptability assessment. JMIR Mhealth Uhealth 2017 Dec 06;5(12):e184 [FREE Full text] [doi: 10.2196/mhealth.8349] [Medline: 29212628]
75. Brett J, Boulton M, Watson E. Development of an e-health app to support women prescribed adjuvant endocrine therapy after treatment for breast cancer. Patient Prefer Adherence 2018 Dec 11;12:2639-2647 [FREE Full text] [doi: 10.2147/PPA.S187692] [Medline: 30587936]

Abbreviations

AMSTAR: A Measurement Tool to Assess Systematic Reviews
MA: medication adherence
OACM: oral anticancer medicine
PICO: population, intervention, comparison, and outcome
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROSPERO: International Prospective Register of Systematic Reviews

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Review

eHealth Interventions for Dutch Cancer Care: Systematic Review Using the Triple Aim Lens

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Abstract

Background: Globally, the burden of cancer on population health is growing. Recent trends such as increasing survival rates have resulted in a need to adapt cancer care to ensure a good care experience and manageable expenditures. eHealth is a promising way to increase the quality of cancer care and support patients and survivors.

Objective: The aim of this systematic review was 2-fold. First, we aimed to provide an overview of eHealth interventions and their characteristics for Dutch patients with and survivors of cancer. Second, we aimed to provide an overview of the empirical evidence regarding the impact of eHealth interventions in cancer care on population health, quality of care, and per capita costs (the Triple Aim domains).

Methods: The electronic databases Web of Science, PubMed, Cochrane, and Ovid PsycINFO were searched using 3 key search themes: eHealth interventions, cancer care, and the Netherlands. The identified interventions were classified according to predetermined criteria describing the intervention characteristics (eg, type, function, and target population). Their impact was subsequently examined using the Triple Aim framework.

Results: A total of 38 interventions were identified. Most of these were web portals or web applications functioning to inform and self-manage, and target psychosocial factors or problems. Few interventions have been tailored to age, disease severity, or gender. The results of this study indicate that eHealth interventions could positively affect sleep quality, fatigue, and physical activity of patients with and survivors of cancer. Inconclusive results were found regarding daily functioning and quality of life, psychological complaints, and psychological adjustment to the disease.

Conclusions: eHealth can improve outcomes in the Triple Aim domains, particularly in the population health and quality of care domains. Cancer-related pain and common symptoms of active treatment were not targeted in the included interventions and should receive more attention. Further research is needed to fully understand the impact of eHealth interventions in cancer care on participation, accessibility, and costs. The latter can be examined in economic evaluations by comparing eHealth interventions with care as usual.

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KEYWORDS

cancer; eHealth; digital care; Triple Aim; population health; quality of care; costs; systematic review; psychosocial; intervention; mobile phone

Introduction

Background

Globally, population health is greatly affected by cancer. An estimated 19.3 million new cancer cases and almost 10 million cancer deaths occurred in 2020 [1]. The related health care expenditure amounted to €103 (US $110) billion in Europe in 2018, corresponding to 6.2% of the total health expenditures [2]. The global cancer incidence is estimated to double by 2035 [3]. Owing to better screening and treatment options, survival rates have increased. Hence, cancer is increasingly becoming a chronic disease. Therefore, it is essential to develop and implement interventions to promote the long-term health and well-being of patients and survivors and to support daily disease coping [4].

Increasing attention is being paid to the use of eHealth to improve cancer care and support patients with cancer and survivors in coping with their illness. The World Health Organization defines eHealth as "the use of information and communication technology in support of health and health-related fields" [5]. There are several definitions of cancer survivors. Here, we use the definition of the National Cancer Institute: "persons with cancer post-treatment until the end of life" [6]. Currently, various eHealth interventions are available for patients with cancer and survivors. These interventions show considerable variations in function, target population, and type of eHealth technology. For instance, interventions can provide patients with and survivors of cancer with information about the disease and its treatment [7,8], support decision-making and self-management [9,10], alleviate physical and emotional problems [11,12], or provide peer social support [13,14]. Furthermore, interventions target different groups of patients with or survivors of cancer using various technologies and can be used as unguided self-help or with the support of health care professionals. Several studies have evaluated specific eHealth interventions in cancer care [15-20]. These studies considered a variety of outcomes, such as psychological complaints [15,16], symptom distress [17,19], and insomnia severity [18], and examined the effect of intervention characteristics, such as the amount of support, on intervention efficacy [21].

Currently, a general overview of eHealth interventions in cancer care and their characteristics is lacking. Such an overview would provide insights into the broad range of eHealth interventions available in cancer care, making it easier to compare interventions and their efficacy. In addition, no reviews that investigate the empirical evidence of the impact of eHealth interventions in cancer care are available. The absence of such overviews limits our understanding of the added value of eHealth interventions in cancer care. One way of evaluating interventions is through the Triple Aim framework. This model focuses on (1) improving population health, (2) improving the quality of care and patient experience, and (3) reducing the per capita health care costs [22]. Many areas of health reform can be helped forward and strengthened by Triple Aim framework, including the integration of information technologies such as eHealth. Deploying the Triple Aim lens offers an opportunity for a holistic and versatile evaluation.

Objective

The aim of this systematic review is 2-fold: (1) to provide an overview of available eHealth interventions in cancer care and their characteristics as described in the scientific literature and (2) to provide an overview of the empirical evidence regarding the impact of eHealth interventions in cancer care on population health, quality of care, and per capita costs—the Triple Aim domains [23]. As eHealth interventions are likely to be context-specific or even context-dependent, we will examine eHealth interventions applied in the Dutch context [24]. The Dutch context has been chosen as a case study and serves as an example for other Western countries.

Methods

Search Strategy

The following 4 databases were searched electronically from the earliest available date to June 14, 2021, to identify relevant literature: Web of Science, PubMed, Cochrane, and Ovid PsycINFO. Three key search components were used: eHealth interventions, cancer, and the Netherlands. An overview of the search strategies for each database can be found in Multimedia Appendix 1. Other potentially relevant publications were identified by tracking the reference lists of included articles.

Eligibility Criteria

Studies were eligible if the following criteria were met:

- Population: the eHealth intervention was offered in the Netherlands and targeted adults (>18 years) diagnosed with cancer who were about to start, are currently undergoing, or have finished treatment (ie, cancer survivors) within the Dutch health care system.
- Intervention: the study focused on eHealth interventions according to the definition of eHealth by the World Health Organization [5]: "the use of information and communication technology in support of health and health-related fields." Both fully web-based and blended eHealth interventions (ie, interventions combining web-based components with face-to-face contact) were included [25]. The eHealth intervention did not consist of business intelligence and big data solutions, such as analyzing structured and unstructured data to gather information to support decision-making [26].
- Comparison: studies were included independently of the presence and type of control group.
- Outcome: there was no focus on specific research outcomes for the first aim—to provide an overview of available eHealth interventions. The goal was to obtain a broad picture of available eHealth interventions. For the second aim—to provide an overview of empirical evidence

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regarding the impact of eHealth interventions—only studies that measured one or more of the Triple Aim domains were included.
- Setting: using any study designs except for incomplete trials, editorials, letters, and reviews. Nonetheless, the latter method was used to identify additional relevant studies from the reference lists. We excluded these 3 study designs as they were non–peer-reviewed or did not discuss a specific intervention.
- Time: all years were included as long as the study was published in the Dutch or English language.

Selection Procedure

The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2020 Statement was used to ensure the validity and reliability of the selection procedure [27]. The PRISMA 2020 checklist can be found in Multimedia Appendix 2 [28]. One investigator (LvD) searched for eligible studies. Subsequently, the reference software program Endnote (Endnote X7; Thomson Reuters) was used to remove duplicates. Two investigators (LvD and LS) independently screened the titles and abstracts of the articles to identify relevant studies. Next, full texts of the potentially relevant articles were assessed. Discrepancies between investigators were mutually resolved through discussion until a consensus was reached. Web-based software Covidence (Veritas Health Innovation) [29] was used for the screening process.

Data Selection and Extraction

The following intervention characteristics were extracted at the application level (Multimedia Appendix 3 [7-13,21,30-106]):

- Summary of the intervention: a short description of the intervention type (eg, web-based training modules) and purpose.
- Functional category: the functional category classification of the interventions was based on CEN (Comité Européen de Normalisation)-ISO (International Organization for Standardization) DTS (Draft Technical Specification) 82304-2:2020 [107]—a document providing quality requirements for health applications. The following categories were distinguished: (1) inform; (2) simple monitoring, to allow users to record health parameters to create health diaries; (3) communicate, to allow 2-way communication; (4) preventive behavior change, to change intended user behavior, such as related to smoking or sexual health; (5) self-management, to help persons with specific health issues to manage their health; (6) treat, to provide treatment for specific health issues or to guide treatment decisions; (7) active monitoring, to automatically record information for remote monitoring; and (8) diagnose, to use data to diagnose health issues.
- Type of eHealth: the classification of the type of eHealth of the intervention was based on the categorization of Nictiz [26], a Dutch knowledge center for national applications of information and communications technology in health care [108]: (1) web application or web portal (offered via a web browser, place, and time-independent), (2) mobile app (available on a smartphone), (3) health sensor (to measure vital bodily functions) or health gateway (to collect and transmit data from health sensors to medical professionals) or wearable devices (health sensors carried on the body), (4) electronic health records or personal health records, and (5) video communication tools.
- Intended setting to use the intervention: primary care, secondary care, or community
- Target population: type of cancer, demographics (gender, age, and nationality), and specific characteristics (eg, smokers)
- Support of health care professional: yes or no, with an explanation
- Use of theory in the development of the intervention: yes or no, with an explanation
- Stakeholder involvement in the development of the intervention: yes or no, with an explanation

Information on research methods and outcomes was extracted at the study level for each empirical evaluation study. More specifically, we extracted information on the study design and objective, the number of participants included at baseline, description of the control group (if applicable), data collection period, study measures, and outcomes. Study outcomes were classified using the Triple Aim [23]. The Triple Aim describes an approach to improve health system performance by focusing on the following:

1. Improving the health of populations
2. Improving patient experience (including quality, patient-centeredness, safety, and timeliness of care)
3. Reducing the per capita cost of health care [23]

We used the framework by Struijs et al [109,110], who elaborated on this model by breaking down the 3 aims into more concrete dimensions (Textbox 1).

Furthermore, a quality appraisal was conducted for each empirical evaluation study using the Effective Public Health Practice Project Quality Assessment Tool for Quantitative Studies [111]. This tool has been reported to have construct and content validity [112,113]. Furthermore, the tool can be used to gain insight into the quality of different study designs, making it easier to compare the results of the quality appraisal in this review. This tool assesses 6 components: (1) selection bias, (2) study design, (3) confounders, (4) blinding, (5) data collection methods, and (6) withdrawals and dropouts. Each component can be rated as strong, moderate, or weak based on the guidelines for the tool. Based on the ratings of each component, the tool allocates an overall methodological score for the study: strong, moderate, or weak.

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Textbox 1. Overview of levels in Triple Aim based framework by Struijs et al [109,110].

Population health:

- Health outcomes
- Disease burden
- Behavioral and physiological factors
- Participation
- Functioning and quality of life

Quality of care:

- Patient safety
- Effectivity
- Responsiveness
- Timeliness
- Support
- Accessibility

Per capita costs:

- Costs of care
- Volume
- Organizational costs
- Productivity loss

Finally, an overview of funding sources per article can be found in Multimedia Appendix 4.

Customized data extraction sheets were developed for the intervention characteristics and the study design, quality appraisal, and study outcomes. To ensure consistency in data extraction, one researcher (LvD) independently subtracted the data of each study and a second researcher (LS) subtracted data of a random sample of 15% of these studies. The interrater agreement was 83.5%, which was considered good. Data were narratively synthesized in 2 sections. The first section discusses the intervention characteristics of the identified interventions. The second section discusses the study design, quality appraisal, and empirical study outcomes.

Results

Study Selection and Characteristics

Figure 1 shows the flow diagram of the study selection. We identified 577 articles, and reference tracking yielded an additional 31 peer-reviewed studies. Removal of duplicates resulted in 364 publications. After screening the records and assessing the full-text articles, 85 articles were included in this review. Multimedia Appendix 5 lists excluded studies in the full-text screening stage.

The resulting 85 included articles described 38 unique interventions. An empirical evaluation of eHealth interventions in cancer care was performed in 26 of these 85 articles. These 26 evaluation studies evaluated 18 of the 38 identified eHealth interventions, as in some cases, multiple articles evaluated the same intervention.

The main characteristics of the interventions are described in the subsequent section to provide an overview of available eHealth interventions in cancer care and their characteristics as described in the scientific literature (the first study aim). The described intervention characteristics are purpose, functional category, type of eHealth, setting, target population, support of health care professionals, and the use of theory.

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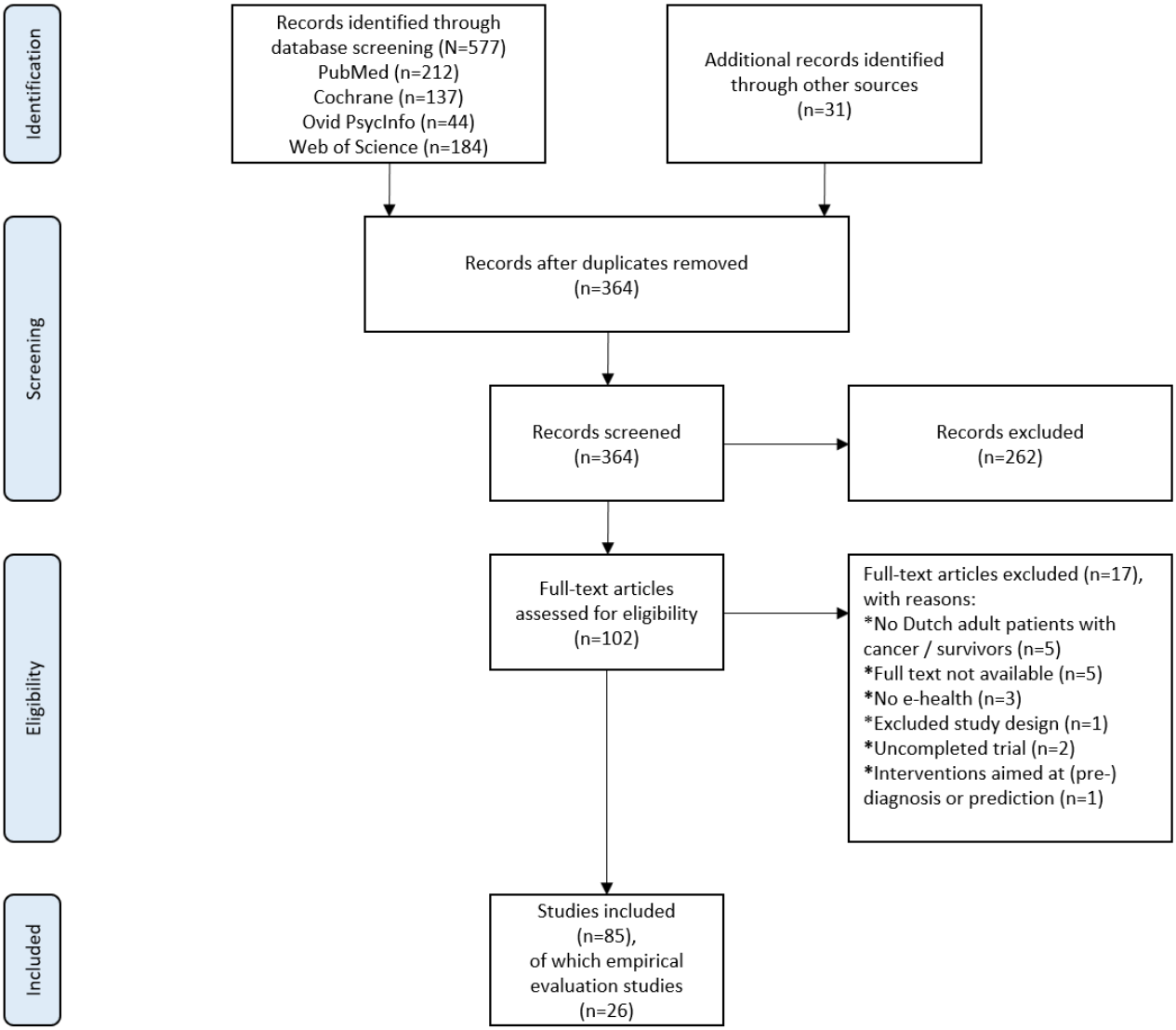
Figure 1. Study selection flow diagram according to PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2020 [27].



Intervention Purpose

The included interventions had a broad range of purposes, such as supporting decision-making (eg, decision aids), communicating with health care professionals, monitoring patient-reported outcomes, and participating in online support communities. Almost half of the interventions targeted psychosocial factors (eg, cognitive or sexual functioning and psychological adjustment) or problems (eg, smoking, drinking behavior, depression, and anxiety). Approximately two-thirds of these psychosocial interventions aimed to reduce general psychosocial issues or psychological complaints or foster patients' self-efficacy or disease coping.

Functional Category, Type of eHealth Intervention, and Setting

The interventions had various functions, in some cases, more than one. The most common functions were inform (n=35), self-manage (n=14), treat (n=11), and preventive behavior change (n=7). Most interventions were web applications or web portals (n=34) or mobile apps (n=7). Most of the interventions were used in secondary care (n=32).

Target Population

Approximately half (17/38, 45%) of the interventions targeted the general population of patients with cancer or survivors, whereas others targeted a specific type (15/38, 39%) or multiple types (6/38, 16%) of cancer. A total of 14 interventions were aimed at patients or survivors with specific demographics, namely age (eg, young adults or older adult patients; 4/38, 10%), origin (Turkish-Dutch or Moroccan Dutch migrants; 1/38, 3%), or gender (9/38, 24%). The latter interventions were often specifically designed for female patients with or survivors of breast cancer (8/38, 21%). A total of 8 interventions targeted patients or survivors with specific clinical characteristics (eg, smokers and patients with depressive symptoms). Finally, 3 interventions focused on patients with a specific disease severity: stable lower-grade glioma (1/3, 33%) and patients treated with palliative intent (2/3, 67%).

Support of Health Care Professionals and Use of Theory

Support from a health care professional was possible in 55% (21/38) of the interventions. Support comprised, among others, web-based support from a coach [30,31], weekly feedback from

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a health care provider [32-34], and teleconsultation with a health care provider [35,36]. Approximately 60% (23/38) of the interventions were theory-based, using, for example, principles from cognitive behavioral theory and the theory of planned behavior.

More details on the intervention characteristics can be found in Multimedia Appendix 3.

Characteristics of the empirical studies and the study results are described in the subsequent sections to provide an overview of the empirical evidence regarding the impact of eHealth interventions in cancer care on population health, quality of care, and per capita costs, the Triple Aim domains (the second study aim).

Description of Empirical Studies

General Characteristics

Table 1 shows the characteristics of the 26 available studies that evaluated 18 different interventions for Dutch patients with or survivors of cancer. Approximately 88% (23/26) of the studies were randomized controlled trials, 8% (2/26) were prospective controlled trials, and 4% (1/26) were a before-and-after design. The control condition involved either usual care (9/26, 35%), being placed on a waiting list to participate after the research period ended (2/26, 8%), a combination of usual care and being placed on a waiting list (9/26, 35%), or receiving another intervention (5/26, 19%). In one study, no control group was used (1/26, 4%). Most studies used 1 (4/26, 15%), 2 (7/26, 27%), or 3 (12/26, 46%) follow-up measurements. One study had 4 follow-up measurements (1/26, 4%) and one did not have follow up measurements (1/26, 4%). The measurement period ranged from 1 week to 1 year after baseline measurement. The average number of patients who participated in the study was 250 (SD 181; range 34-625).

Quality Appraisal

A moderate global rating for the quality of evidence was assigned to 16 studies. Six studies were assigned a weak global rating and 4 received a strong global rating. Selection bias was likely present in most studies (18/26, 69%). Most studies were considered to have a low risk of bias concerning the study design, confounders, and data collection. Moderate risk was identified for the majority of studies on the blinding component. Scores for the component withdrawals and dropouts varied considerably. Details can be found in Multimedia Appendix 6 [21,30,32,36-58].

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Table 1. Characteristics of the empirical evaluation studies.

Intervention	Study design	Participants	Study aim	Description of the control group (CG) usual care (UC)	Data collection period
Cancer aftercare guide (Kanker Nazorg Wijzer [KNW])					
Study 1 [37]	RCT[a]	Total (N=462), IC[b] (n=231), CG (n=231)	Present short-term effects of the Cancer Aftercare Guide (KNW) on QoL[c], anxiety, depression and fatigue	Usual care and a waiting list	BM[d], follow-up at 3 months, 6 months, and 1 year
Study 2 [38]	RCT	Total (N=462), IC (n=231), CG (n=231)	Explore the influence of gender, age, educational level, and treatment type on intervention effectiveness	Usual care and a waiting list	BM, follow-up at 3 months, 6 months, and 1 year
Study 3 [39]	RCT	Total (N=462), IC (n=231), CG (n=231)	Assess the short-term effects of the KNW on lifestyle outcomes	Usual care and a waiting list	BM, follow-up at 3 months, 6 months, and 1 year
Study 4 [40]	RCT	Total (N=462), IC (n=231), CG (n=231)	Examine the long-term effects of the KNW on moderate physical activity and vegetable consumption	Usual care and a waiting list	BM, follow-up at 3 months, 6 months, and 1 year
OncoCompass (OncoKompas)					
Study 1 [41]	RCT	Total (N=625), IC (n=320), CG (n=305)	Evaluate the efficacy of Oncokompas OncoKompas to improve knowledge, skills, and confidence for self-management among survivors of different cancer types	Usual care and a waiting list	BM, follow-up post intervention, and at 3 months and 6 months
Study 2 [42]	RCT and economic evaluation	Total (N=625), IC (n=320), CG (n=305)	Evaluate the cost-utility of Oncokompas compared with usual care among cancer survivors	Usual care and a waiting list	BM, post intervention, and 3 months and 6 months follow-up
Transmural Oncological Support (TOS)					
Study 1 [43]	PCT[e]	Total (N=36)	Determine the use, appreciation, and effectiveness of an eHealth information support system in head and neck cancer care	N/A[f]	BM, follow-up at 6 weeks
Study 2 [44]	PCT	Total (N=184), IC (n=145), CG (n=39)	Investigate whether telemedicine could be beneficial to the quality of life of patients with cancer	Usual care	BM, follow-up at 6 weeks and 3 months
Everything under control (Alles onder controle) [31]	RCT	Total (N=115), glioma intervention group (n=45), glioma waiting list control group (GWL; n=44), non–central nervous system (CNS) cancer control group (n=26)	Evaluate the effects of the intervention on depressive symptoms in adult patients with glioma	GWL patients: a waiting list. Non-CNS cancer control group patients: regular intervention	BM, follow-up at 6 and 12 weeks, 6 months, and 12 months
Prostate cancer decision aid (Prostaatkanker keuzehulp) [45]	RCT	Total (N=336), IC (n=235), CG (n=101)	Compare patients' evaluation of treatment decision-making process in localized prostate cancer between counseling including an online decision aid (DA) and standard counseling	Usual care	BM, follow-up 1 week after the indicated date of the next consultation

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Intervention	Study design	Participants	Study aim	Description of the control group (CG) usual care (UC)	Data collection period
Less tired (Minder Moe) [32]	RCT	Total (N=167), IC 1 (ambulant activity feedback [AAF]; n=62), IC 2 (Minder Moe; n=55), CG (psychoeducation; n=50)	Report on the clinical effectiveness of AAF and eMBCT in reducing fatigue severity and improving mental health in severely fatigued cancer survivors, compared with psychoeducation	Other intervention: psycho-educational mails	BM, follow-up at 2 weeks, 3 months, 6 months, and 12 months
Less tired for anxiety and depression complaints [46]	RCT	Total (N=245), IC 1 (mindfulness based cognitive therapy [MBCT]; n=77), IC 2 (eMBCT; n=90), CG (treatment as usual [TAU]); n=78)	Compare MBCT and eMBCT with treatment as usual for psychological distress in patients with cancer	Usual care	BM, posttreatment, 3 months and 9 months posttreatment
BREATH [47]	RCT	Total (N=150), IC (n=70), CG (n=80)	Study whether care as usual plus BREATH[g] can effectively target negative and positive adjustment	Usual care	BM, follow-up at 4, 6, and 10 months
Less fear after cancer (Minder angst bij kanker) [48]	RCT	Total (N=262), IC (n=130), CG (n=132)	Evaluate the cost-effectiveness of a web-based CBT[h]-based self-help training in reducing fear of cancer recurrence (FCR) in women with curatively treated BC	Usual care	BM, follow-up at 3 months and 9 months
OncoActive [49]	RCT	Total (N=478), IC (n=249), CG (n=229)	Gain insight into the efficacy of the intervention to increase PA	Usual care and a waiting list	BM, follow-up at 3 and 6 months
PatientTIME [50]	RCT	Total (N=97), IC (n=63), CG (n=34)	Evaluate if and in what way patients benefit from PatientTIME and if it enhances their confidence in clinical communication	A waiting list	BM, follow-up at T1 (exact timing unclear) and 3 months after participation
ENCOURAGE [51]	RCT	Total (N=138), IC (n=70), CG (n=69)	Examine the effectiveness of the intervention to empower BC patients to take control over prevailing problems	Usual care	BM, follow-up at 6 and 12 weeks
Cancer, intimacy, and sexuality (kanker, intimiteit en seksualiteit)					
Study 1 [52]	RCT	Total (N=169); IC (n=84), CG (n=85)	Evaluate the effect of the intervention on sexual functioning and relationship intimacy in BC survivors with sexual dysfunction	Other intervention: receive an information booklet on sexuality issues after BC treatment	BM, follow-up at 10 weeks after the start of therapy and post therapy, at 3 and 9 months
Study 2 [53]	RCT	Total (N=169). Only the IC group is taken into account in this study: n=84	Evaluate the long-term efficacy of the intervention for sexual dysfunctions in BC survivors	Other intervention: receive an information booklet on sexuality issues after BC treatment	BM, follow-up at 10 weeks after the start of therapy and post therapy, at 3 and 9 months
Home monitoring tool for adequate pain treatment [54]	Before-and-after design	Total (N=108), IC (n=54), CG (n=54)	Assess whether home telemonitoring increased registration of pain in medical records of patients visiting a Dutch teaching hospital	Usual care	The authors analyzed medical records from the first 3 visits (a total of 162 visits)
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Intervention	Study design	Participants	Study aim	Description of the control group (CG) usual care (UC)	Data collection period
Study 1 [21]	RCT	Total (N=254), IC 1 (n=85), IC 2 (n=85), CG (n=84)	Evaluate the efficacy of an iCBT program in women with BC treatment-induced menopausal symptoms	Usual care and a waiting list	BM, follow-up at 10 weeks and 24 weeks
Study 2 [55]	RCT and economic evaluation	Total (N=254), IC 1 (n=85), IC 2 (n=85), CG (n=84)	Evaluate the cost-utility, cost-effectiveness, and budget impact of both iCBT formats compared with a waiting list control group	Usual care and a waiting list	BM, follow-up at 10 weeks and 24 weeks
Home-based exercise intervention					
Study 1 [56]	RCT	Total (N=34), IC (n=23), CG (n=11)	Present a detailed evaluation of the intervention regarding accrual, attrition, adherence, safety and patient satisfaction	Other intervention: 2 brochures with lifestyle advise	BM, follow-up at 6 months
Study 2 [57]	RCT	Total (N=34), IC (n=23), CG (n=11)	Explore the possible impact of an exercise intervention on cognitive test performance and patient-reported outcomes in patients with glioma	Other intervention: 2 brochures with lifestyle advice	BM, follow-up at 6 months
My-GMC [58]	RCT	Total (N=109), IC (n=59), CG (n=50)	Evaluate the efficacy of the intervention	Usual care	BM, follow-up at 1 week, 3 months, and 6 months
Teleconsultation for patients receiving palliative home care [36]	RCT	Total (N=74), IC (n=38), CG (n=36)	Determine whether weekly teleconsultations improved patient-experienced symptom burden compared with "care as usual"	Usual care	BM, at 4 weeks, 8 weeks, and 12 weeks

[a]RCT: randomized controlled trial.

[b]IC: intervention condition.

[c]QoL: quality of life.

[d]BM: baseline measurement.

[e]PCT: prospective clinical trial.

[f]N/A: not applicable.

[g]BREATH: breast cancer eHealth.

[h]CBT: cognitive behavioral therapy.

Study Outcomes

Most studies measured at least one dimension within either the population health or quality of care domain (23 and 24 studies, respectively).

Three studies measured at least one dimension within the per capita costs domain (Table 2 and Multimedia Appendix 7 [21,30,32,36-58]). An overview of the domains and dimensions measured per study can be found in Multimedia Appendix 8 [21,30,32,36-58]. The outcomes are described by dimension in subsequent sections. Unless stated otherwise, significant between-group differences were described by comparing the intervention and control groups.

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Table 2. Overview of the found effects per empirical evaluation study (randomized controlled trial [RCT] studies, prospective clinical trial [PCT] studies, and before-and-after design studies are study designs).

Intervention	Results[a]
RCT studies	
Cancer aftercare guide (Kanker Nazorg Wijzer)	
Study 1 [37]	e: After 6 months: Emotional functioning *sig**[b]. Social functioning *sig;** MT[c]*sig.*
	g: After 6 months: Depression *sig***; MT *sig;* ITT *sig**. Fatigue *sig**; MT *sig;* ITT[d]*sig**.
	h*:* Participants in the IC who completed the 6-month measurement on average used 2.2 modules. Loss to follow-up in the IC was 16.2%.
Study 2 [38]	e: After 12 months: Emotional functioning *n.s.* Social functioning *n.s.*
	g: After 12 months: Depression *n.s.* Fatigue *n.s.*
	h*:* Overall appreciation of the KNW is 7.48 (10-point scale).
Study 3 [39]	c: After 6 months: Moderate PA *sig;** MT *n.s.* vegetable consumption *sig;** MT *n.s.* other PA outcomes *n.s.;* MT *n.s.* other dietary outcomes *n.s.* smoking behavior *n.s.*
	h: Loss to follow-up after 6 months was low (11.5%) vs mean percentage of dropouts (19.7%) of web-based trials for cancer survivors.
Study 4 [40]	c: After 12 months: moderate physical activity *sig***. Vegetable consumption *n.s.*
	h: Loss to follow-up in the IC was 45.5%.
OncoCompass (OncoKompas)	
Study 1 [41]	b: The course of symptoms in head and neck cancer survivors, colorectal cancer survivors and high-grade non-Hodgkin lymphoma survivors *sig**. The course of symptoms in BC survivors *n.s.*
	e*:* HRQoL *sig**.
	g: Course of mental adjustment to cancer *n.s.*
	h*:* Course of supportive care needs *n.s.* Patient-physician interaction over time *n.s.* Self-efficacy *n.s.* Personal control *n.s.* Patient activation *n.s.* In the IC, 78% activated their account and 52% used the intervention as intended.
Study 2 [42]	h: The loss to follow up in the IC was 36%.
	l: OncoCompass is likely to be equally effective on utilities and not more expensive than usual care.
Everything under control (Alles onder controle) [31]	e: Physical health after 12 months ITT and protocol analysis n.s.
	g: After 6 weeks: Depression (GI vs GWL group and Total glioma group vs non-CNS cancer group) *n.s.* Fatigue (GI vs GWL group) *sig**. After 12 weeks: depression *n.s.* Fatigue *n.s.* Other measures (GI vs GWL group) *n.s.*
	h: Most patients said they had benefitted from participating (73% glioma; 67% non-CNS), and the program was useful (92% in both groups) and informative (86% glioma; 92% non-CNS). The participation rate was 40%. The adherence of the IC was 85% for the introduction and 77%, 52%, 40%, 37%, and 35% for modules 1 through 5, respectively.
Prostate cancer decision aid (Prostaatkanker keuzehulp) [45]	h: Satisfaction with information *sig**. Involvement *n.s.* Decisional conflict *n.s.* Knowledge scores *n.s.* Subjective knowledge *sig***. Objective knowledge *n.s.*
Less tired (Minder Moe) [32]	g: Fatigue severity *sig**. Psychic complaints *n.s.* Positive and negative affect *n.s.*
	h: The proportion of participants who dropped out before completing 6 weeks of the protocol was 18% in the AAF condition, 38% in the eMBCT, and 6% in the psychoeducation condition.
Less tired for anxiety and depression complaints [46]	b: Psychiatric diagnosis *n.s.*
	c: Mindfulness skills *sig**.
	e: Mental HRQoL *sig**. Positive mental health *sig**. Physical HRQoL *n.s.*
	g: Psychological distress *sig***. Fear of cancer recurrence *sig**. Rumination *sig**.
	h*:* 90.9% started MBCT and 92.2% completed ≥4 sessions. 91.1% started eMBCT and 71 completed ≥4 sessions. The dropout rate was higher in eMBCT than in the MBCT.
BREATH [47]	g: At T1: Distress *sig**. 5 out of 7 negative adjustment variables (general and cancer-specific distress, fatigue, and 2 fear of cancer recurrence outcomes) and 3 out of 10 positive adjustment variables (self-efficacy, remoralization, new ways of living) *sig**. Clinically significant improvement *sig**. At T2 and T3*:* Distress *n.s.* One negative adjustment variable (Fear of cancer recurrence) *sig**. One positive adjustment outcome (Acceptance) *sig***. All other outcomes *n.s.*
	h: At T1: Empowerment *n.s.* The frequency of logins ranged from 0 to 45. Total duration ranged from 0 to 2.324 minutes.

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Intervention	Results[a]
Less fear after cancer (Minder angst bij kanker) [48]	g: Fear of cancer recurrence *ns* h: The dropout rate in the IC was 30%.
OncoActive [49]	c: At 3 months: PA *sig;*[*] ITT *sig.* e: At 3 months: Physical functioning *sig;*[**] ITT *sig.* HRQoL *n.s.* At 6 months follow-up: physical functioning *sig;*[*] ITT *n.s.* HRQoL *n.s.* g: At 3 months follow-up: Fatigue *sig**. At 6 months follow-up: Fatigue *sig***. Depression *sig,*[**] ITT *sig.* Anxiety *n.s.* h: Dropout rates were 4.4% at 3-month follow-up and 7.3% at 6-month follow-up.
PatientTIME [50]	h: System usability scale: 73 points (100-point scale), considered "good." At T1 and T2*:* PEPPI score *n.s.* The participation rate was 90%.
ENCOURAGE [51]	e: At T2: QoL *n.s.* g: At T1: Increased acceptance *n.s.* Other primary outcomes *n.s.* At T2: All outcomes *n.s.* h: Usefulness score of the program 3.75 (5-point scale). At T1: Being better-informed *sig**. At T2*: n.s.* 61% of the patients logged in more than once.
Cancer, intimacy, and sexuality (Kanker, intimiteit en seksualiteit)	
Study 1 [52]	e: At T1: Sexual desire *sig***. Sexual pleasure *sig***. Discomfort during sex *sig***. Orgasmic function *n.s.* Sexual satisfaction *n.s.* Sex frequency *n.s.* Relationship intimacy *n.s.* Marital functioning *n.s.* Health-related quality of life *n.s.* At T2: Overall sexual functioning *sig**. Sexual desire *sig***. Sexual arousal *sig***. Vaginal lubrication *sig**. Sexual pleasure. Discomfort during sex *sig***. Orgasmic function *n.s.* Sexual satisfaction *n.s.* Sex frequency *n.s.* Relationship intimacy *n.s.* Marital functioning *n.s.* Health-related quality of life *n.s.* g: At T1: Menopausal symptoms *sig***. Body image *sig***. Psychological distress *n.s.* At T2: Menopausal symptoms *n.s.* Body image *sig***. Psychological distress *n.s.* h: The CBT was completed by 61.9% of women.
Study 2 [53]	a: *Only time effect was taken into account as T3 and T4 assessments were completed only by the IC*. At T3 and T4: general health *positiveeffect was maintained.* e: At T3 and T4: Sexual functioning, sexual desire, vaginal lubrication, sexual satisfaction, discomfort during sex, sexual distress, marital sexual satisfaction *positiveeffect maintained.* Sex frequency, intellectual intimacy, and sexual pleasure *decreased over time*. Marital satisfaction and other health-related quality of life domains *n.s. time effect.* g*:* At T3 and T4: Menopausal symptoms and body image *positive effect maintained*, quadratic effect *n.s. time effect.* Distress *n.s. time effect.* h*:* The CBT was completed by 61.9% of women.
EvaOnline	
Study 1 [21]	e: Sexual functioning *n.s.* HRQoL *n.s.* g: At T1: Both IC groups' (guided and self-managed) perceived impact of HF and NS *sig***. Guided group overall levels of menopausal symptoms *sig***. Both IC groups sleep quality *sig***. Guided hot flush frequency *sig.* Guided group night sweats frequency *sig***. Psychological distress *n.s.* *h:* Minimum compliance rate was 90.6% for the guided and 78.8% for the self-managed IC's.
Study 2 [55]	l: The guided and self-managed iCBT are cost-effective. Self-managed iCBT is the most cost-effective strategy.
Home-based exercise intervention	
Study 1 [56]	c: Self-reported physical activity at 6 months *sig**. BMI at 6 months *n.s.* Mean absolute VO_2 peak at 6 months *n.s.* Aerobic fitness at 6 months *sig.* h*:* 16 (84%) patients evaluated the physical exercise program as good or excellent, and 4 as moderately or sufficiently satisfactory. Mean adherence was 79%.
Study 2 [57]	e: For attention, 4 measures (attentional inhibition, attention span, auditory selective attention, and working memory) *sig.* Information processing speed *sig*. Sustained selective attention *n.s.* For memory, immediate verbal recall *sig.* Two measures of executive function (auditory working memory and alternating attention) *sig.* One of 2 measures of cognitive functioning *sig.* Mood *sig.* Mental health-related quality of life *sig.* Brain cancer-specific health-related quality of life scales *n.s.* h*:* Loss to follow-up in the IC was 8.7%. g: Two scales of fatigue (physical fatigue and reduced activity) *sig.* Sleep *sig.*

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Intervention	Results[a]
My-GMC [58]	c: Medication adherence at T2 *sig.* e: Quality of life at all time points *n.s.* g: Distress at all time points *n.s.* Cancer worry at all time points *n.s.* h: Satisfaction with the online app was rated 2.8 (5-point scale). Professional satisfaction with the video GMCs was 2.7 (5-point scale). Empowerment at all time points *n.s.* The participation rate was 35%.
Teleconsultation for patients receiving palliative home care [36]	b: Symptom burden *n.s.* g: Anxiety *n.s.* Depression *n.s.* All 3 subscales for continuity of care *n.s.* h: Study outcome measures regarding GP contacts and complex interventions *n.s.* Mean number of unmet needs *n.s.* The attrition rates were 61% in the IC and 53% in the CG. m: Mean number of hospital admissions *n.s.*
PCT studies	
Transmural oncological support	
Study 1 [43]	h: The average score of all patients for the monitoring function was 8.0 (10-point scale). The average score rated by 7 GPs of the electronic health information support system was 5.6 (10-point scale). The participation rate was 66%. All patients used the system.
Study 2 [44]	e: After the intervention: 5 of the 22 QoL subscales (state anxiety, fear related to specific head and neck problems, physical self-efficacy, perceived abilities in swallowing and food intake, and general physical complaints) *sig.* At 3 months: 1 subscale (physical self-efficacy) *sig**. Other subscales *n.s.* h: The participation rate in the IC was 66%, and 35 out of 39 patients completed all questionnaires.
Before-and-after design studies	
Home monitoring tool for adequate pain treatment [54]	g: Total number of "pain registrations" in the medical records *sig**.

[a]Triple Aim domains: a=health outcomes, b=disease burden, c=behavioral and physiological factors, d=Participation, e=Functioning and quality of life, f=Patient safety, g=Effectivity, h=Responsiveness, I=Timeliness, j=Support, k=Accessibility, l=Costs of care, m=Volume, n=Organizational costs, o=Productivity loss.

[b]*sig*=significant positive between-group difference in favor of IC, *P* value unknown; *sig**=significant positive between-group difference in favor of IC, α≤.05; *sig***=significant positive between-group difference in favor of IC, α≤.01; *ns*=nonsignificant between-group difference in favor of IC.

[c]*MT*=controlling for multiple testing or comparisons;

[d]*ITT*=intention-to-treat analysis.

Population Health

A total of 23 studies measured at least one dimension within the *population health* domain, and 6 studies measured the dimension *behavioral and physiological factors* [39,40,46,49,56,58]. Positive effects were found for aerobic fitness [56] and physical activity [39,49,56]; however, these effects did not always hold after controlling for multiple testing [39] or in follow-up studies [40]. There were also significant effects on mindfulness skills [46] and medication adherence [58]. No effects were found for smoking behavior [39,40], physical fitness level [56], and changes in BMI [56]. A total of 13 studies measured the dimension *functioning and quality of life* [21,31,37,38,41,44,46,49,51-53,57,58]. Six studies focused on daily functioning. The studies showed positive effects for emotional and social functioning [37]; however, these effects were not significant at follow-up [38]. Furthermore, positive effects were found for physical functioning [49]; however, these effects were not significant after multiple testing [49]. One study demonstrated positive effects on cognitive functioning [57]. Mixed effects were found in terms of sexual functioning [21,53]. Most studies measuring health-related quality of life did not find positive effects (4/6, 67%) [21,41,44,49,51,58]. Positive effects were found for mental health-related quality of life [46,57] but not for physical health [31,46]. The dimensions *health outcomes* (*n*=1) [53] and *disease burden* (*n*=3) [36,41,46] were less prevalent, and the dimension *participation* was not studied at all.

Quality of Care

A total of 24 studies measured at least one dimension within the domain *quality of care*. Furthermore, 17 studies measured the dimension *effectivity* [21,31,32,36-38,41,46-49,51-54,57,58]. Most of these studies examined the effect of eHealth interventions on psychological complaints (n=12; eg, depression, anxiety, and psychological distress). Of these 12 studies, more than half (7/12, 58%) did not find positive effects [21,31,32,36,52,53,58]. Four studies found positive effects [37,46,47,49]; however, no significant results were found in 2 studies that measured the follow-up effects [38,47]. Six studies assessed positive or negative adjustment to cancer (eg, fear of cancer recurrence, mental adjustment, and acceptance), and half of them (3/6, 50%) found positive effects [41,46-48,51,58]. Except for one study, all studies measuring fatigue and sleep quality found positive effects (6/7, 86%) [21,31,32,37,38,49,57]; however, in both studies, where follow-up effects were measured, no significant results were found [31,38]. All studies measuring menopausal symptoms or body image found positive effects [21,52,53]. In total, 7 studies measured outcomes within the dimension *responsiveness* [36,41,45,47,50,51,58]. Mixed

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effects were found in studies measuring responsiveness in the form of patient-physician interaction (eg, satisfaction with information, patient-physician interaction over time) [36,41,45,51]: 2 found positive effects [45,51] and 2 did not [36,41]. In addition, 80% (4/5) studies measuring patient involvement in the care process (eg, empowerment, patient activation, self-efficacy, shared decision-making, and being better informed) found positive effects [41,45,47,50,58]. The interventions used different scales and outcome measures to measure patients' and health care providers' experiences with the intervention. The outcome measures were satisfaction rate, usability, and overall appreciation. Overall, users were fairly positive about their experiences with the intervention and gave satisfactory ratings [31,37,43,50,51,56,58]. Participation in the intervention was also assessed using several outcome measures. The most frequently used measurements were loss to follow-up and participation rate. The loss to follow-up ranged from 8.7% to 45.5% and the participation rate ranged from 35% to 90% [21,31,32,36-53,56-58]. None of the studies measured the dimensions *patient safety*, *timeliness*, *support*, or *accessibility*.

Per Capita Costs

Three studies measured a dimension within the domain *per capita costs* [42,54,55]. Two studies [42,55] measured the dimension *costs of care*, and both found through economic evaluation that the intervention was likely to be equally cost-effective compared with care as usual. One study [54] measured the dimension *volume* and did not find significant effects. None of the studies measured the dimensions *organizational costs* or *productivity loss*.

Discussion

Principal Findings

This systematic review is the first to provide an overview of eHealth interventions in Dutch cancer care and use the Triple Aim framework to examine the empirical evidence of these interventions on population health, quality of care, and per capita costs (the Triple Aim domains). The review focused on Dutch cancer care; however, the results are also relevant to other Western countries involved in digital care for patients with and survivors of cancer. A total of 38 interventions were identified, and the results showed that most eHealth interventions targeted psychosocial factors or problems. In addition, interventions were aimed at many different target groups, including the general population of patients with and survivors of cancer, patients with a specific type of cancer, or patients who experienced a specific problem, such as cancer-related fatigue or smoking behavior. Few interventions were tailored to age, gender, or disease severity. The most common intervention types studied were web portals or web applications. These function to inform and facilitate self-management. Other types of interventions (eg, electronic health records or video communication tools), functions (eg, communication or diagnosis), and target outcomes (eg, communication with health care professionals or access to electronic health records) were rarely found.

Most outcome measures could be related to the Triple Aim domains *population health* and *quality of care*, whereas the *per capita costs* domain was largely neglected. Within the population health domain, mixed effects were found regarding the impact of eHealth on functioning and quality of life. Most studies measuring behavioral and physiological factors found positive effects. More specifically, there was preliminary evidence for the positive effects of eHealth interventions on physical activity and aerobic fitness. None of the studies considered the dimension *participation*, including outcome measures such as social inclusion. Within the quality of care domain, eHealth interventions seemed effective in increasing sleep quality and decreasing fatigue, in line with a meta-analysis showing that eHealth interventions effectively manage fatigue in highly fatigued cancer survivors [114]. Findings in terms of positive and negative adjustment to cancer and psychological complaints were inconsistent. One of the measures that was not considered was accessibility, which is worthy of mention as there is increasing global awareness that eHealth should be equally accessible to different populations [115]. The per capita cost dimension was largely neglected in the evaluation studies; only 3 studies considered dimensions within this domain.

This study yielded several interesting findings. With 38 interventions in Dutch cancer care, there appears to be a wide range of eHealth interventions for patients with and survivors of cancer. It seems valuable that most interventions targeting psychosocial factors or problems were aimed at general psychosocial issues, psychological complaints, patients' self-efficacy, and disease coping. Recent research shows that almost all cancer survivors are affected by fatigue [116], 1 in 2 patients with cancer is significantly distressed, and 47% have problems *getting around* [117]. In contrast, few interventions focused on pain from cancer, which is experienced by half of the patients with cancer during active treatment and 65% of the patients with advanced disease [118]. Some common symptoms of active treatment, such as vomiting, nausea, and constipation [119], were not considered. The lack of tailored interventions according to age, gender, or disease severity is noteworthy as subgroups within these categories are likely to have different preferences and needs. For example, older patients may find it more challenging to use eHealth interventions [120]. In addition, patients in different stages of the disease may have different needs as far as information and support are concerned [14].

We found that most interventions consisted of a specific type (web portals or web applications), function (information provision or facilitation of self-management), and target outcome (psychosocial factors or problems). We assume that besides the interventions we identified, more eHealth interventions are being developed and used by patients with or survivors of cancer. These interventions are likely to be designed or evaluated for a broader target population than patients with and survivors of cancer alone. For example, multiple studies have evaluated the general use of electronic health records and patient portals in academic hospitals without targeting a specific patient population [121-124]. Our search strategy included only patients with or survivors of cancer as a critical criterion; therefore, our search results did not include these interventions. As a result, the number of interventions available for patients with and survivors of cancer may be more significant and versatile than the results of this review.

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Another interesting finding is that the results of the evaluation of study outcomes are mainly in line with the literature. For example, several meta-analyses have been conducted to examine the effect of eHealth on the quality of life of patients with or survivors of cancer do find a statistically significant effect [114,125], while others do not [126,127]. These mixed findings, which we also found in the review, can be explained by the fact that quality of life is a multidimensional variable influenced by multiple factors [128]. The current inconsistent findings for psychological complaints and adjustment to cancer were also found in a previous meta-review, which found inconsistent results for the effect of eHealth on psychological well-being, depression, and anxiety in patients with cancer [14]. When interpreting the study results, it is important to remember that many eHealth interventions are not implemented in daily practice. In addition, many expected benefits of such interventions are not realized in daily clinical practice [129,130] as they are not being used as intended [131,132]. The latter has several root causes such as lack of trust and digital literacy [133]. The suboptimal use of eHealth interventions in daily practice is a significant problem that future research needs to address.

Finally, it is notable that some domains and dimensions are primarily omitted from the studies, such as per capita costs and participation. The scarcity of per capita cost-related study outcomes is in line with previous research on the effectiveness of eHealth interventions in cancer detection, treatment, and survivorship care [134]. As health care costs are increasing in most countries, organizations are actively trying to develop solutions to curb health care expenditures while maintaining access to and harnessing the quality and safety of health care [135]. Digital health care is often viewed as a solution to increasing health care costs. Evaluating eHealth interventions is relevant for adequate resource allocation decisions and designing services for competing health interventions and limited resources. Participation is also an essential theme for eHealth because eHealth interventions can either foster social inclusion or create new risks of social exclusion (eg, for digitally illiterate patients) [136]. In future studies, it will be essential to consider the needs of patients at risk of social exclusion when developing and evaluating eHealth interventions.

Limitations

This review had some limitations. First, this review may not have included all available eHealth interventions, as not all available interventions have been scientifically evaluated. Gray literature and ongoing studies in trial registries were not included in this review, nor were experts consulted nor the authors contacted. Second, the Triple Aim framework used in this review provides a comprehensive overview of the domains and dimensions. However, creating an objective distinction between different dimensions was not always possible. For example, an outcome measure such as improved sleep quality could be classified as *effectiveness* or *behavioral or physiological factors*. Hence, categorizing outcome measures into different dimensions was, to some extent, subjective. Third, for each category of study outcomes, we examined only a small number of studies that evaluated the impact of the intervention on the outcome. Publication bias was not investigated in this study. Therefore, we should be cautious about the conclusions drawn regarding the impact of eHealth interventions on certain subdimensions. Finally, the study protocol was not registered.

Future Research

Future research should examine the dimensions of the Triple Aim that have rarely or not been taken into account in previous research, such as participation and accessibility. Furthermore, studies should examine in further detail what explains the mixed results for studies measuring specific dimensions such as functioning and quality of life. This could be done, for example, in experimental studies examining the effect of particular intervention characteristics on the Triple Aim domains. Further research is needed to increase our understanding of how different intervention characteristics influence intervention outcomes and the underlying causal mechanisms that cause an intervention to be effective. Interventions aimed at coping with pain were rarely found. eHealth interventions such as digital training to develop pain coping skills and pain management apps custom-made for patients with cancer have proven feasible and effective in decreasing pain [137,138]. Future research should explore the potential of such interventions in the Dutch context. Furthermore, this review may be repeated in other countries to compare the intervention characteristics and outcomes of eHealth interventions in cancer care internationally, facilitating learning and sharing best practices. Finally, this review focused on specific eHealth interventions in cancer care. Research on the structural embedding of eHealth interventions in care processes is essential for optimally deploying these interventions. Therefore, future research can examine local care pathways to identify new possibilities for eHealth to address challenges and needs across existing care pathways. Potentially, these insights may lead to new care pathways to optimize cancer care quality. *Conclusions*

Most of the 38 interventions in this review included eHealth interventions for patients with or survivors of cancer in the Dutch health care system consisting of a specific type (web portals or web applications), function (information provision and facilitation of self-management), and target outcome (psychosocial factors or problems). Almost none of the interventions were tailored to the needs of patients with or survivors of cancer based on age group, gender, or disease severity. The Triple Aim domains *population health* and *quality of care* have been studied thoroughly, whereas the domain *per capita costs* is understudied. Most of the included evaluation studies were assigned a moderate quality appraisal score, and selection bias was likely present in most studies. Our results indicate that eHealth could benefit patients and survivors by improving sleep quality, reducing fatigue, and increasing physical activity. Further research is needed to fully understand the effect of eHealth on aspects such as participation (in the form of social inclusion), accessibility, and the effect on quality of life, patient behavior, physiological health, psychological well-being, and per capita costs. Finally, more economic evaluation of eHealth interventions is required. Overall, continuing a holistic evaluation of eHealth interventions in cancer care will be critical to improve population health, enhance the quality of care, and decrease per capita costs.

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Acknowledgments

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Authors' Contributions

LvD, JJA, AV, JNS, and RvdV conceptualized the idea for this review. LvD formulated the review questions and objectives and developed the search strategy. LvD and LS performed the primary search and data extraction. LvD contributed to data analysis and interpretation and wrote the manuscript. RvdV, JJA, AV, JNS, NHC, and LS critically revised the manuscript. All authors read and approved the final version of the manuscript for submission and publication in this journal.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Overview of search strategies per database.
[DOCX File , 14 KB - cancer_v8i2e37093_app1.docx]

Multimedia Appendix 2
PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2020 checklist.
[DOCX File , 21 KB - cancer_v8i2e37093_app2.docx]

Multimedia Appendix 3
Characteristics of eHealth interventions for cancer care in the Netherlands.
[DOCX File , 139 KB - cancer_v8i2e37093_app3.docx]

Multimedia Appendix 4
Overview of funding sources per included study.
[DOCX File , 29 KB - cancer_v8i2e37093_app4.docx]

Multimedia Appendix 5
List of excluded studies in the full-text screening stage.
[DOCX File , 19 KB - cancer_v8i2e37093_app5.docx]

Multimedia Appendix 6
Quality appraisal of the empirical evaluation studies.
[DOCX File , 53 KB - cancer_v8i2e37093_app6.docx]

Multimedia Appendix 7
Overview of outcome measurements and found effects per empirical evaluation study.
[DOCX File , 64 KB - cancer_v8i2e37093_app7.docx]

Multimedia Appendix 8
Overview of measured study outcomes per empirical study.
[DOCX File , 56 KB - cancer_v8i2e37093_app8.docx]

References

1. Sung H, Ferlay J, Siegel RL, Laversanne M, Soerjomataram I, Jemal A, et al. Global Cancer Statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA Cancer J Clin 2021 May;71(3):209-249 [FREE Full text] [doi: 10.3322/caac.21660] [Medline: 33538338]

XSL•FO
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2. Hofmarcher T, Lindgren P, Wilking N, Jönsson B. The cost of cancer in Europe 2018. Eur J Cancer 2020 Apr;129:41-49 [FREE Full text] [doi: 10.1016/j.ejca.2020.01.011] [Medline: 32120274]
3. Pilleron S, Sarfati D, Janssen-Heijnen M, Vignat J, Ferlay J, Bray F, et al. Global cancer incidence in older adults, 2012 and 2035: a population-based study. Int J Cancer 2019 Jan 01;144(1):49-58 [FREE Full text] [doi: 10.1002/ijc.31664] [Medline: 29978474]
4. Grassi L, Spiegel D, Riba M. Advancing psychosocial care in cancer patients. F1000Res 2017 Dec 4;6:2083 [FREE Full text] [doi: 10.12688/f1000research.11902.1] [Medline: 29259774]
5. WHO guideline: recommendations on digital interventions for health system strengthening: web supplement 2: summary of findings and GRADE tables. World Health Organization. 2019. URL: https://apps.who.int/iris/handle/10665/324998 [accessed 2021-11-08]
6. Mayer DK, Nasso SF, Earp JA. Defining cancer survivors, their needs, and perspectives on survivorship health care in the USA. Lancet Oncol 2017 Jan;18(1):e11-e18. [doi: 10.1016/S1470-2045(16)30573-3] [Medline: 28049573]
7. Schook RM, Linssen C, Festen J, Schramel FM, Lammers E, Zaanen P, et al. Website visitors asking questions online to lung cancer specialists: what do they want to know? Interact J Med Res 2013 Aug 06;2(2):e15 [FREE Full text] [doi: 10.2196/ijmr.1749] [Medline: 23919980]
8. Linssen C, Schook RM, The AM, Lammers E, Festen J, Postmus PE. A web site on lung cancer: who are the users and what are they looking for? J Thorac Oncol 2007 Sep;2(9):813-818 [FREE Full text] [doi: 10.1097/JTO.0b013e31811f472a] [Medline: 17805058]
9. Keikes L, de Vos-Geelen J, de Groot JW, Punt CJ, Simkens LH, Trajkovic-Vidakovic M, et al. Implementation, participation and satisfaction rates of a Web-based decision support tool for patients with metastatic colorectal cancer. Patient Educ Couns 2019 Jul;102(7):1331-1335. [doi: 10.1016/j.pec.2019.02.020] [Medline: 30852117]
10. van den Berg M, van der Meij E, Bos AM, Boshuizen MC, Determann D, van Eekeren RR, et al. Development and testing of a tailored online fertility preservation decision aid for female cancer patients. Cancer Med 2021 Mar;10(5):1576-1588 [FREE Full text] [doi: 10.1002/cam4.3711] [Medline: 33580749]
11. Drijver AJ, Reijneveld JC, Wesselman LM, Klein M. A Web-based lifestyle intervention aimed at improving cognition in patients with cancer returning to work in an outpatient setting: protocol for a randomized controlled trial. JMIR Res Protoc 2021 Apr 26;10(4):e22670 [FREE Full text] [doi: 10.2196/22670] [Medline: 33900201]
12. Hummel SB, van Lankveld JJ, Oldenburg HS, Hahn DE, Broomans E, Aaronson NK. Internet-based cognitive behavioral therapy for sexual dysfunctions in women treated for breast cancer: design of a multicenter, randomized controlled trial. BMC Cancer 2015 Apr 28;15:321 [FREE Full text] [doi: 10.1186/s12885-015-1320-z] [Medline: 25927495]
13. Kaal SE, Husson O, van Dartel F, Hermans K, Jansen R, Manten-Horst E, et al. Online support community for adolescents and young adults (AYAs) with cancer: user statistics, evaluation, and content analysis. Patient Prefer Adherence 2018 Dec 6;12:2615-2622 [FREE Full text] [doi: 10.2147/PPA.S171892] [Medline: 30584285]
14. Slev VN, Mistiaen P, Pasman HR, Verdonck-de Leeuw IM, van Uden-Kraan CF, Francke AL. Effects of eHealth for patients and informal caregivers confronted with cancer: a meta-review. Int J Med Inform 2016 Mar;87:54-67. [doi: 10.1016/j.ijmedinf.2015.12.013] [Medline: 26806712]
15. Børøsund E, Cvancarova M, Moore SM, Ekstedt M, Ruland CM. Comparing effects in regular practice of e-communication and Web-based self-management support among breast cancer patients: preliminary results from a randomized controlled trial. J Med Internet Res 2014 Dec 18;16(12):e295 [FREE Full text] [doi: 10.2196/jmir.3348] [Medline: 25525672]
16. David N, Schlenker P, Prudlo U, Larbig W. Internet-based program for coping with cancer: a randomized controlled trial with hematologic cancer patients. Psychooncology 2013 May;22(5):1064-1072. [doi: 10.1002/pon.3104] [Medline: 22565413]
17. Kearney N, McCann L, Norrie J, Taylor L, Gray P, McGee-Lennon M, et al. Evaluation of a mobile phone-based, advanced symptom management system (ASyMS) in the management of chemotherapy-related toxicity. Support Care Cancer 2009 Apr;17(4):437-444. [doi: 10.1007/s00520-008-0515-0] [Medline: 18953579]
18. Ritterband LM, Bailey ET, Thorndike FP, Lord HR, Farrell-Carnahan L, Baum LD. Initial evaluation of an Internet intervention to improve the sleep of cancer survivors with insomnia. Psychooncology 2012 Jul;21(7):695-705 [FREE Full text] [doi: 10.1002/pon.1969] [Medline: 21538678]
19. Donovan HS, Ward SE, Sereika SM, Knapp JE, Sherwood PR, Bender CM, et al. Web-based symptom management for women with recurrent ovarian cancer: a pilot randomized controlled trial of the WRITE Symptoms intervention. J Pain Symptom Manage 2014 Feb;47(2):218-230 [FREE Full text] [doi: 10.1016/j.jpainsymman.2013.04.005] [Medline: 24018206]
20. Denis F, Basch E, Septans AL, Bennouna J, Urban T, Dueck AC, et al. Two-year survival comparing Web-based symptom monitoring vs routine surveillance following treatment for lung cancer. JAMA 2019 Jan 22;321(3):306-307 [FREE Full text] [doi: 10.1001/jama.2018.18085] [Medline: 30667494]
21. Atema V, van Leeuwen M, Kieffer JM, Oldenburg HS, van Beurden M, Gerritsma MA, et al. Efficacy of Internet-based cognitive behavioral therapy for treatment-induced menopausal symptoms in breast cancer survivors: results of a randomized controlled trial. J Clin Oncol 2019 Apr 01;37(10):809-822. [doi: 10.1200/JCO.18.00655] [Medline: 30763176]
22. IHI Triple Aim Initiative. Institute for Healthcare Improvement. URL: http://www.ihi.org/Engage/Initiatives/TripleAim/Pages/default.aspx201 [accessed 2021-11-08]

XSL•FO
RenderX

23. Berwick DM, Nolan TW, Whittington J. The triple aim: care, health, and cost. Health Aff (Millwood) 2008;27(3):759-769. [doi: 10.1377/hlthaff.27.3.759] [Medline: 18474969]
24. Coles E, Wells M, Maxwell M, Harris FM, Anderson J, Gray NM, et al. The influence of contextual factors on healthcare quality improvement initiatives: what works, for whom and in what setting? Protocol for a realist review. Syst Rev 2017 Aug 23;6(1):168 [FREE Full text] [doi: 10.1186/s13643-017-0566-8] [Medline: 28830572]
25. van der Vaart R, Witting M, Riper H, Kooistra L, Bohlmeijer ET, van Gemert-Pijnen LJ. Blending online therapy into regular face-to-face therapy for depression: content, ratio and preconditions according to patients and therapists using a Delphi study. BMC Psychiatry 2014 Dec 14;14:355 [FREE Full text] [doi: 10.1186/s12888-014-0355-z] [Medline: 25496393]
26. Krijgsman J, Wolterink GK. Ordening in de wereld van e-health. Nictiz. 2012 Aug 24. URL: https://www.nictiz.nl/wp-content/uploads/2012/08/Whitepaper-Ordening-in-de-wereld-van-eHealth.pdf2012 [accessed 2021-11-12]
27. Moher D, Liberati A, Tetzlaff J, Altman DG, PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. PLoS Med 2009 Jul 21;6(7):e1000097 [FREE Full text] [doi: 10.1371/journal.pmed.1000097] [Medline: 19621072]
28. Page MJ, Moher D, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. PRISMA 2020 explanation and elaboration: updated guidance and exemplars for reporting systematic reviews. BMJ 2021 Mar 29;372:n160 [FREE Full text] [doi: 10.1136/bmj.n160] [Medline: 33781993]
29. Covidence for systematic reviews. covidence. URL: https://www.covidence.org/ [accessed 2022-01-17]
30. Boele FW, Verdonck-de Leeuw IM, Cuijpers P, Reijneveld JC, Heimans JJ, Klein M. Internet-based guided self-help for glioma patients with depressive symptoms: design of a randomized controlled trial. BMC Neurol 2014 Apr 10;14:81 [FREE Full text] [doi: 10.1186/1471-2377-14-81] [Medline: 24721108]
31. Boele FW, Klein M, Verdonck-de Leeuw IM, Cuijpers P, Heimans JJ, Snijders TJ, Dutch Society for Neuro-Oncology (LWNO). Internet-based guided self-help for glioma patients with depressive symptoms: a randomized controlled trial. J Neurooncol 2018 Mar;137(1):191-203 [FREE Full text] [doi: 10.1007/s11060-017-2712-5] [Medline: 29236238]
32. Bruggeman-Everts FZ, Wolvers MD, van de Schoot R, Vollenbroek-Hutten MM, Van der Lee ML. Effectiveness of two Web-based interventions for chronic cancer-related fatigue compared to an active control condition: results of the "Fitter na kanker" randomized controlled trial. J Med Internet Res 2017 Oct 19;19(10):e336 [FREE Full text] [doi: 10.2196/jmir.7180] [Medline: 29051138]
33. Wolvers MD, Bruggeman-Everts FZ, Van der Lee ML, Van de Schoot R, Vollenbroek-Hutten MM. Effectiveness, mediators, and effect predictors of Internet interventions for chronic cancer-related fatigue: the design and an analysis plan of a 3-armed randomized controlled trial. JMIR Res Protoc 2015 Jun 23;4(2):e77 [FREE Full text] [doi: 10.2196/resprot.4363] [Medline: 26104114]
34. Schellekens M, Wolvers M, Compen F, Bisseling E, Bruggeman-Everts F, Vollenbroek-Hutten M, et al. Online mindfulness-based cognitieve therapie bij kanker. Tijdschrift voor Gedragstherapie. 2021 Mar 8. URL: https://www.tijdschriftgedragstherapie.nl/inhoud/tijdschrift_artikel/TG-2019-2-5/Online-mindfulness-based-cognitieve-therapie-bij-kanker [accessed 2021-10-20]
35. Duursma F, Schers HJ, Vissers KC, Hasselaar J. Study protocol: optimization of complex palliative care at home via telemedicine. A cluster randomized controlled trial. BMC Palliat Care 2011 Aug 09;10:13 [FREE Full text] [doi: 10.1186/1472-684X-10-13] [Medline: 21827696]
36. Hoek PD, Schers HJ, Bronkhorst EM, Vissers KC, Hasselaar JG. The effect of weekly specialist palliative care teleconsultations in patients with advanced cancer -a randomized clinical trial. BMC Med 2017 Jun 19;15(1):119 [FREE Full text] [doi: 10.1186/s12916-017-0866-9] [Medline: 28625164]
37. Willems RA, Bolman CA, Mesters I, Kanera IM, Beaulen AA, Lechner L. Short-term effectiveness of a Web-based tailored intervention for cancer survivors on quality of life, anxiety, depression, and fatigue: randomized controlled trial. Psychooncology 2017 Feb;26(2):222-230. [doi: 10.1002/pon.4113] [Medline: 26988800]
38. Willems RA, Mesters I, Lechner L, Kanera IM, Bolman CA. Long-term effectiveness and moderators of a Web-based tailored intervention for cancer survivors on social and emotional functioning, depression, and fatigue: randomized controlled trial. J Cancer Surviv 2017 Dec;11(6):691-703 [FREE Full text] [doi: 10.1007/s11764-017-0625-0] [Medline: 28698999]
39. Kanera IM, Bolman CA, Willems RA, Mesters I, Lechner L. Lifestyle-related effects of the Web-based Kanker Nazorg Wijzer (Cancer Aftercare Guide) intervention for cancer survivors: a randomized controlled trial. J Cancer Surviv 2016 Oct;10(5):883-897 [FREE Full text] [doi: 10.1007/s11764-016-0535-6] [Medline: 26984534]
40. Kanera IM, Willems RA, Bolman CA, Mesters I, Verboon P, Lechner L. Long-term effects of a Web-based cancer aftercare intervention on moderate physical activity and vegetable consumption among early cancer survivors: a randomized controlled trial. Int J Behav Nutr Phys Act 2017 Feb 10;14(1):19 [FREE Full text] [doi: 10.1186/s12966-017-0474-2] [Medline: 28187725]
41. van der Hout A, van Uden-Kraan CF, Holtmaat K, Jansen F, Lissenberg-Witte BI, Nieuwenhuijzen GA, et al. Role of eHealth application Oncokompas in supporting self-management of symptoms and health-related quality of life in cancer survivors: a randomised, controlled trial. Lancet Oncol 2020 Jan;21(1):80-94. [doi: 10.1016/S1470-2045(19)30675-8] [Medline: 31838009]

XSL•FO
RenderX

42. van der Hout A, Jansen F, van Uden-Kraan CF, Coupé VM, Holtmaat K, Nieuwenhuijzen GA, et al. Cost-utility of an eHealth application 'Oncokompas' that supports cancer survivors in self-management: results of a randomised controlled trial. J Cancer Surviv 2021 Feb;15(1):77-86 [FREE Full text] [doi: 10.1007/s11764-020-00912-9] [Medline: 32656739]
43. van den Brink JL, Moorman PW, de Boer MF, Pruyn JF, Verwoerd CD, van Bemmel JH. Involving the patient: a prospective study on use, appreciation and effectiveness of an information system in head and neck cancer care. Int J Med Inform 2005 Oct;74(10):839-849. [doi: 10.1016/j.ijmedinf.2005.03.021] [Medline: 16043392]
44. van den Brink JL, Moorman PW, de Boer MF, Hop WC, Pruyn JF, Verwoerd CD, et al. Impact on quality of life of a telemedicine system supporting head and neck cancer patients: a controlled trial during the postoperative period at home. J Am Med Inform Assoc 2007;14(2):198-205 [FREE Full text] [doi: 10.1197/jamia.M2199] [Medline: 17213498]
45. Cuypers M, Lamers RE, Kil PJ, van de Poll-Franse LV, de Vries M. Impact of a Web-based prostate cancer treatment decision aid on patient-reported decision process parameters: results from the Prostate Cancer Patient Centered Care trial. Support Care Cancer 2018 Nov;26(11):3739-3748 [FREE Full text] [doi: 10.1007/s00520-018-4236-8] [Medline: 29752528]
46. Compen F, Bisseling E, Schellekens M, Donders R, Carlson L, van der Lee M, et al. Face-to-face and Internet-based mindfulness-based cognitive therapy compared with treatment as usual in reducing psychological distress in patients with cancer: a multicenter randomized controlled trial. J Clin Oncol 2018 Aug 10;36(23):2413-2421. [doi: 10.1200/JCO.2017.76.5669] [Medline: 29953304]
47. van den Berg SW, Gielissen MF, Custers JA, van der Graaf WT, Ottevanger PB, Prins JB. BREATH: Web-based self-management for psychological adjustment after primary breast cancer--results of a multicenter randomized controlled trial. J Clin Oncol 2015 Sep 01;33(25):2763-2771. [doi: 10.1200/JCO.2013.54.9386] [Medline: 26169621]
48. van Helmondt SJ, van der Lee ML, van Woezik RA, Lodder P, de Vries J. No effect of CBT-based online self-help training to reduce fear of cancer recurrence: first results of the CAREST multicenter randomized controlled trial. Psychooncology 2020 Jan;29(1):86-97. [doi: 10.1002/pon.5233] [Medline: 31595627]
49. Golsteijn RH, Bolman C, Volders E, Peels DA, de Vries H, Lechner L. Short-term efficacy of a computer-tailored physical activity intervention for prostate and colorectal cancer patients and survivors: a randomized controlled trial. Int J Behav Nutr Phys Act 2018 Oct 30;15(1):106 [FREE Full text] [doi: 10.1186/s12966-018-0734-9] [Medline: 30376857]
50. van Bruinessen IR, van Weel-Baumgarten EM, Gouw H, Zijlstra JM, van Dulmen S. An integrated process and outcome evaluation of a Web-based communication tool for patients with malignant lymphoma: randomized controlled trial. J Med Internet Res 2016 Jul 29;18(7):e206 [FREE Full text] [doi: 10.2196/jmir.5877] [Medline: 27473173]
51. Admiraal JM, van der Velden AW, Geerling JI, Burgerhof JG, Bouma G, Walenkamp AM, et al. Web-based tailored psychoeducation for breast cancer patients at the onset of the survivorship phase: a multicenter randomized controlled trial. J Pain Symptom Manage 2017 Oct;54(4):466-475 [FREE Full text] [doi: 10.1016/j.jpainsymman.2017.07.009] [Medline: 28711750]
52. Hummel SB, van Lankveld JJ, Oldenburg HS, Hahn DE, Kieffer JM, Gerritsma MA, et al. Efficacy of Internet-based cognitive behavioral therapy in improving sexual functioning of breast cancer survivors: results of a randomized controlled trial. J Clin Oncol 2017 Apr 20;35(12):1328-1340. [doi: 10.1200/JCO.2016.69.6021] [Medline: 28240966]
53. Hummel SB, van Lankveld JJ, Oldenburg HS, Hahn DE, Kieffer JM, Gerritsma MA, et al. Internet-based cognitive behavioral therapy realizes long-term improvement in the sexual functioning and body image of breast cancer survivors. J Sex Marital Ther 2018;44(5):485-496. [doi: 10.1080/0092623X.2017.1408047] [Medline: 29297781]
54. Knegtmans MF, Wauben LS, Wagemans MF, Oldenmenger WH. Home telemonitoring improved pain registration in patients with cancer. Pain Pract 2020 Feb;20(2):122-128 [FREE Full text] [doi: 10.1111/papr.12830] [Medline: 31419371]
55. Verbeek JG, Atema V, Mewes JC, van Leeuwen M, Oldenburg HS, van Beurden M, et al. Cost-utility, cost-effectiveness, and budget impact of Internet-based cognitive behavioral therapy for breast cancer survivors with treatment-induced menopausal symptoms. Breast Cancer Res Treat 2019 Dec;178(3):573-585 [FREE Full text] [doi: 10.1007/s10549-019-05410-w] [Medline: 31451978]
56. Gehring K, Kloek CJ, Aaronson NK, Janssen KW, Jones LW, Sitskoorn MM, et al. Feasibility of a home-based exercise intervention with remote guidance for patients with stable grade II and III gliomas: a pilot randomized controlled trial. Clin Rehabil 2018 Mar;32(3):352-366 [FREE Full text] [doi: 10.1177/0269215517728326] [Medline: 28882061]
57. Gehring K, Stuiver MM, Visser E, Kloek C, van den Bent M, Hanse M, et al. A pilot randomized controlled trial of exercise to improve cognitive performance in patients with stable glioma: a proof of concept. Neuro Oncol 2020 Jan 11;22(1):103-115 [FREE Full text] [doi: 10.1093/neuonc/noz178] [Medline: 31755917]
58. Visser A, Prins JB, Jansen L, Radema SA, Schlooz MS, van Dalen T, et al. Group medical consultations (GMCs) and tablet-based online support group sessions in the follow-up of breast cancer: a multicenter randomized controlled trial. Breast 2018 Aug;40:181-188. [doi: 10.1016/j.breast.2018.05.012] [Medline: 29906741]
59. Willems RA, Lechner L, Verboon P, Mesters I, Kanera IM, Bolman CA. Working mechanisms of a Web-based self-management intervention for cancer survivors: a randomised controlled trial. Psychol Health 2017 May;32(5):605-625. [doi: 10.1080/08870446.2017.1293054] [Medline: 28276741]
60. Willems RA, Bolman CA, Mesters I, Kanera IM, Beaulen AA, Lechner L. The Kanker Nazorg Wijzer (Cancer Aftercare Guide) protocol: the systematic development of a Web-based computer tailored intervention providing psychosocial and

XSL•FO
RenderX

lifestyle support for cancer survivors. BMC Cancer 2015 Aug 11;15:580 [FREE Full text] [doi: 10.1186/s12885-015-1588-z] [Medline: 26260318]
61. Kanera IM, Willems RA, Bolman CA, Mesters I, Zambon V, Gijsen BC, et al. Use and appreciation of a tailored self-management eHealth intervention for early cancer survivors: process evaluation of a randomized controlled trial. J Med Internet Res 2016 Aug 23;18(8):e229 [FREE Full text] [doi: 10.2196/jmir.5975] [Medline: 27554525]
62. Duineveld LA, Wieldraaijer T, Wind J, Verdonck-de Leeuw IM, van Weert HC, van Uden-Kraan CF. Primary care-led survivorship care for patients with colon cancer and the use of eHealth: a qualitative study on perspectives of general practitioners. BMJ Open 2016 Apr 28;6(4):e010777 [FREE Full text] [doi: 10.1136/bmjopen-2015-010777] [Medline: 27126977]
63. Duman-Lubberding S, van Uden-Kraan CF, Peek N, Cuijpers P, Leemans CR, Verdonck-de Leeuw IM. An eHealth application in head and neck cancer survivorship care: health care professionals' perspectives. J Med Internet Res 2015 Oct 21;17(10):e235 [FREE Full text] [doi: 10.2196/jmir.4870] [Medline: 26489918]
64. Duman-Lubberding S, van Uden-Kraan CF, Jansen F, Witte BI, van der Velden LA, Lacko M, et al. Feasibility of an eHealth application "OncoKompas" to improve personalized survivorship cancer care. Support Care Cancer 2016 May;24(5):2163-2171 [FREE Full text] [doi: 10.1007/s00520-015-3004-2] [Medline: 26563178]
65. Lubberding S, van Uden-Kraan CF, Te Velde EA, Cuijpers P, Leemans CR, Verdonck-de Leeuw IM. Improving access to supportive cancer care through an eHealth application: a qualitative needs assessment among cancer survivors. J Clin Nurs 2015 May;24(9-10):1367-1379. [doi: 10.1111/jocn.12753] [Medline: 25677218]
66. van der Hout A, van Uden-Kraan CF, Witte BI, Coupé VM, Jansen F, Leemans CR, et al. Efficacy, cost-utility and reach of an eHealth self-management application 'Oncokompas' that helps cancer survivors to obtain optimal supportive care: study protocol for a randomised controlled trial. Trials 2017 May 22;18(1):228 [FREE Full text] [doi: 10.1186/s13063-017-1952-1] [Medline: 28532439]
67. Schuit A, Holtmaat K, Hooghiemstra N, Jansen F, Lissenberg-Witte B, Coupé V, et al. Efficacy and cost-utility of the eHealth self-management application 'Oncokompas' tailored to patients with incurable cancer: study protocol of a randomized controlled trial. Support Care Cancer 2019;27(Suppl 1):S183.
68. Duineveld LA, Wieldraaijer T, van Asselt KM, Nugteren IC, Donkervoort SC, van de Ven AW, et al. Improving care after colon cancer treatment in The Netherlands, personalised care to enhance quality of life (I CARE study): study protocol for a randomised controlled trial. Trials 2015 Jun 26;16:284 [FREE Full text] [doi: 10.1186/s13063-015-0798-7] [Medline: 26112050]
69. Boele FW, van Uden-Kraan CF, Hilverda K, Reijneveld JC, Cleijne W, Klein M, et al. Attitudes and preferences toward monitoring symptoms, distress, and quality of life in glioma patients and their informal caregivers. Support Care Cancer 2016 Jul;24(7):3011-3022 [FREE Full text] [doi: 10.1007/s00520-016-3112-7] [Medline: 26879825]
70. Melissant HC, Verdonck-de Leeuw IM, Lissenberg-Witte BI, Konings IR, Cuijpers P, Van Uden-Kraan CF. 'Oncokompas', a Web-based self-management application to support patient activation and optimal supportive care: a feasibility study among breast cancer survivors. Acta Oncol 2018 Jul;57(7):924-934. [doi: 10.1080/0284186X.2018.1438654] [Medline: 29451059]
71. van der Hout A, Holtmaat K, Jansen F, Lissenberg-Witte BI, van Uden-Kraan CF, Nieuwenhuijzen GA, et al. The eHealth self-management application 'Oncokompas' that supports cancer survivors to improve health-related quality of life and reduce symptoms: which groups benefit most? Acta Oncol 2021 Apr;60(4):403-411. [doi: 10.1080/0284186X.2020.1851764] [Medline: 33345659]
72. van den Brink JL, Moorman PW, de Boer MF, van Bemmel JH, Pruyn JF, Verwoerd CD. An information system to support the care for head and neck cancer patients. Support Care Cancer 2003 Jul;11(7):452-459. [doi: 10.1007/s00520-002-0425-5] [Medline: 12707835]
73. Mujcic A, Blankers M, Boon B, Engels R, van Laar M. Internet-based self-help smoking cessation and alcohol moderation interventions for cancer survivors: a study protocol of two RCTs. BMC Cancer 2018 Apr 02;18(1):364 [FREE Full text] [doi: 10.1186/s12885-018-4206-z] [Medline: 29609554]
74. van de Wiel HJ, Stuiver MM, May AM, van Grinsven S, Aaronson NK, Retèl VP, et al. (Cost-)effectiveness of an Internet-based physical activity support program (with and without physiotherapy counselling) on physical activity levels of breast and prostate cancer survivors: design of the PABLO trial. BMC Cancer 2018 Nov 06;18(1):1073 [FREE Full text] [doi: 10.1186/s12885-018-4927-z] [Medline: 30400784]
75. Kuijpers W, Groen WG, Loos R, Oldenburg HS, Wouters MW, Aaronson NK, et al. An interactive portal to empower cancer survivors: a qualitative study on user expectations. Support Care Cancer 2015 Sep;23(9):2535-2542 [FREE Full text] [doi: 10.1007/s00520-015-2605-0] [Medline: 25876157]
76. Groen WG, Kuijpers W, Oldenburg HS, Wouters MW, Aaronson NK, van Harten WH. Supporting lung cancer patients with an interactive patient portal: feasibility study. JMIR Cancer 2017 Aug 08;3(2):e10 [FREE Full text] [doi: 10.2196/cancer.7443] [Medline: 28790025]
77. Kuijpers W, Groen WG, Oldenburg HS, Wouters MW, Aaronson NK, van Harten WH. eHealth for breast cancer survivors: use, feasibility and impact of an interactive portal. JMIR Cancer 2016 May 10;2(1):e3 [FREE Full text] [doi: 10.2196/cancer.5456] [Medline: 28410178]

XSL•FO
RenderX

78. Kuijpers W, Groen WG, Oldenburg HS, Wouters MW, Aaronson NK, van Harten WH. Development of MijnAVL, an interactive portal to empower breast and lung cancer survivors: an iterative, multi-stakeholder approach. JMIR Res Protoc 2015 Jan 22;4(1):e14 [FREE Full text] [doi: 10.2196/resprot.3796] [Medline: 25614924]
79. Cuypers M, Lamers RE, Kil PJ, The R, Karssen K, van de Poll-Franse LV, et al. A global, incremental development method for a Web-based prostate cancer treatment decision aid and usability testing in a Dutch clinical setting. Health Informatics J 2019 Sep;25(3):701-714 [FREE Full text] [doi: 10.1177/1460458217720393] [Medline: 28747076]
80. Lamers RE, Cuypers M, de Vries M, van de Poll-Franse LV, Ruud Bosch J, Kil PJ. How do patients choose between active surveillance, radical prostatectomy, and radiotherapy? The effect of a preference-sensitive decision aid on treatment decision making for localized prostate cancer. Urol Oncol 2017 Feb;35(2):37.e9-37.17. [doi: 10.1016/j.urolonc.2016.09.007] [Medline: 28341494]
81. Cuypers M, Lamers RE, Kil PJ, van de Poll-Franse LV, de Vries M. Impact of a Web-based treatment decision aid for early-stage prostate cancer on shared decision-making and health outcomes: study protocol for a randomized controlled trial. Trials 2015 May 27;16:231 [FREE Full text] [doi: 10.1186/s13063-015-0750-x] [Medline: 26012700]
82. Cuypers M, Lamers RE, Kil PJ, van Tol-Geerdink JJ, van Uden-Kraan CF, van de Poll-Franse LV, et al. Uptake and usage of an online prostate cancer treatment decision aid in Dutch clinical practice: a quantitative analysis from the Prostate Cancer Patient Centered Care trial. Health Informatics J 2019 Dec;25(4):1498-1510 [FREE Full text] [doi: 10.1177/1460458218779110] [Medline: 29857789]
83. Compen FR, Bisseling EM, Van der Lee ML, Adang EM, Donders AR, Speckens AE. Study protocol of a multicenter randomized controlled trial comparing the effectiveness of group and individual internet-based Mindfulness-Based Cognitive Therapy with treatment as usual in reducing psychological distress in cancer patients: the BeMind study. BMC Psychol 2015 Aug 13;3(1):27 [FREE Full text] [doi: 10.1186/s40359-015-0084-1] [Medline: 26273472]
84. Wolvers MD, Vollenbroek-Hutten MM. An mHealth intervention strategy for physical activity coaching in cancer survivors. In: Personalization and Adaptation in Technology for Health Workshop held in conjunction with 23rd Conference on User Modelling, Adaptation and Personalization. 2015 Presented at: UMAP '15; June 29-July 3, 2015; Dublin, Ireland.
85. van den Berg SW, Peters EJ, Kraaijeveld JF, Gielissen MF, Prins JB. Usage of a generic Web-based self-management intervention for breast cancer survivors: substudy analysis of the BREATH trial. J Med Internet Res 2013 Aug 19;15(8):e170 [FREE Full text] [doi: 10.2196/jmir.2566] [Medline: 23958584]
86. van den Berg SW, Gielissen MF, Ottevanger PB, Prins JB. Rationale of the BREAst cancer e-healTH [BREATH] multicentre randomised controlled trial: an Internet-based self-management intervention to foster adjustment after curative breast cancer by decreasing distress and increasing empowerment. BMC Cancer 2012 Sep 07;12:394 [FREE Full text] [doi: 10.1186/1471-2407-12-394] [Medline: 22958799]
87. van Helmondt SJ, van der Lee ML, de Vries J. Study protocol of the CAREST-trial: a randomised controlled trial on the (cost-) effectiveness of a CBT-based online self-help training for fear of cancer recurrence in women with curatively treated breast cancer. BMC Cancer 2016 Jul 25;16:527 [FREE Full text] [doi: 10.1186/s12885-016-2562-0] [Medline: 27455846]
88. Abrahams HJ, Gielissen MF, Goedendorp MM, Berends T, Peters ME, Poort H, et al. A randomized controlled trial of Web-based cognitive behavioral therapy for severely fatigued breast cancer survivors (CHANGE-study): study protocol. BMC Cancer 2015 Oct 23;15:765 [FREE Full text] [doi: 10.1186/s12885-015-1787-7] [Medline: 26500019]
89. Ter Stege JA, Woerdeman LA, Hahn DE, van Huizum MA, van Duijnhoven FH, Kieffer JM, et al. The impact of an online patient decision aid for women with breast cancer considering immediate breast reconstruction: study protocol of a multicenter randomized controlled trial. BMC Med Inform Decis Mak 2019 Aug 19;19(1):165 [FREE Full text] [doi: 10.1186/s12911-019-0873-1] [Medline: 31426772]
90. Garvelink MM, ter Kuile MM, Fischer MJ, Louwé LA, Hilders CG, Kroep JR, et al. Development of a decision aid about fertility preservation for women with breast cancer in The Netherlands. J Psychosom Obstet Gynaecol 2013 Dec;34(4):170-178. [doi: 10.3109/0167482X.2013.851663] [Medline: 24188788]
91. Golsteijn RH, Bolman C, Volders E, Peels DA, de Vries H, Lechner L. Development of a computer-tailored physical activity intervention for prostate and colorectal cancer patients and survivors: OncoActive. BMC Cancer 2017 Jun 26;17(1):446 [FREE Full text] [doi: 10.1186/s12885-017-3397-z] [Medline: 28651586]
92. van Bruinessen IR, van Weel-Baumgarten EM, Snippe HW, Gouw H, Zijlstra JM, van Dulmen S. Active patient participation in the development of an online intervention. JMIR Res Protoc 2014 Nov 06;3(4):e59 [FREE Full text] [doi: 10.2196/resprot.3695] [Medline: 25379679]
93. Tamminga SJ, van Hezel S, de Boer AG, Frings-Dresen MH. Enhancing the return to work of cancer survivors: development and feasibility of the nurse-led eHealth intervention Cancer@Work. JMIR Res Protoc 2016 Jun 10;5(2):e118 [FREE Full text] [doi: 10.2196/resprot.5565] [Medline: 27286819]
94. Tamminga SJ, Hoving JL, Frings-Dresen MH, de Boer AG. Cancer@Work - a nurse-led, stepped-care, e-health intervention to enhance the return to work of patients with cancer: study protocol for a randomized controlled trial. Trials 2016 Sep 15;17(1):453 [FREE Full text] [doi: 10.1186/s13063-016-1578-8] [Medline: 27634549]
95. Noordman J, Driesenaar JA, van Bruinessen IR, Portielje JE, van Dulmen S. Evaluation and implementation of ListeningTime: a Web-based preparatory communication tool for elderly patients with cancer and their health care providers. JMIR Cancer 2019 Jan 30;5(1):e11556 [FREE Full text] [doi: 10.2196/11556] [Medline: 30698525]

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96. Noordman J, Driesenaar JA, van Bruinessen IR, van Dulmen S. ListeningTime; participatory development of a Web-based preparatory communication tool for elderly cancer patients and their healthcare providers. Internet Interv 2017 Sep;9:51-56 [FREE Full text] [doi: 10.1016/j.invent.2017.05.002] [Medline: 30135837]
97. Arts LP, van de Poll-Franse LV, van den Berg SW, Prins JB, Husson O, Mols F, et al. Lymphoma InterVEntion (LIVE) - patient-reported outcome feedback and a Web-based self-management intervention for patients with lymphoma: study protocol for a randomised controlled trial. Trials 2017 Apr 28;18(1):199 [FREE Full text] [doi: 10.1186/s13063-017-1943-2] [Medline: 28454583]
98. Arts L, Oerlemans S, van den Berg S, Prins J, van de Poll-Franse L. Participation and characterization of patients with lymphoma in a Web-based self-management intervention. Psycho Oncol 2016;25(S3):108.
99. van Eenbergen MC, van den Hurk C, Mols F, van de Poll-Franse LV. Usability of an online application for reporting the burden of side effects in cancer patients. Support Care Cancer 2019 Sep;27(9):3411-3419. [doi: 10.1007/s00520-019-4639-1] [Medline: 30656400]
100. den Bakker CM, Huirne JA, Schaafsma FG, de Geus C, Bonjer HJ, Anema JR. Electronic health program to empower patients in returning to normal activities after colorectal surgical procedures: mixed-methods process evaluation alongside a randomized controlled trial. J Med Internet Res 2019 Jan 29;21(1):e10674 [FREE Full text] [doi: 10.2196/10674] [Medline: 30694205]
101. den Bakker CM, Schaafsma FG, van der Meij E, Meijerink WJ, van den Heuvel B, Baan AH, et al. Electronic health program to empower patients in returning to normal activities after general surgical and gynecological procedures: intervention mapping as a useful method for further development. J Med Internet Res 2019 Feb 06;21(2):e9938 [FREE Full text] [doi: 10.2196/jmir.9938] [Medline: 30724740]
102. Atema V, van Leeuwen M, Oldenburg HS, van Beurden M, Hunter MS, Aaronson NK. An Internet-based cognitive behavioral therapy for treatment-induced menopausal symptoms in breast cancer survivors: results of a pilot study. Menopause 2017 Jul;24(7):762-767. [doi: 10.1097/GME.0000000000000836] [Medline: 28195994]
103. Atema V, van Leeuwen M, Oldenburg HS, Retèl V, van Beurden M, Hunter MS, et al. Design of a randomized controlled trial of Internet-based cognitive behavioral therapy for treatment-induced menopausal symptoms in breast cancer survivors. BMC Cancer 2016 Nov 25;16(1):920 [FREE Full text] [doi: 10.1186/s12885-016-2946-1] [Medline: 27887581]
104. van Veen MR, Beijer S, Adriaans AM, Vogel-Boezeman J, Kampman E. Development of a website providing evidence-based information about nutrition and cancer: fighting fiction and supporting facts online. JMIR Res Protoc 2015 Sep 08;4(3):e110 [FREE Full text] [doi: 10.2196/resprot.4757] [Medline: 26350824]
105. Sungur H, Yılmaz NG, Chan BM, van den Muijsenbergh ME, van Weert JC, Schouten BC. Development and evaluation of a digital intervention for fulfilling the needs of older migrant patients with cancer: user-centered design approach. J Med Internet Res 2020 Oct 26;22(10):e21238 [FREE Full text] [doi: 10.2196/21238] [Medline: 33104008]
106. Yılmaz NG, Sungur H, van Weert JC, van den Muijsenbergh ME, Schouten BC. Enhancing patient participation of older migrant cancer patients: needs, barriers, and eHealth. Ethn Health (forthcoming) 2020 Dec 14:1-24. [doi: 10.1080/13557858.2020.1857338] [Medline: 33316171]
107. Health Software — Part 2 Health and wellness apps - Quality and reliability. International Organization for Standardization. 2020. URL: https://confluence.hl7.org/download/attachments/35717877/ISO%20DTS%2082304_2_final.pdf?api=v22020 [accessed 2021-10-10]
108. Over Nictiz. Nictiz. URL: https://www.nictiz.nl/over-nictiz [accessed 2021-11-12]
109. Struijs JN, Drewes HW, Heijink R, Baan CA. How to evaluate population management? Transforming the Care Continuum Alliance population health guide toward a broadly applicable analytical framework. Health Policy 2015 Apr;119(4):522-529. [doi: 10.1016/j.healthpol.2014.12.003] [Medline: 25516015]
110. Hendrikx RJ, Drewes HW, Spreeuwenberg M, Ruwaard D, Struijs JN, Baan CA. Which Triple Aim related measures are being used to evaluate population management initiatives? An international comparative analysis. Health Policy 2016 May;120(5):471-485. [doi: 10.1016/j.healthpol.2016.03.008] [Medline: 27066729]
111. Quality Assessment Tool for Quantitative Studies. Effective Public Healthcare Panacea Project. 2018. URL: https://www.ephpp.ca/quality-assessment-tool-for-quantitative-studies/ [accessed 2021-10-10]
112. Thomas BH, Ciliska D, Dobbins M, Micucci S. A process for systematically reviewing the literature: providing the research evidence for public health nursing interventions. Worldviews Evid Based Nurs 2004;1(3):176-184. [doi: 10.1111/j.1524-475X.2004.04006.x] [Medline: 17163895]
113. Jackson N, Waters E, Guidelines for Systematic Reviews in Health Promotion and Public Health Taskforce. Criteria for the systematic review of health promotion and public health interventions. Health Promot Int 2005 Dec;20(4):367-374. [doi: 10.1093/heapro/dai022] [Medline: 16169885]
114. Seiler A, Klaas V, Tröster G, Fagundes CP. eHealth and mHealth interventions in the treatment of fatigued cancer survivors: a systematic review and meta-analysis. Psychooncology 2017 Sep;26(9):1239-1253. [doi: 10.1002/pon.4489] [Medline: 28665554]
115. Kleinpeter E. Four ethical issues of “E-Health”. IRBM 2017 Oct;38(5):245-249 [FREE Full text] [doi: 10.1016/j.irbm.2017.07.006]

XSL•FO
RenderX

116. Mock V, Atkinson A, Barsevick A, Cella D, Cimprich B, Cleeland C, National Comprehensive Cancer Network. NCCN practice guidelines for cancer-related fatigue. Oncology (Williston Park) 2000 Nov;14(11A):151-161. [Medline: 11195408]
117. Mehnert A, Hartung TJ, Friedrich M, Vehling S, Brähler E, Härter M, et al. One in two cancer patients is significantly distressed: prevalence and indicators of distress. Psychooncology 2018 Jan;27(1):75-82. [doi: 10.1002/pon.4464] [Medline: 28568377]
118. van den Beuken-van Everdingen MH, Hochstenbach LM, Joosten EA, Tjan-Heijnen VC, Janssen DJ. Update on prevalence of pain in patients with cancer: systematic review and meta-analysis. J Pain Symptom Manage 2016 Jun;51(6):1070-90.e9 [FREE Full text] [doi: 10.1016/j.jpainsymman.2015.12.340] [Medline: 27112310]
119. Penedo FJ, Oswald LB, Kronenfeld JP, Garcia SF, Cella D, Yanez B. The increasing value of eHealth in the delivery of patient-centred cancer care. Lancet Oncol 2020 May;21(5):e240-e251 [FREE Full text] [doi: 10.1016/S1470-2045(20)30021-8] [Medline: 32359500]
120. Xie B. Older adults, e-health literacy, and collaborative learning: an experimental study. J Am Soc Inf Sci Technol 2011 Mar 14;62(5):933-946 [FREE Full text] [doi: 10.1002/asi.21507]
121. Hoogenbosch B, Postma J, de Man-van Ginkel JM, Tiemessen NA, van Delden JJ, van Os-Medendorp H. Use and the users of a patient portal: cross-sectional study. J Med Internet Res 2018 Sep 17;20(9):e262 [FREE Full text] [doi: 10.2196/jmir.9418] [Medline: 30224334]
122. Vreugdenhil MM, Ranke S, de Man Y, Haan MM, Kool RB. Patient and health care provider experiences with a recently introduced patient portal in an academic hospital in the Netherlands: mixed methods study. J Med Internet Res 2019 Aug 20;21(8):13743 [FREE Full text] [doi: 10.2196/13743] [Medline: 31432782]
123. Verstraete E, Koehorst AM, van Os-Medendorp H. [Does the patient benefit from real-time access to one's electronic record? Evaluation of the patient portal in University Medical Centre Utrecht, the Netherlands]. Ned Tijdschr Geneeskd 2016;160:D325. [Medline: 27299495]
124. Spil TA, Katsma CP, Stegwee RA, Albers EF, Freriks A, Ligt E. Value, participation and quality of electronic health records in the Netherlands. In: Proceedings of the 43rd Hawaii International Conference on System Sciences. 2010 Presented at: HICSS '10; January 5-8, 2010; Honolulu, HI, USA p. 1-10 URL: https://doi.org/10.1109/hicss.2010.433 [doi: 10.1109/hicss.2010.433]
125. Chen YY, Guan BS, Li ZK, Li XY. Effect of telehealth intervention on breast cancer patients' quality of life and psychological outcomes: a meta-analysis. J Telemed Telecare 2018 Apr;24(3):157-167. [doi: 10.1177/1357633X16686777] [Medline: 28081664]
126. Xu A, Wang Y, Wu X. Effectiveness of e-health based self-management to improve cancer-related fatigue, self-efficacy and quality of life in cancer patients: systematic review and meta-analysis. J Adv Nurs 2019 Dec;75(12):3434-3447. [doi: 10.1111/jan.14197] [Medline: 31566769]
127. Wang Y, Lin Y, Chen J, Wang C, Hu R, Wu Y. Effects of Internet-based psycho-educational interventions on mental health and quality of life among cancer patients: a systematic review and meta-analysis. Support Care Cancer 2020 Jun;28(6):2541-2552. [doi: 10.1007/s00520-020-05383-3] [Medline: 32179998]
128. Pingree S, Hawkins R, Baker T, duBenske L, Roberts LJ, Gustafson DH. The value of theory for enhancing and understanding e-health interventions. Am J Prev Med 2010 Jan;38(1):103-109 [FREE Full text] [doi: 10.1016/j.amepre.2009.09.035] [Medline: 20117565]
129. Griebel L, Kolominsky-Rabas P, Schaller S, Siudyka J, Sierpinski R, Papapavlou D, et al. Acceptance by laypersons and medical professionals of the personalized eHealth platform, eHealthMonitor. Inform Health Soc Care 2017 Sep;42(3):232-249. [doi: 10.1080/17538157.2016.1237953] [Medline: 27764580]
130. Ossebaard HC, Van Gemert-Pijnen L. eHealth and quality in health care: implementation time. Int J Qual Health Care 2016 Jun;28(3):415-419. [doi: 10.1093/intqhc/mzw032] [Medline: 27029590]
131. Huygens MW. A patient perspective on eHealth in primary care: critical reflections on the implementation and use of online care services. Universitaire Pers Maastricht. 2018 Jan 11. URL: https://doi.org/10.26481/dis.20180111mh [accessed 2021-11-30]
132. van Gemert-Pijnen L, Kip H, Kelders SM, Sanderman R. Introducing eHealth. In: van Gemert-Pijnen L, Kelders SM, Kip H, Sanderman R, editors. eHealth Research, Theory and Development: A Multidisciplinary Approach. London, UK: Routledge; 2018:3-26.
133. Ehrismann M, Stegwee R. Trust in eHealth Services - A Practice Driven Review of the Literature. Capgemini Consulting. 2015 Jan. URL: https://doi.org/10.13140/rg.2.1.1610.7129 [accessed 2021-11-30]
134. Soloe C, Burrus O, Subramanian S. The effectiveness of mHealth and eHealth tools in improving provider knowledge, confidence, and behaviors related to cancer detection, treatment, and survivorship care: a systematic review. J Cancer Educ 2021 Dec;36(6):1134-1146 [FREE Full text] [doi: 10.1007/s13187-021-01961-z] [Medline: 33598832]
135. Dávalos ME, French MT, Burdick AE, Simmons SC. Economic evaluation of telemedicine: review of the literature and research guidelines for benefit-cost analysis. Telemed J E Health 2009 Dec;15(10):933-948. [doi: 10.1089/tmj.2009.0067] [Medline: 19954346]
136. Casal JP, Ramos AC. E-government policies in health care: the social cost of digitalization. In: Proceedings of 17th European Conference on Digital Government. 2017 Presented at: ECDG '17; June 12-13, 2017; Lisbon, Portugal.

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137. Somers TJ, Kelleher SA, Westbrook KW, Kimmick GG, Shelby RA, Abernethy AP, et al. A small randomized controlled pilot trial comparing mobile and traditional pain coping skills training protocols for cancer patients with pain. Pain Res Treat 2016;2016:2473629 [FREE Full text] [doi: 10.1155/2016/2473629] [Medline: 27891252]
138. Jibb LA, Stevens BJ, Nathan PC, Seto E, Cafazzo JA, Johnston DL, et al. Implementation and preliminary effectiveness of a real-time pain management smartphone app for adolescents with cancer: a multicenter pilot clinical study. Pediatr Blood Cancer 2017 Oct;64(10):e26554. [doi: 10.1002/pbc.26554] [Medline: 28423223]

Abbreviations

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

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Viewpoint

Physicians' Perceptions of and Satisfaction With Artificial Intelligence in Cancer Treatment: A Clinical Decision Support System Experience and Implications for Low-Middle–Income Countries

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Abstract

As technology continues to improve, health care systems have the opportunity to use a variety of innovative tools for decision-making, including artificial intelligence (AI) applications. However, there has been little research on the feasibility and efficacy of integrating AI systems into real-world clinical practice, especially from the perspectives of clinicians who use such tools. In this paper, we review physicians' perceptions of and satisfaction with an AI tool, Watson for Oncology, which is used for the treatment of cancer. Watson for Oncology has been implemented in several different settings, including Brazil, China, India, South Korea, and Mexico. By focusing on the implementation of an AI-based clinical decision support system for oncology, we aim to demonstrate how AI can be both beneficial and challenging for cancer management globally and particularly for low-middle–income countries. By doing so, we hope to highlight the need for additional research on user experience and the unique social, cultural, and political barriers to the successful implementation of AI in low-middle–income countries for cancer care.

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KEYWORDS

artificial intelligence; cancer; low-middle–income countries; physicians; perceptions; Watson for Oncology; implementation; local context

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Introduction

The last several decades have witnessed the rapid growth of artificial intelligence (AI) applications in health care. AI is considered to comprise areas like machine learning, natural language processing, expert systems, and image and signal processing [1]. One group, who cited a study from Global Market Insights, noted that the use of AI in health care was expected to grow annually from 2016 to 2024, with expenditures increasing from US $760 million in 2016 to over US $10 billion in 2024 [2]. In a 2020 study, Global Market Insights noted that the AI in the health care market exceeded US $4 billion in 2020 and would grow at a compound annual growth rate of 33.7% between 2021 and 2027, with an expenditure of US $34.5 billion in 2027 [3]. This market growth has been accompanied by both national initiatives for AI and the rapid growth of academic literature on the use of AI in health care. For example, in India, an "AI for All" policy was established along with NITI (National Institution for Transforming India) Aayog—a Government of India think tank for formulating a national strategy for AI [4]. A bibliometric analysis of the literature reported in the *Journal of Medical Internet Research* found a growth rate of 45.15% in publications from 2014 to 2019, with 70.67% of all publications occurring in the same period [5]. This analysis also found the following top five health problems in the publications (in order of frequency): cancer, depression, Alzheimer disease, heart failure, and diabetes. Another review of AI applications in health care found the following areas of focus in the applications: sepsis, breast cancer, diabetic retinopathy, and polyps and adenomas [6]. Additionally, this review noted that the implementation of AI applications in real-world clinical settings is not widespread. Another recent review with a focus on patient safety outcomes also noted the lack of AI applications in real-world settings [7]. These articles, and others in the *Journal of Medical Internet Research* and elsewhere, have started to capture the use and role of AI in health care [8-11].

In this viewpoint, we contribute to this growing literature by detailing physicians' experiences with an AI application—Watson for Oncology (WfO)—in the treatment of cancer. Physicians' experiences with WfO are especially relevant, as the application has been implemented in diverse, real-world social and cultural settings. Our summary of physicians' experiences with WfO relies on the extensive, published literature on this topic. After we describe physicians' experiences with WfO, we comment about the opportunities and challenges associated with using AI for cancer care in low-middle–income countries (LMICs).

The WfO Clinical Decision Support System Tool

WfO is a therapeutic oncology clinical decision support system (CDSS) that was trained by experts from the Memorial Sloan Kettering Cancer Center [12]. WfO uses both natural language processing and machine learning to process structured and unstructured data about patients with cancer and generate therapeutic options based on available evidence [13]. WfO provides 3 categories of therapeutic options: "recommended" treatments are those that adhere to the preferred training approach of the Memorial Sloan Kettering Cancer Center, treatments "for consideration" refer to alternative treatments based on evidence, and "not recommended" treatments refer to those that are not appropriate for certain patients [14]. Many early adopters of WfO measured the degree to which WfO therapeutic options were concordant with either clinical practice or the decisions of a multidisciplinary tumor board. WfO concordance rates varied widely across countries for many reasons, including differences in standard treatment guidelines, resource availability, and physician or patient preferences [15]. It is well recognized that concordance studies do not measure system accuracy but instead assess agreement with decisions made in practice, which may or may not reflect evidence-based decisions [16].

In this viewpoint, we focus on physicians' perceptions of and satisfaction with WfO. We believe that an evaluation of physicians' perceptions of this AI tool will provide valuable insights for the successful implementation of AI-based CDSSs for cancer treatment, especially in LMICs. Additionally, little is known about how physicians perceive the use of AI tools for cancer treatment. We present physicians' perceptions of the advantages of, as well as the disadvantages and concerns with, AI in a real-world setting. Our summary relies on published literature on physicians' perceptions of WfO implementation in a number of countries, including China, India, Mexico, South Korea, and Thailand. Multimedia Appendix 1 provides a comprehensive list of the studies on WfO [13-74].

Advantages

The positive perceptions of WfO relate to the system's ability to aid clinicians during the therapeutic decision-making process by quickly providing relevant scientific evidence. In China, a satisfaction survey, which was completed by 51 oncologists who used WfO, found that 86.3% of oncologists approved the quality of WfO and 88.2% approved the comprehensibility of WfO's treatment options, justifications, and external literature [17]. The clinicians rated WfO highly in terms of its ability to provide evidence-based medicine medical education (score: 8.1/10) and literature assistance (score: 7.7/10), assist in medical care quality control (score: 7.3/10), act as a second-opinion consultation resource (score: 7.0/10), perform case reviews with a tumor board (score: 6.9/10), and provide decision support (score: 6.4/10). Overall, the oncologists recommended using WfO as a CDSS to other clinicians (score: 7.3/10). At Shanghai Tenth People's Hospital, the multiple disciplinary team (MDT) also used WfO and found that their treatment plans became "more standardized, reasonable, and personalized" [18].

WfO's ability to compare treatment options was tested in Mexico, where it was used for a total of 100 patient cases involving lung, breast, gastric, colon, and rectal cancers diagnosed within the last 5 years [19]. In terms of perceived utility, oncologists found WfO to be "very useful" in comparing treatment options. They reported that WfO might be especially valuable for individuals, such as medical students and residents who lack oncology experience, as well as clinics that do not have enough subspecialists. Several implementations of WfO

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in China indicate the role of WfO in enhancing the learning experience and efficiency of physicians, particularly junior physicians, and the facilitation of better diagnoses and treatment recommendations [20,21]. This perspective was also substantiated by students from Taipei Medical University Hospital in Taiwan who had limited clinical experience; by using WfO, they performed better on their colon cancer learning assessment than their peers who used traditional search methods and were more clinically experienced [22]. The study also found that students with less clinical experience felt that WfO was "clearer and more understandable" than information found through traditional methods.

WfO's links to recent and relevant scientific information may provide treatment information that clinicians may not know. In India, an MDT changed their treatment recommendations for 136 of 1000 cases of breast, lung, colon, and rectal cancers because of the data provided by WfO [23]. For 55% of those cases, WfO provided recent evidence of newer treatments. For 30% of the cases, WfO provided new information about genotypic and phenotypic data. For 15% of the cases, WfO provided information on evolving clinical experiences, which influenced the MDT to change their treatment decisions. These results demonstrate the potential of WfO to positively impact cancer outcomes by providing scientific evidence and up-to-date information on clinical guidelines. In a separate study that focused on adjuvant systemic therapy for breast carcinoma, treatment decisions were changed for 4 of 11 patients after the MDT reviewed WfO's recommendations and EndoPredict (Myriad Genetics Inc) test reports [24]. WfO was able to aid clinicians in providing personalized cancer care while addressing the difficulties of staying informed on evolving cancer guidelines and studies.

Another aspect that must be considered is whether WfO can be useful as a CDSS. At the Instituto Câncer do Ceará in Brazil, a majority of oncologists chose the "agree" or "strongly agree" option for statements that were used to confirm if WfO meets the "CDS Five Rights" criteria [25]. The "CDS Five Rights" contain clinical quality criteria for determining if a CDSS offers benefits that are optimal for a given setting [75]. In the study, 6 of the 7 oncologists at the Instituto Câncer do Ceará believed that WfO provided relevant information that resulted in action being taken and presented the information in a manner that positively aligned with their individual workflows. Further, 5 oncologists agreed that the additional details for each treatment option were easily comprehensible, and 4 oncologists agreed that WfO exceeded their expectations as a CDSS tool for patient management.

Disadvantages and Concerns

Although WfO appears to be useful for displaying information in a succinct and timely manner, there are concerns regarding the system's usability and integration into clinician workflows. First, at sites without integrated patient record systems, some users found manual data entry to be a burdensome process [13,26]. At Manipal Hospital in India, it was observed that acclimation to the system reduced the time needed for each patient case [27]. The mean time needed to collect and enter data for nonmetastatic diseases was 20 minutes. This was reduced to 12 minutes after an increased acquaintance of 10 cases with WfO. In comparison, the time needed to collect and enter data for metastatic diseases was 5 to 7 minutes longer than that for localized diseases. On average, WfO took a median of 40 seconds to capture, analyze, and provide treatment recommendations. For physicians with a high patient load, the time needed to enter information into the system may be an issue. Users also want WfO to provide an explanation of its process for scoring and ranking treatment options [26]. In doing so, users would feel more comfortable with trusting the information and recommendations provided by WfO.

A second important concern that has been identified in studies is localizing WfO's treatment recommendations to the country of implementation. In the previously mentioned satisfaction study conducted in China, 66.7% of physicians recommended that WfO should integrate data on locally available treatments to improve the system [17]. For example, WfO did not take into consideration whether the immunotherapy drugs it recommended had been approved by the China Food and Drug Administration. Physicians also chose chemotherapy instead of WfO's recommended medication because the medication was too expensive for patients. Similar challenges were found for WfO users in Mexico and Thailand [19,28]. In Mexico, clinicians deviated from WfO's recommendations due to the high costs associated with them and the fact that they did not adhere to Mexican cancer treatment guidelines [19]. In Thailand, oncologists preferred basing their treatment recommendations on other countries' guidelines instead of US guidelines [28].

Implications for LMICs

In 2012, 65% of all cancer deaths worldwide occurred in LMICs, and the projection for 2030 is that this will increase to 75% [76]. LMICs may also be experiencing an even higher burden from cancer than that experienced by high-income countries (HICs) for several reasons. LMICs have restrained funding and often lack optimal cancer registries and surveillance data; thus, they are unable to implement evidence-based cancer control programs [76]. Treatment modalities are also more limited in LMICs than in HICs; radiotherapy and chemotherapy are available in 43% to 51% of LMICs but are available in 94% of HICs [77]. However, there is a high demand for such therapies, as 5 million new people annually are estimated to need radiation therapy in LMICs [78]. LMICs also lack specialized medical personnel, such as oncologists and oncology nurses, who are needed to address those affected by cancer in LMICs [79]. According to a World Health Organization report, LMICs have the lowest density of health care workers in comparison to HICs, where the density of health care workers is significantly higher [80]. A lack of health care workers for serving the population makes offering high-quality, personalized care a difficult task.

Oncologists also often require the expertise of their colleagues and additional literary resources to determine a course of treatment for unique cancer cases. Gaining access to high-quality medical information is key for creating an appropriate treatment plan, but oncologists may need additional help with sorting information that is both relevant to their patients and viable in

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terms of what resources are available. AI-based platforms such as WfO may be able to address the growing challenges of providing cancer treatment plans in LMICs. AI can address issues of access to knowledge bases in a comprehensive and easy-to-access manner. The ability of AI tools to quickly provide evidence-based cancer treatment options would be especially helpful in low-resource settings where the lack of time, expertise, and other needed resources can become a barrier to providing care. Using AI in this manner may also promote international partnerships on cancer therapy research and standardize guidelines for certain cancer types. The studies reviewed in this viewpoint demonstrate the potential of AI to reduce the cognitive burdens of less experienced physicians who would benefit from additional medical education resources.

The experiences with WfO in different settings also reveal a positive perception of AI with regard to its ability to reassure clinicians and confirm their interpretations of data and the potential of such a tool to do so in an LMIC. The ability of AI to act as a second opinion resource and standardize treatments may prove especially useful for cancer care in LMICs where the likelihood of receiving comprehensive care and achieving positive outcomes is lower than that in HICs. A lack of available specialized medical personnel in LMICs, especially in rural regions, is one of the factors contributing to poor cancer outcomes in LMICs [81]. The ability of AI tools, such as WfO, to provide subspecialty treatment information makes such tools a much-needed resource that existing physicians can use to meet population demands, especially in rural areas, as envisioned for the use of AI in an LMIC like India [4,82]. Approximately 60 oncologists serve over 300 million people in West Africa, and only 2000 oncologists are available for 10 million patients in India [83-85]. WfO's open-access information, which can be used to supplement self-paced learning, would be an ideal resource for cancer physicians in LMICs where medical education resources are lacking [86,87].

The use of an AI tool such as WfO in LMICs also poses certain challenges. The technological challenges that are unique to LMICs and should be mentioned include access to the internet, technology training, and whether local technology teams would be able to address technical issues [87]. Providing a decision support tool, such as WfO, that is user-friendly and aligns with daily workflows is essential for implementation in LMICs, where physicians' experiences with technology can vary [87]. Additionally, there is concern about whether AI tools would exacerbate the divide in health care access and use, especially with respect to socioeconomic status. There is a fear that AI would recommend treatment options that patients cannot afford or that only high-income and educated patients who are aware of AI tools may benefit from the use of AI in LMICs [4,19,28] Another important concern—one that applies to a tool such as WfO—is that the data and training of AI tools may not incorporate patient characteristics into treatment recommendations. For example, in China, local patient characteristics such as gene mutations and the weaker physiques of Chinese patients, which can influence treatment recommendations, were not accounted for in WfO recommendations [20]. Similarly, the need to consider the presence of multiple ethnic groups in countries like India during the implementation of AI tools developed by Western countries will be an important factor to address in LMICs [88].

Conclusion

It is undeniable that oncology physicians in LMICs need as much additional support as possible. The implementation of AI tools, such as WfO, in different settings has revealed that access to a second opinion CDSS resource, concise scientific evidence, and international clinical guidelines can help physicians feel more confident in their final treatment decisions. To improve the clinical utility of AI tools such as WfO, it is necessary that the experiences and satisfaction of physicians who use such tools are explored more in-depth, especially those of physicians in LMICs. These perspectives are especially key to tailoring AI systems for use in real-world clinical settings [6,7]. Such perspectives are of course embedded in the local social, cultural, and political LMIC contexts within which AI is implemented and the ways in which local contexts can shape the use of AI. We are gaining experience with respect to the implementation of AI tools, such as WfO, in real-world settings for the treatment of cancer. However, we still need to address some of the challenges in the "last mile" stage of implementation, specifically those related to local contexts [89].

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Conflicts of Interest

SE, AR, and DWB received salary support from a grant funded by IBM Watson Health. DWB has received research support from and consults for EarlySense, which makes patient safety monitoring systems. He receives cash compensation from the Center for Digital Innovation (Negev), which is a not-for-profit incubator for health information technology start-ups. He receives equity from ValeraHealth, which makes software to help patients with chronic diseases; Clew, which makes software to support clinical decision-making in intensive care; and MDClone, which takes clinical data and produces deidentified versions of them. He consults for and receives equity from AESOP, which makes software to reduce medication error rates, and FeelBetter. He has received research support from MedAware. RFR is employed by IBM Watson Health. GPJ was employed by IBM Watson Health at the time of manuscript submission and GPJ's compensation included salary and equity. All other authors declare no conflicts of interests.

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Multimedia Appendix 1
Studies on Watson for Oncology (WfO).
[DOCX File , 23 KB - cancer_v8i2e31461_app1.docx]

References

1. Wahl B, Cossy-Gantner A, Germann S, Schwalbe NR. Artificial intelligence (AI) and global health: how can AI contribute to health in resource-poor settings? BMJ Glob Health 2018 Aug 29;3(4):e000798 [FREE Full text] [doi: 10.1136/bmjgh-2018-000798] [Medline: 30233828]
2. Healthcare artificial intelligence outlook: Benefits, projected growth and challenges. The SSI Group. URL: https://thessigroup.com/healthcare-artificial-intelligence-outlook-benefits-projected-growth-challenges/ [accessed 2022-01-04]
3. Artificial intelligence in healthcare market size by application (medical imaging and diagnosis, drug discovery, therapy planning, hospital workflow, wearables, virtual assistants), COVID-19 impact analysis, regional outlook, application potential, price trends, competitive market share and forecast, 2021 - 2027. Global Market Insights. 2020. URL: https://www.gminsights.com/industry-analysis/healthcare-artificial-intelligence-market [accessed 2022-01-04]
4. Pradhan K, John P, Sandhu N. Use of artificial intelligence in healthcare delivery in India. J Hosp Manag Health Policy 2021 Sep;5:1-10 [FREE Full text] [doi: 10.21037/jhmhp-20-126]
5. Guo Y, Hao Z, Zhao S, Gong J, Yang F. Artificial intelligence in health care: Bibliometric analysis. J Med Internet Res 2020 Jul 29;22(7):e18228 [FREE Full text] [doi: 10.2196/18228] [Medline: 32723713]
6. Yin J, Ngiam KY, Teo HH. Role of artificial intelligence applications in real-life clinical practice: Systematic review. J Med Internet Res 2021 Apr 22;23(4):e25759 [FREE Full text] [doi: 10.2196/25759] [Medline: 33885365]
7. Choudhury A, Asan O. Role of artificial intelligence in patient safety outcomes: Systematic literature review. JMIR Med Inform 2020 Jul 24;8(7):e18599 [FREE Full text] [doi: 10.2196/18599] [Medline: 32706688]
8. Iqbal U, Celi LA, Li YCJ. How can artificial intelligence make medicine more preemptive? J Med Internet Res 2020 Aug 11;22(8):e17211 [FREE Full text] [doi: 10.2196/17211] [Medline: 32780024]
9. Lee J. Is artificial intelligence better than human clinicians in predicting patient outcomes? J Med Internet Res 2020 Aug 26;22(8):e19918 [FREE Full text] [doi: 10.2196/19918] [Medline: 32845249]
10. Vuong QH, Ho MT, Vuong TT, La VP, Ho MT, Nghiem KCP, et al. Artificial intelligence vs. natural stupidity: Evaluating AI readiness for the Vietnamese Medical Information System. J Clin Med 2019 Feb 01;8(2):168 [FREE Full text] [doi: 10.3390/jcm8020168] [Medline: 30717268]
11. Hosny A, Aerts HJWL. Artificial intelligence for global health. Science 2019 Nov 22;366(6468):955-956 [FREE Full text] [doi: 10.1126/science.aay5189] [Medline: 31753987]
12. Luxton DD. Should Watson be consulted for a second opinion? AMA J Ethics 2019 Feb 01;21(2):E131-E137 [FREE Full text] [doi: 10.1001/amajethics.2019.131] [Medline: 30794122]
13. Keikes L, Medlock S, van de Berg DJ, Zhang S, Guicherit OR, Punt CJA, et al. The first steps in the evaluation of a "black-box" decision support tool: a protocol and feasibility study for the evaluation of Watson for Oncology. J Clin Transl Res 2018 Jul 27;3(Suppl 3):411-423 [FREE Full text] [Medline: 30873490]
14. Lee WS, Ahn SM, Chung JW, Kim KO, Kwon KA, Kim Y, et al. Assessing concordance with Watson for Oncology, a cognitive computing decision support system for colon cancer treatment in Korea. JCO Clin Cancer Inform 2018 Dec;2:1-8 [FREE Full text] [doi: 10.1200/CCI.17.00109] [Medline: 30652564]
15. Liang J, Li T, Zhang SS, Chen C, VanHouten C, Preininger A, et al. Reasons for discordance in treatment approaches between oncology practice and clinical decision support in China. J Clin Oncol 2019 May 20;37(15_suppl):6555. [doi: 10.1200/jco.2019.37.15_suppl.6555]
16. Suwanvecho S, Suwanrusme H, Jirakulaporn T, Issarachai S, Taechakraichana N, Lungchukiet P, et al. Comparison of an oncology clinical decision-support system's recommendations with actual treatment decisions. J Am Med Inform Assoc 2021 Mar 18;28(4):832-838 [FREE Full text] [doi: 10.1093/jamia/ocaa334] [Medline: 33517389]
17. Li T, Chen C, Zhang SS, Dankwa-Mullan I, Chen A, Preininger A, et al. Deployment and integration of a cognitive technology in China: Experiences and lessons learned. J Clin Oncol 2019 May 20;37(15_suppl):6538. [doi: 10.1200/jco.2019.37.15_suppl.6538]
18. Fang J, Zhu Z, Wang H, Hu F, Liu Z, Guo X, et al. The establishment of a new medical model for tumor treatment combined with Watson for Oncology, MDT and patient involvement. J Clin Oncol 2018 Jun 01;36(15_suppl):e18504. [doi: 10.1200/jco.2018.36.15_suppl.e18504]
19. Sarre-Lazcano C, Alonso AA, Melendez FDH, Arrieta O, Norden AD, Urman A, et al. Cognitive computing in oncology: A qualitative assessment of IBM Watson for Oncology in Mexico. J Clin Oncol 2017 May 30;35(15_suppl):e18166. [doi: 10.1200/jco.2017.35.15_suppl.e18166]
20. Liu C, Liu X, Wu F, Xie M, Feng Y, Hu C. Using artificial intelligence (Watson for Oncology) for treatment recommendations amongst Chinese patients with lung cancer: Feasibility study. J Med Internet Res 2018 Sep 25;20(9):e11087 [FREE Full text] [doi: 10.2196/11087] [Medline: 30257820]

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21. Tian Y, Liu X, Wang Z, Cao S, Liu Z, Ji Q, et al. Concordance between Watson for Oncology and a multidisciplinary clinical decision-making team for gastric cancer and the prognostic implications: Retrospective study. J Med Internet Res 2020 Feb 20;22(2):e14122 [FREE Full text] [doi: 10.2196/14122] [Medline: 32130123]
22. Chen CY, Hung HC, Chiu HY, Wei PL, Kuo PL, Chiou JF, et al. Enhancing evidence-based medicine skills in oncology training with cognitive technology. J Clin Oncol 2019 May 26;37(15_suppl):10532. [doi: 10.1200/jco.2019.37.15_suppl.10532]
23. Somashekhar SP, Sepúlveda MJ, Shortliffe EH, C RK, Rauthan A, Patil P, et al. A prospective blinded study of 1000 cases analyzing the role of artificial intelligence: Watson for oncology and change in decision making of a Multidisciplinary Tumor Board (MDT) from a tertiary care cancer center. J Clin Oncol 2019 May 26;37(15_suppl):6533. [doi: 10.1200/jco.2019.37.15_suppl.6533]
24. Somashekhar SP, Yethadka R, C RK, Rajgopal AK, Rauthan A, Patil P. Triple blinded prospective study assessing the impact of genomics: EndoPredict and artificial intelligence Watson for Oncology (WFO) on MDT's decision of adjuvant systemic therapy for hormone receptor positive early breast carcinoma. J Clin Oncol 2019 May 26;37(15_suppl):e18013. [doi: 10.1200/jco.2019.37.15_suppl.e18013]
25. Rocha HAL, Dankwa-Mullan I, Juacaba SF, Preininger A, Felix W, Thompson JV, et al. An evaluation of artificial intelligence-based clinical decision supports use in Brazil. J Clin Oncol 2019 May 26;37(15_suppl):e18081. [doi: 10.1200/jco.2019.37.15_suppl.e18081]
26. Zauderer MG, Gucalp A, Epstein AS, Seidman AD, Caroline A, Granovsky S, et al. Piloting IBM Watson Oncology within Memorial Sloan Kettering's regional network. J Clin Oncol 2014 May 20;32(15_suppl):e17653. [doi: 10.1200/jco.2014.32.15_suppl.e17653]
27. Somashekhar SP, Kumarc R, Rauthan A, Arun KR, Ramya YE. Abstract S6-07: Double blinded validation study to assess performance of IBM artificial intelligence platform, Watson for oncology in comparison with Manipal multidisciplinary tumour board – First study of 638 breast cancer cases. Cancer Res 2017;77(4_Supplement):S6-07. [doi: 10.1158/1538-7445.sabcs16-s6-07]
28. Suwanvecho S, Suwanrusme H, Sangtian M, Norden AD, Urman A, Hicks A, et al. Concordance assessment of a cognitive computing system in Thailand. J Clin Oncol 2017 May 30;35(15_suppl):6589. [doi: 10.1200/JCO.2017.35.15_suppl.6589]
29. Zhang XC, Zhou N, Zhang CT, Lv HY, Li TJ, Zhu JJ, et al. Concordance study between IBM Watson for Oncology (WFO) and clinical practice for breast and lung cancer patients in China. Ann Oncol 2017 Nov 01;28(Supplement 10):x170. [doi: 10.1093/annonc/mdx678.001]
30. Bach P, Zauderer MG, Gucalp A, Epstein AS, Norton L, Seidman AD, et al. Beyond Jeopardy!: Harnessing IBM's Watson to improve oncology decision making. J Clin Oncol 2013 May 20;31(15_suppl):6508. [doi: 10.1200/jco.2013.31.15_suppl.6508]
31. Epstein AS, Zauderer MG, Gucalp A, Seidman AD, Caroline A, Fu J, et al. Next steps for IBM Watson Oncology: Scalability to additional malignancies. J Clin Oncol 2014 May 20;32(15_suppl):6618. [doi: 10.1200/jco.2014.32.15_suppl.6618]
32. Fu J, Gucalp A, Zauderer MG, Epstein AS, Kris MG, Keesing J, et al. Steps in developing Watson for Oncology, a decision support system to assist physicians choosing first-line metastatic breast cancer (MBC) therapies: Improved performance with machine learning. J Clin Oncol 2015 May 20;33(15_suppl):566. [doi: 10.1200/jco.2015.33.15_suppl.566]
33. Kris MG, Gucalp A, Epstein AS, Seidman AD, Fu J, Keesing J, et al. Assessing the performance of Watson for oncology, a decision support system, using actual contemporary clinical cases. J Clin Oncol 2015 May 20;33(15_suppl):8023. [doi: 10.1200/jco.2015.33.15_suppl.8023]
34. Seidman AD, Pilewskie ML, Robson ME, Kelvin JF, Zauderer MG, Epstein AS, et al. Integration of multi-modality treatment planning for early stage breast cancer (BC) into Watson for Oncology, a Decision Support System: Seeing the forest and the trees. J Clin Oncol 2015 May 20;33(15_suppl):e12042. [doi: 10.1200/jco.2015.33.15_suppl.e12042]
35. Herath DH, Wilson-Ing D, Ramos E, Morstyn G. Assessing the natural language processing capabilities of IBM Watson for oncology using real Australian lung cancer cases. J Clin Oncol 2016 May 20;34(15_suppl):e18229. [doi: 10.1200/JCO.2016.34.15_suppl.e18229]
36. Somashekhar SSP, Kumar R, Kumar A, Patil P, Rauthan A. 551PD Validation study to assess performance of IBM cognitive computing system Watson for oncology with Manipal multidisciplinary tumour board for 1000 consecutive cases: An Indian experience. Ann Oncol 2016 Dec;27:ix179. [doi: 10.1016/S0923-7534(21)00709-2]
37. Zhou N, Lv H, Zhang C, Li T, Zhu J, Jiang M, et al. P1.01-069 Clinical experience with IBM Watson for Oncology (WFO) cognitive system for lung cancer treatment in China. J Thorac Oncol 2017 Nov;12(11):S1921. [doi: 10.1016/j.jtho.2017.09.723]
38. Yue L, Yang L. Clinical experience with IBM Watson for Oncology (WFO) for multiple types of cancer patients in China. Ann Oncol 2017 Nov;28:x162. [doi: 10.1093/annonc/mdx676.024]
39. Somashekhar S, Sepúlveda M, Norden AD, Rauthan A, Arun K, Patil P, et al. Early experience with IBM Watson for Oncology (WFO) cognitive computing system for lung and colorectal cancer treatment. J Clin Oncol 2017 May 30;35(15_suppl):8527. [doi: 10.1200/JCO.2017.35.15_suppl.8527]

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40. Baek JH, Ahn SM, Urman A, Kim YS, Ahn HK, Won PS, et al. Use of a cognitive computing system for treatment of colon and gastric cancer in South Korea. J Clin Oncol 2017 May 30;35(15_suppl):e18204. [doi: 10.1200/JCO.2017.35.15_suppl.e18204]
41. Lim S, Lee KB. Use of a cognitive computing system for treatment of cervical cancer. J Gynecol Oncol 2017 Sep;28(5):e67 [FREE Full text] [doi: 10.3802/jgo.2017.28.e67] [Medline: 28657228]
42. Zhou N, Zhang CT, Lv HY, Hao CX, Li TJ, Zhu JJ, et al. Concordance study between IBM Watson for Oncology and clinical practice for patients with cancer in China. Oncologist 2019 Jun;24(6):812-819 [FREE Full text] [doi: 10.1634/theoncologist.2018-0255] [Medline: 30181315]
43. Chen PJ, Sun TT, Li TI, Dankwa-Mullan I, Urman A, Wang CK, et al. Can AI technology augment tumor board treatment decisions for stage II colon cancer care? J Clin Oncol 2018 Jun 01;36(15_suppl):e18582. [doi: 10.1200/JCO.2018.36.15_suppl.e18582]
44. Wu A, Chen PJ, Li TI, Dankwa-Mullan I, Sun TT, Rhee K. Real world survival outcomes in patients with high risk stage II colon cancer at a Beijing Cancer Hospital. J Clin Oncol 2018 May 20;36(15_suppl):e15670-e15670. [doi: 10.1200/JCO.2018.36.15_suppl.e15670]
45. Jiang Z, Xu F, Sepúlveda M, Li J, Wang H, Liu Z, et al. Concordance, decision impact and guidelines adherence using artificial intelligence in high-risk breast cancer. J Clin Oncol 2018 Jun 01;36(15_suppl):e18566. [doi: 10.1200/JCO.2018.36.15_suppl.e18566]
46. Yuwen D, Zhang W, Wu J, Zhang J, Shen Y, Shi J, et al. Concordance evaluation of an artificial intelligence technology with a multidisciplinary tumor board in gastric cancer. J Clin Oncol 2018 Jun 01;36(15_suppl):e18569. [doi: 10.1200/JCO.2018.36.15_suppl.e18569]
47. Somashekhar SP, Sepúlveda MJ, Puglielli S, Norden AD, Shortliffe EH, Rohit Kumar C, et al. Watson for Oncology and breast cancer treatment recommendations: agreement with an expert multidisciplinary tumor board. Ann Oncol 2018 Feb 01;29(2):418-423 [FREE Full text] [doi: 10.1093/annonc/mdx781] [Medline: 29324970]
48. Kim YY, Oh SJ, Chun YS, Lee WK, Park HK. Gene expression assay and Watson for Oncology for optimization of treatment in ER-positive, HER2-negative breast cancer. PLoS One 2018 Jul 06;13(7):e0200100. [doi: 10.1371/journal.pone.0200100] [Medline: 29979736]
49. Suwanrusme H, Issarachai S, Umsawasdi T, Suwanvecho S, Decha W, Dankwa-Mullan I, et al. Concordance assessment of a clinical decision support software in patients with solid tumors. J Clin Oncol 2018 Jun 01;36(15_suppl):e18584. [doi: 10.1200/JCO.2018.36.15_suppl.e18584]
50. Simon G, DiNardo CD, Takahashi K, Cascone T, Powers C, Stevens R, et al. Applying artificial intelligence to address the knowledge gaps in cancer care. Oncologist 2019 Jun;24(6):772-782 [FREE Full text] [doi: 10.1634/theoncologist.2018-0257] [Medline: 30446581]
51. Saiz FJS, Urman A, Sanders C, Britt MW, Nielsen R, Stevens RJ. IBM Watson Evidence Service (WES): A system for retrieval, summation and insight generation of relevant clinical evidence for personalized oncology. J Clin Oncol 2018 Jun 01;36(15_suppl):e18588. [doi: 10.1200/JCO.2018.36.15_suppl.e18588]
52. Graham DMA, McNamara DM, Waintraub SE, Goldberg SL, Norden AD, Hervey J, et al. Are treatment recommendations provided by cognitive computing supported by real world data (Watson for Oncology with Cota RWE) concordant with expert opinions? Ann Oncol 2018 Oct;29:viii571. [doi: 10.1093/annonc/mdy297.031]
53. Waintraub SE, McNamara DM, Graham DMA, Goldberg SL, Norden AD, Hervey J, et al. Can the cognitive computing system Watson for Oncology with Cota RWE help oncologists deliver subspecialist level care? 2018 Presented at: 36th Annual Chemotherapy Foundation Symposium (CFS); November 7-9, 2018; New York, New York.
54. Rocha HAL, Dankwa-Mullan I, Juacaba SF, Willis V, Arriaga YE, Jackson GP, et al. Shared-decision making in prostate cancer with clinical decision-support. J Clin Oncol 2019 May 26;37(15_suppl):e16576. [doi: 10.1200/JCO.2019.37.15_suppl.e16576]
55. Wang Z, Yu Z, Zhang X. Artificial intelligence-based clinical decision-support system improves cancer treatment and patient satisfaction. J Clin Oncol 2019 May 26;37(15_suppl):e18303. [doi: 10.1200/JCO.2019.37.15_suppl.e18303]
56. Yu Z, Wang Z, Ren X, Lou D, Li X, Liu H, et al. Practical exploration and research of Watson for oncology clinical decision support system in real-world and localized practice. J Clin Oncol 2019 May 26;37(15_suppl):e18304. [doi: 10.1200/JCO.2019.37.15_suppl.e18304]
57. Chen ZB, Chen SL, Liang RM, Peng ZW, Shen JX, Zhu WJ, et al. Can artificial intelligence support the clinical decision making for Barcelona clinic liver cancer stage 0/a hepatocellular carcinoma in China? J Clin Oncol 2019 May 26;37(15_suppl):e15634. [doi: 10.1200/JCO.2019.37.15_suppl.e15634]
58. Chen S, Chen Z, Xiao H, Peng Z, Peng S, Kuang M. IDDF2019-ABS-0095 Can artificial intelligence support the clinical decision making for hepatocellular carcinoma? Gut 2019;68:A134. [doi: 10.1136/gutjnl-2019-IDDFAbstracts.263]
59. Liang J, Tang C, Wang X, Guo Z, Ni J, Xu W, et al. Impact of decision-support system and guideline treatment concordance on response rate in advanced lung cancer. J Clin Oncol 2019 May 26;37(15_suppl):e20006. [doi: 10.1200/JCO.2019.37.15_suppl.e20006]
60. Liang J, Dankwa-Mullan I, Ren Y, Chen A, Willis V, Jackson G, et al. Employing an oncology decision-support system to quantify treatment variation. J Clin Oncol 2019 May 26;37(15_suppl):e18067. [doi: 10.1200/JCO.2019.37.15_suppl.e18067]

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61. Fang J, Guo X, Zhu Z, Wang H, Hu F, Chen J, et al. Quality control system of Watson for oncology: Artificial intelligence for supporting clinical decisions in oncology. J Clin Oncol 2019 May 26;37(15_suppl):6616. [doi: 10.1200/JCO.2019.37.15_suppl.6616]
62. Fang J, Guo X, Zhu Z, Wang H, Hu F, Chen J, et al. Watson for Oncology applied to teaching and remote consulting model. J Clin Oncol 2019 May 26;37(15_suppl):6545. [doi: 10.1200/JCO.2019.37.15_suppl.6545]
63. Choi YI, Chung JW, Kim KO, Kwon KA, Kim YJ, Park DK, et al. Concordance rate between clinicians and Watson for Oncology among patients with advanced gastric cancer: Early, real-world experience in Korea. Can J Gastroenterol Hepatol 2019 Feb 03;2019:8072928 [FREE Full text] [doi: 10.1155/2019/8072928] [Medline: 30854352]
64. Kim EJ, Woo HS, Cho JH, Sym SJ, Baek JH, Lee WS, et al. Early experience with Watson for oncology in Korean patients with colorectal cancer. PLoS One 2019 Mar 25;14(3):e0213640. [doi: 10.1371/journal.pone.0213640] [Medline: 30908530]
65. Kim D, Kim YY, Lee JH, Chung YS, Choi S, Kang JM, et al. A comparative study of Watson for Oncology and tumor boards in breast cancer treatment. Korean Journal of Clinical Oncology 2019 Jun 30;15(1):3-6 [FREE Full text] [doi: 10.14216/kjco.19002]
66. Kim M, Kim BH, Kim JM, Kim EH, Kim K, Pak K, et al. Concordance in postsurgical radioactive iodine therapy recommendations between Watson for Oncology and clinical practice in patients with differentiated thyroid carcinoma. Cancer 2019 Aug 15;125(16):2803-2809 [FREE Full text] [doi: 10.1002/cncr.32166] [Medline: 31216369]
67. Suwanvecho S, Shortliffe EH, Suwanrusme H, Issarachai S, Jirakulaporn T, Taechakraichana N, et al. A blinded evaluation of a clinical decision-support system at a regional cancer care center. J Clin Oncol 2019 May 26;37(15_suppl):6553. [doi: 10.1200/JCO.2019.37.15_suppl.6553]
68. Saiz FJS, Sanders C, Stevens RJ, Nielsen R, Britt MW, Preininger A, et al. Use of machine learning to identify relevant research publications in clinical oncology. J Clin Oncol 2019 May 26;37(15_suppl):6558. [doi: 10.1200/JCO.2019.37.15_suppl.6558]
69. Waintraub SC, Pecora AL. Cognitive computing and real world data in a breast cancer clinic. 2019 Presented at: Machine Learning & AI for Healthcare: A HIMSS Event; Orlando, Florida; February 11, 2019 URL: https://365.himss.org/sites/himss365/files/365/handouts/552672001/handout-MLAI09.pdf
70. Hamilton JG, Garzon MG, Westerman JS, Shuk E, Hay JL, Walters C, et al. "A Tool, Not a Crutch": Patient perspectives about IBM Watson for Oncology trained by Memorial Sloan Kettering. J Oncol Pract 2019 Apr;15(4):e277-e288 [FREE Full text] [doi: 10.1200/JOP.18.00417] [Medline: 30689492]
71. Saiz FS, Sanders C, Stevens R, Nielsen R, Britt M, Yuravlivker L, et al. Artificial intelligence clinical evidence engine for automatic identification, prioritization, and extraction of relevant clinical oncology research. JCO Clin Cancer Inform 2021 Jan;5:102-111 [FREE Full text] [doi: 10.1200/CCI.20.00087] [Medline: 33439724]
72. Zou FW, Tang YF, Liu CY, Ma JA, Hu CH. Concordance study between IBM Watson for Oncology and real clinical practice for cervical cancer patients in China: A retrospective analysis. Front Genet 2020 Mar 24;11:200 [FREE Full text] [doi: 10.3389/fgene.2020.00200] [Medline: 32265980]
73. Soochit A, Zhang C, Li T, Dankwa-Mullan I, Liu J. Concordance assessment of an artificial intelligence decision support tool for primary and recurrent cervical cancer at an academic cancer center. In: Int J Gynecol Cancer. 2018 Presented at: 17th Biennial Meeting of the International Gynecologic Cancer Society; September 14-16, 2018; Kyoto, Japan.
74. Zhang C, Soochit A, Dankwa-Mullan I, Li T, Liu J. Evaluation of personalized treatment with artificial intelligence decision-support tools for patients with ovarian cancer. In: Int J Gynecol Cancer. 2018 Presented at: 17th Biennial Meeting of the International Gynecologic Cancer Society; September 14-16, 2018; Kyoto, Japan.
75. Clinical decision support: More than just 'alerts' tipsheet. Centers for Medicare & Medicaid Services. 2014. URL: https://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Downloads/ClinicalDecisionSupport_Tipsheet-.pdf [accessed 2022-03-15]
76. Bray F, Ferlay J, Soerjomataram I, Siegel RL, Torre LA, Jemal A. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA Cancer J Clin 2018 Nov;68(6):394-424 [FREE Full text] [doi: 10.3322/caac.21492] [Medline: 30207593]
77. Bellanger M, Zeinomar N, Tehranifar P, Terry MB. Are global breast cancer incidence and mortality patterns related to country-specific economic development and prevention strategies? J Glob Oncol 2018 Jul;4:1-16 [FREE Full text] [doi: 10.1200/JGO.17.00207] [Medline: 30085889]
78. Shah SC, Kayamba V, Peek RMJ, Heimburger D. Cancer control in low- and middle-income countries: Is it time to consider screening? J Glob Oncol 2019 Mar;5:1-8 [FREE Full text] [doi: 10.1200/JGO.18.00200] [Medline: 30908147]
79. Institute of Medicine (US) Committee on Cancer Control in Low- and Middle-Income Countries. In: Sloan FA, Gelband H, editors. Cancer Control Opportunities in Low- and Middle-Income Countries. Washington (DC): National Academies Press (US); 2007.
80. World Health Statistics 2019: Monitoring health for the SDGs, sustainable development goals. World Health Organization. 2019. URL: https://apps.who.int/iris/bitstream/handle/10665/324835/9789241565707-eng.pdf?sequence=9&isAllowed=y [accessed 2022-03-15]
81. Mathew A. Global survey of clinical oncology workforce. J Glob Oncol 2018 Sep;4:1-12 [FREE Full text] [doi: 10.1200/JGO.17.00188] [Medline: 30241241]

XSL•FO
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82. Paul Y, Hickok E, Sinha A, Tiwari U. Artificial intelligence in the healthcare industry in India. The Centre for Internet and Society. URL: https://cis-india.org/internet-governance/ai-and-healthcare-report [accessed 2022-01-07]
83. Omeje C. Nigeria has fewer than 50 specialists for cancer treatment, says Chidebe. International Centre for Investigative Reporting. 2018 Aug 14. URL: https://www.icirnigeria.org/nigeria-has-fewer-than-50-specialists-for-cancer-treatment-says-chidibe/ [accessed 2022-03-15]
84. Obinna C. Shortage of oncologists threatens cancer care in W-Africa. Vanguard. 2014 Jun 30. URL: https://www.vanguardngr.com/2014/06/shortage-oncologists-threatens-cancer-care-w-africa/ [accessed 2022-03-15]
85. Mallath MK, Taylor DG, Badwe RA, Rath GK, Shanta V, Pramesh CS, et al. The growing burden of cancer in India: epidemiology and social context. Lancet Oncol 2014 May;15(6):e205-e212. [doi: 10.1016/S1470-2045(14)70115-9] [Medline: 24731885]
86. Ma X, Vervoort D. Leveraging e-learning for medical education in low- and middle-income countries. Cardiol Young 2020 Jun;30(6):903-904. [doi: 10.1017/S1047951120001109] [Medline: 32389137]
87. Barteit S, Guzek D, Jahn A, Bärnighausen T, Jorge MM, Neuhann F. Evaluation of e-learning for medical education in low- and middle-income countries: A systematic review. Comput Educ 2020 Feb;145:103726 [FREE Full text] [doi: 10.1016/j.compedu.2019.103726] [Medline: 32565611]
88. Pinninti R, Rajappa S. Artificial intelligence in health-care: How long to go? Cancer Res Stat Treat 2020;3(1):133-134. [doi: 10.4103/CRST.CRST_7_20]
89. Coiera E. The last mile: Where artificial intelligence meets reality. J Med Internet Res 2019 Nov 08;21(11):e16323 [FREE Full text] [doi: 10.2196/16323] [Medline: 31702559]

Abbreviations

AI: artificial intelligence
CDSS: clinical decision support system
HIC: high-income country
LMIC: low-middle–income country
MDT: multiple disciplinary team
NITI: National Institution for Transforming India
WfO: Watson for Oncology

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Viewpoint

Optimizing Social Support in Oncology with Digital Platforms

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Abstract

Increased cancer prevalence and survival rates coupled with earlier patient discharges from hospitals have created a greater need for social support. Cancer care is both short term and long term, requiring acute treatments, treatments for remission, and long-term screenings and treatment regimens. Health care systems are already overwhelmed and often struggle to provide social support systems for everyone. Caregivers are limited in number, and even when they are available, they often lack necessary information, skills, or resources to meet the needs of patients with cancer. The act of caregiving presents various challenges, and caregivers themselves often need social support as well. Despite these needs, most social support programs are targeted toward patients alone. Given the prevalence of cancer and known needs of these patients and their caregivers, the ability to identify those who need social support is crucial. Further, the scalability and overall availability of social support programs is vital for successful patient care. This paper establishes the benefits of social support for both patients and caregivers coping with cancer treatments, explores innovative ways of identifying patients who may need social support using digital tools, and reviews potential advantages of digital social support programs.

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KEYWORDS

social support; chronic disease; social networks; oncology; cancer; digital biomarkers; digital health; caregiver support

Introduction

Life expectancy in the United States has risen over 66% in the past century due, in part, to medical advancements [1]. Importantly, the fastest growing segment includes those aged 65 years and over, with the number of older adults worldwide in 2015 projected to more than double by 2050 [2]. Extended life expectancy has coincided with a steady rise in chronic disease, with incidence rates increasing by 7 to 8 million every 5 years for the past two decades [3].

Advancements in diagnostics and therapeutics have resulted in an increased number of cancer survivors [4]. Cancer is no longer strictly an acute disease; over the next decade, nearly 40% of patients diagnosed with cancer are expected to live greater than or equal to 5 years after diagnosis [4]. With patients living longer, cancer treatment is now often chronic in nature, requiring ongoing care and support for long-term management [5]. Despite advancements in treatments, however, cancer remains a leading cause of both death and disability worldwide [6,7]. Notably, the reported figures from 2020 may be a gross underestimation due to the debilitating effects of the COVID-19 pandemic on cancer screenings, diagnoses, and treatments. As a result, the coming years may show an even greater uptick in cancer incidence and mortality rates on a global level [6].

Social restrictions during the COVID-19 pandemic have drawn attention to the impact of social support, and lack thereof, on mental health in the general population [8]. However, the particular importance of social support for patients with chronic disease has been long established. In this context, social support is multifaceted and consists of providing patients with emotional, information, or practical support. Social support may come from various sources, such as family, friends, partners, and health care professionals [9]. Social support that comes from casual

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interactions with family, friends, or peers is often called informal social support, while support that comes from professional services, such as a nurses, physicians, or social workers, is considered formal social support [10].

While formalized social support programs exist, their use is not widespread among patients with cancer. Commonly cited reasons for underuse of formal social support programs include lack of awareness of existence among patients, absence of recommendation from physicians, practical constraints, and financial barriers. Further, formal social support programs are generally used more frequently by White, female, and higher-educated individuals, leading to further underuse by minority groups [11].

With formal social support having many barriers to use, patients often turn to their social network for informal social support [11]. Informal social support has been shown to impact clinical outcomes, including morbidity and mortality, as well as psychological outcomes, such as mood, mental health, and quality of life (QoL) [12-19]. For many patients with cancer, however, casual social interactions are not enough and, in turn, many patients rely on their caregiver for these interactions. Increased cancer prevalence and survival rates coupled with earlier hospital discharges to conserve financial resources have created an even larger and more important role for caregivers [6,20]. However, caregivers often lack necessary information, skills, or resources to meet the needs of patients with cancer and often need to cope with the significant emotional burden associated with caring for such patients [20,21]. Thus, caregivers must also be considered when discussing the importance of social support in cancer.

Considering these factors, a newfound structure for social support that encompasses both patients and caregivers will be essential to ensure quality and scalability of cancer care. With potential increases in global cancer incidence, prevalence, and mortality in the coming decades, achieving adequate social support may require leveraging digital tools that can proactively meet patient and caregiver needs. This paper seeks to summarize the importance of social support in chronic disease, outline its different components, suggest the use of digital biomarkers to identify patients who need social support, establish the advantages of digital social support programs, and review currently available digital modalities of social support for patients and caregivers in the oncology space.

Components of Social Support

While prior literature has defined social support in different ways, it is often comprised of three main facets: emotional, practical, and informational support [22-25]. These aspects of social support are summarized in Table 1. Emotional support focuses on expressing empathy and compassion to patients and caregivers, and fostering the sentiment that they are not alone in their experiences. Practical support fulfills the physical needs that patients or caregivers may have, such as transportation to the hospital or picking up medications. Informational support involves sharing education or tips about managing the disease state with patients or caregivers. As mentioned previously, social support can come via formal support programs or informal support from friends, families, or peers. While formal medical information should come from health care providers (HCPs), a patient's peers can provide valuable information, such as what to expect with certain treatments, particularly if the peer has the same chronic disease. Patients are not medical experts, but they often have valuable personal experiences from coping with disease that many providers may not.

Table 1. Major aspects of social support.

Major aspects of social support	Description
Emotional and physiological	Empathy, encouragement, and reassurance
Practical	Support with physical needs of daily living
Informational	Personal experiences, tips, and facts

Importance of Social Support in Patient Care

The clinical complexity of a cancer diagnosis poses a significant burden on patients. However, burden is not solely related to clinical complexity but is also a function of the dynamic interplay between personal, social, and clinical aspects of a patient's experience [26]. Thus, even if therapeutics have favorable side effect profiles and minimal disruption to patients' lives, the social aspect of a cancer diagnosis could pose a significant burden. A recent large-scale analysis found that nearly 40% of patients with chronic disease reported that they are unable to sustain their current investments of energy, time, and money into health care lifelong [27]. As patients with chronic diseases often have complex care plans that can be discouraging and difficult to manage independently, social support may play a crucial role in helping them be successful and feel less overwhelmed in trying to cope with their disease. Moreover, chronic disease is also associated with a higher risk of mental health conditions, such as depression and anxiety, which can limit patients' activity levels and social interactions [28].

Given the known challenges associated with managing chronic conditions, several studies have sought to understand the potential benefits of providing social support services in this setting [10-14]. One study of older adults with diabetes found that greater social support was associated with less stress, lower rates of depression, and reduced risk of myocardial infarction. Further, social support was also associated with fewer impairments in activities of daily living (eg, eating, drinking, bathing, and dressing) and instrumental activities of daily living (eg, using the telephone, transportation, laundry, and finances) [13]. Another large-scale meta-analysis found that greater perceived social support had a protective impact on mortality

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of up to 66% [17]. The same analysis found that a greater social network, such as regularly seeing friends and family members, can reduce the risk of mortality up to 70% [17].

While once not considered a chronic disease, improvements in diagnostics and therapeutics have transformed cancer into a condition requiring long-term care and support [5]. Compared to other diseases, cancer may be far more demanding and may, therefore, require a higher degree of social support [29]. Patients with cancer and their caregivers often cope with convoluted treatment plans, regimens associated with significant toxicities, symptom and side effect management, high disease severity, higher care costs, and more stressful decision-making [29]. Along with physical and medical impacts, a cancer diagnosis often brings along a heavy emotional burden; the prevalence of both depression and anxiety are significantly higher in patients with cancer [30]. Prognosis, pain levels, body image disruption, and tumor- or treatment-related side effects can all heavily impact a patient's psychological state [30].

The importance of social support for patients with cancer is well recognized, as current clinical guidelines recommend the incorporation of social support into oncology patients' care plans to help mitigate the distress associated with their disease [31].

Patients with cancer commonly express a desire for social support, as one study found patients often requested companionship, empathy, and home care support. More specifically, companionship was requested by nearly half of patients [32]. Beyond just a desire for social support, numerous studies have specifically demonstrated the benefit of social support services for patients with cancer. In terms of emotional benefit, providing social support has been shown to lessen feelings of anxiety and depression associated with the disease [33,34]. Social support has also been shown to have tangible outcomes, including increased medication adherence. In a prospective study of women with breast cancer, greater social support during oral endocrine therapy initiation was associated with higher rates of adherence and fewer depressive symptoms [35]. The costs associated with medication nonadherence in the United States is estimated to be US $100 billion to $290 billion, and nonadherence to cancer therapies is reported to be significantly higher than that of other disease states [36]. Thus, improving medication adherence among patients with cancer could have significant implications for reducing health care costs.

Beyond medication adherence, social support has been associated with improved physical and emotional health, well-being, and overall survival in patients with cancer [37]. One meta-analysis of 87 studies found a 12% to 25% reduction in relative mortality in patients with high levels of perceived social support and large social networks as well as in those who were married [38]. Social networks can also have a significant impact on overall QoL. One study of over 3000 breast cancer survivors found that larger social networks were associated with statistically significant higher QoL. More specifically, the study found that "the availability of someone with whom to have fun, relax, and get one's mind off things for a while" had the strongest association with QoL improvement [39]. Despite the established benefit, formal social support is not widely adopted in clinical practice. One study found that only 8% of patients reported attending a cancer support group, and almost 60% of patients did not know where to find a group [11]. While HCPs commonly recommend patient support programs, they often do not give direct recommendations on where to find such programs. Further, certain demographics, such as patients living in distant or rural areas, reported less use of social groups [11]. While support groups may be beneficial for such patients, the current infrastructure of physical support groups renders them impractical for many patients, and new approaches to provide social support are warranted.

Social Support for Caregivers

Given the rise in cancer prevalence and desire for more convenient treatments, a significant proportion of cancer care has shifted to the outpatient setting [2,7,40]. New oncologic agents have facilitated this transition, as they are more targeted and less invasive, making outpatient administration feasible [40]. While this offers more freedom to patients, it may place a larger strain on caregivers who are often relied on by many cancer patients for logistical support, including assistance with treatments, home care, and other tasks of daily living. These caregivers are frequently family members or friends who are not paid for the services they provide [41]. Along with the difficulty of performing complex care tasks with little to no training, a heavy emotional burden is placed on the shoulders of these informal caregivers, which in and of itself has been associated with increased mortality risk. One study found that older adult spousal caregivers who were experiencing caregiver strain had a 63% increase in 4-year mortality compared to a control group matched for age and sex who did not provide caregiving [42].

Moreover, approximately 9% of informal caregivers report having nobody to talk to about private matters. This feeling of isolation is exacerbated in millennial caregivers, with 27% indicating that they are not satisfied with the quality of their social relationships, and with 2 out of 10 reporting that they do not see any of their friends in a given month [21]. Fewer social connections and lower satisfaction with social support also significantly predicted depressive symptoms among caregivers, especially women [21]. Further, caregivers who are socially isolated are at greater risk of experiencing difficulties with complex care [21]. Although social support interventions are available for caregivers of patients with cancer, an estimated one-third of caregivers fail to ask for support when they need it [43].

Psychosocial Burden of Cancer

The psychosocial burden of cancer can be overwhelming, and many patients may not have a support system to help them cope with the emotional aspects of the disease. Unfortunately, psychosocial complications are common in patients with cancer [44]. Concerningly, many patients suffering from psychosocial comorbidities are not adequately treated. One study found that 73% of patients with cancer were not receiving potentially

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effective treatment to manage their depression, and only 5% were seeing a mental health professional [45].

Many of these patients with psychosocial burdens may not have access to informal social support, let alone formal social support. As cancer disproportionately affects the geriatric population, older adults often have a reduced network accessible for social support due to life cycle events, such as retirement, death of loved ones, and biological effects of aging (eg, new sensory impairments and worsening chronic illnesses) [46]. Social isolation and lack of perceived socio-emotional support can be detrimental to patient health, as studies have shown that social isolation can lead to reduced QoL and increased morbidity and mortality among patients with cancer [39,47,48].

These psychosocial burdens of cancer often go unaddressed but have a significant impact on the economic cost of cancer. One systematic review estimated the monetized lifetime psychosocial cost burden of cancer care in Canada, as measured by health-related QoL costs, to be CAD $427,753 to $528,769 (US $320,815 to $396,577), which represents approximately two-thirds of the economic cost of cancer [49]. Unlike clinical burden, psychosocial burden is less tangible and, thus, more difficult to identify, quantify, and formally diagnose [50]. Thus, patients with high needs for social support may not be identified early enough or, in some cases, at all. Moreover, there may be great interpersonal variation in psychosocial burden, even within patient populations with the same diagnosis. Identifying patients with high psychosocial burdens and proactively providing social support could improve the lives of patients and significantly decrease the economic burden associated with cancer.

Digital Biomarkers to Identify Patients in Need of Social Support

Digital biomarkers are objective measurements of physiological, pathologic, or anatomic characteristics continuously collected outside the clinical environment via home-based connected devices [51]. Passively collecting data from patients' mobile or wearable devices potentially offers a convenient and unobtrusive method to prospectively identify psychosocial burden and deliver tailored social support to the right patients at the right time. To our knowledge, digital biomarkers are not currently used to identify social support needs specific to cancer. However, they have been successfully used to identify depression, anxiety, and stress, all of which are common psychosocial complications of cancer [52-54].

One study examined the use of algorithms incorporating digital trace data, such as device location and phone usage, along with voice data from mobile devices to identify behavioral indicators of clinically validated symptoms of depression and posttraumatic stress disorder [52]. The behavioral indicators that were measured included depressed mood most the day, diminished interest or pleasure in all or most activities, fatigue or loss of energy, and avoidance of activities, places, or people. Digital biomarkers have also been used to identify mood disorders, such as major depressive disorder and bipolar disorder. Data on patient movement, captured over 2 weeks, was able to successfully predict diagnosis status of a mood disorder 89% of the time [53]. Another study combined passively collected data about patient movement, using accelerometers, and social contact, using calls and texts, over 2 weeks with machine learning models to predict social anxiety symptom severity [53]. Social anxiety is particularly important in the field of cancer, as it has been referred to as a hidden psychiatric comorbidity in patients with cancer [54]. While less specific, the use of smartwatches, rings, body patches, body scales, and vests can provide physiological proxies of the autonomic nervous stress response, such as resting heart rate, electrodermal activity, cortisol levels, and inflammatory cytokines [55]. Real-time tracking of these objective measures of stress could help identify patients who need social support and help providers monitor patients' stress throughout therapy. Overall, given the high prevalence of mood disorders in patients with cancer, the ability to diagnose psychosocial comorbidities at scale using digital tools could be a crucial means to deliver both social and pharmacologic interventions. This approach could potentially identify patients in need sooner, alleviate the workload required to diagnose psychosocial burdens in current practice, and reduce associated health care use.

The Role of Social Media Platforms in Social Support

Although support in the form of in-person interventions represents a significant portion of the social support provided, in-person programs may not be suitable for many patients. While in-person interventions have known benefits, accessibility to in-person social support groups is not always possible. Transportation, awareness of programs, the ongoing COVID-19 pandemic, or program availability could still hinder a patient's ability to attend physical social support groups. Further, the growing number of patients with cancer is greatly outpacing the capacity for care of the current health care system [56]. The health care system may not be able to physically provide social support for all patients that need it. New social support methods must be flexible enough to allow broad patient and caregiver access despite these limitations.

Unlike physical social support programs, digital support programs offer the potential for continuous access from the comfort of a patient's home without the presence of a physical HCP. While digital support programs may not have been broadly accessible a decade ago, the widespread adoption of computers and smartphones across almost every demographic in the United States enables access for the vast majority of patients with cancer [57]. Digital support programs have the potential to compensate for diminishing face-to-face physical interactions, while always providing an avenue for social support. Social media platforms have historically been used as outlets toward informal social support. Forum-style Facebook groups offer patients the opportunity to connect and form relationships with others who may have gone through or are going through similar experiences. Many platforms also allow users to form or join specific groups. These groups allow patients to find and interact with each other informally and in real time. Importantly, these platforms enable asynchronous interactions with other patients, giving them flexibility depending on when they want social

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support or can invest time into social support. Further, specific groups can be made within these platforms to support minority groups to overcome language or cultural barriers.

While social media platforms offer theoretical benefits, their impact on patients is highly variable. A systematic review found that while 48% of studies indicated benefits from social media platforms, 45% found the effects to be neutral, and 7% of studies actually suggested harm from their use [58]. Still, both patients with cancer and their caregivers have expressed that they wish to use social media for the purpose of both social and emotional support. In one study, caregivers specifically expressed that they wanted to form connections with other caregivers in similar situations with which to share experiences and information [59]. With that said, social media platforms also pose risks to patients and caregivers, including possible privacy and confidentiality concerns, no regulation to ensure that accurate medical information is conveyed, a propagation of negative health behaviors, and information overload [60]. Further, many groups on social media platforms may be hidden, hard to find, or private, which may make it difficult for all patients to benefit. A platform targeted for digital social support in oncology must protect health care information, increase awareness of social support, and improve accessibility to digital social support.

Recommendations

With smartphones and wearable connected devices now ubiquitous, using these devices for data collection is easier than ever to employ from a technological standpoint. Still, collected data must also be systematically translated into useful information for clinicians. Simply providing biomarkers to already-burdened providers will likely not amount to advancements in care delivery. Further research is needed to identify specific algorithms encompassing particular sets of biomarkers that can accurately identify psychosocial burdens in patients with cancer, while limiting required interventions from HCPs.

Once those who require social support are identified, flexible programs must be made available without relying on particular channels (eg, in-person support groups), as these may isolate certain patients or caregivers. Creating both accessible and scalable social support programs will be crucial to accommodate the rise in cancer diagnosis and to decrease the psychosocial impact of cancer on patients and their caregivers. Physical social support programs have established benefits, but these programs also have limitations, such as transportation, pandemic-related concerns, fixed group meeting times, and finite availability. Digital platforms can avoid these limitations and increase availability and accessibility of social support, even among minority groups.

Despite promise, funding for such digital biomarkers to identify social support needs, as well as the associated digital platforms to deliver social support, may be challenging. The economic benefit of providing social support through these avenues is not currently well established, and it is unclear whether health care payers would support new digitally based programs. Targeted research that specifically identifies concrete clinical and economic value in digital social support programs to foster further development is needed.

Conclusions

Despite the established benefits of social support programs, their use among patients with cancer is not widespread. Patients often do not seek social support when they need it or may not even know they need social support. Patients and the health care system alike are in desperate need of a more efficient method of identifying patients who need social support. Digital biomarkers collected via mobile or wearable devices offer an innovative, yet relatively facile, way of identifying a subset of patients that need social support.

Although the need for social support in patients with cancer is high, the current infrastructure to provide social support is largely underdeveloped and unable to accommodate patient needs for support. Health care systems are already struggling with capacity limitations to provide care for all patients. Tailored digital platforms can provide accessible social support, without straining the already-burdened health care system.

Authors' Contributions

JH, DK, TA, and CF were responsible for conceptualization of the study and reviewed and edited the manuscript. DK, JH, JP, and KP prepared the original manuscript draft. CF and TA were responsible for supervision of the study. CF was responsible for project administration. All authors have read and agreed to the published version of the manuscript.

Conflicts of Interest

None declared.

References

1. Crimmins EM. Lifespan and healthspan: Past, present, and promise. Gerontologist 2015 Dec;55(6):901-911 [FREE Full text] [doi: 10.1093/geront/gnv130] [Medline: 26561272]
2. Maresova P, Javanmardi E, Barakovic S, Barakovic Husic J, Tomsone S, Krejcar O, et al. Consequences of chronic diseases and other limitations associated with old age - A scoping review. BMC Public Health 2019 Nov 01;19(1):1431 [FREE Full text] [doi: 10.1186/s12889-019-7762-5] [Medline: 31675997]
3. Holman HR. The relation of the chronic disease epidemic to the health care crisis. ACR Open Rheumatol 2020 Mar;2(3):167-173 [FREE Full text] [doi: 10.1002/acr2.11114] [Medline: 32073759]

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4. de Moor JS, Mariotto AB, Parry C, Alfano CM, Padgett L, Kent EE, et al. Cancer survivors in the United States: Prevalence across the survivorship trajectory and implications for care. Cancer Epidemiol Biomarkers Prev 2013 Apr;22(4):561-570 [FREE Full text] [doi: 10.1158/1055-9965.EPI-12-1356] [Medline: 23535024]
5. Phillips JL, Currow DC. Cancer as a chronic disease. Collegian 2010;17(2):47-50. [doi: 10.1016/j.colegn.2010.04.007] [Medline: 20738055]
6. Siegel RL, Miller KD, Fuchs HE, Jemal A. Cancer statistics, 2021. CA Cancer J Clin 2021 Jan;71(1):7-33 [FREE Full text] [doi: 10.3322/caac.21654] [Medline: 33433946]
7. Sung H, Ferlay J, Siegel RL, Laversanne M, Soerjomataram I, Jemal A, et al. Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA Cancer J Clin 2021 May;71(3):209-249 [FREE Full text] [doi: 10.3322/caac.21660] [Medline: 33538338]
8. Li F, Luo S, Mu W, Li Y, Ye L, Zheng X, et al. Effects of sources of social support and resilience on the mental health of different age groups during the COVID-19 pandemic. BMC Psychiatry 2021 Jan 07;21(1):16 [FREE Full text] [doi: 10.1186/s12888-020-03012-1] [Medline: 33413238]
9. Ruiz-Rodríguez I, Hombrados-Mendieta I, Melguizo-Garín A, Martos-Méndez MJ. The association of sources of support, types of support and satisfaction with support received on perceived stress and quality of life of cancer patients. Integr Cancer Ther 2021;20:1-10 [FREE Full text] [doi: 10.1177/1534735421994905] [Medline: 33736509]
10. Shiba K, Kondo N, Kondo K. Informal and formal social support and caregiver burden: The AGES caregiver survey. J Epidemiol 2016 Dec 05;26(12):622-628 [FREE Full text] [doi: 10.2188/jea.JE20150263] [Medline: 27180934]
11. Sherman AC, Pennington J, Simonton S, Latif U, Arent L, Farley H. Determinants of participation in cancer support groups: The role of health beliefs. Int J Behav Med 2008;15(2):92-100. [doi: 10.1080/10705500801929601] [Medline: 18569127]
12. Ali SM, Merlo J, Rosvall M, Lithman T, Lindström M. Social capital, the miniaturisation of community, traditionalism and first time acute myocardial infarction: A prospective cohort study in southern Sweden. Soc Sci Med 2006 Oct;63(8):2204-2217. [doi: 10.1016/j.socscimed.2006.04.007] [Medline: 16797808]
13. Zhang X, Norris SL, Gregg EW, Beckles G. Social support and mortality among older persons with diabetes. Diabetes Educ 2007;33(2):273-281. [doi: 10.1177/0145721707299265] [Medline: 17426302]
14. Thong MSY, Kaptein AA, Krediet RT, Boeschoten EW, Dekker FW. Social support predicts survival in dialysis patients. Nephrol Dial Transplant 2007 Mar;22(3):845-850. [doi: 10.1093/ndt/gfl700] [Medline: 17164318]
15. Rodríguez-Artalejo F, Guallar-Castillón P, Herrera MC, Otero CM, Chiva MO, Ochoa CC, et al. Social network as a predictor of hospital readmission and mortality among older patients with heart failure. J Card Fail 2006 Oct;12(8):621-627. [doi: 10.1016/j.cardfail.2006.06.471] [Medline: 17045181]
16. Christian BJ, D'Auria JP. Building life skills for children with cystic fibrosis: Effectiveness of an intervention. Nurs Res 2006;55(5):300-307. [doi: 10.1097/00006199-200609000-00002] [Medline: 16980830]
17. Holt-Lunstad J, Smith TB, Layton JB. Social relationships and mortality risk: A meta-analytic review. PLoS Med 2010 Jul 27;7(7):e1000316 [FREE Full text] [doi: 10.1371/journal.pmed.1000316] [Medline: 20668659]
18. Uchino BN. Understanding the links between social support and physical health: A life-span perspective with emphasis on the separability of perceived and received support. Perspect Psychol Sci 2009 May;4(3):236-255. [doi: 10.1111/j.1745-6924.2009.01122.x] [Medline: 26158961]
19. Thoits PA. Mechanisms linking social ties and support to physical and mental health. J Health Soc Behav 2011 Jun;52(2):145-161. [doi: 10.1177/0022146510395592] [Medline: 21673143]
20. Heynsbergh N, Botti M, Heckel L, Livingston PM. Caring for the person with cancer and the role of digital technology in supporting carers. Support Care Cancer 2019 Jun;27(6):2203-2209. [doi: 10.1007/s00520-018-4503-8] [Medline: 30310987]
21. Reinhard SC, Young HM, Levine C, Kelly K, Choula RB, Accius JC. Home Alone Revisited: Family Caregivers Providing Complex Care. Washington, DC: AARP Public Policy Institute; 2019. URL: https://www.aarp.org/content/dam/aarp/ppi/2019/04/home-alone-revisited-family-caregivers-providing-complex-care.pdf [accessed 2021-11-20]
22. Southwick SM, Sippel L, Krystal J, Charney D, Mayes L, Pietrzak R. Why are some individuals more resilient than others: The role of social support. World Psychiatry 2016 Feb;15(1):77-79 [FREE Full text] [doi: 10.1002/wps.20282] [Medline: 26833614]
23. Ko H, Wang L, Xu Y. Understanding the different types of social support offered by audience to A-list diary-like and informative bloggers. Cyberpsychol Behav Soc Netw 2013 Mar;16(3):194-199 [FREE Full text] [doi: 10.1089/cyber.2012.0297] [Medline: 23363225]
24. Reblin M, Uchino BN. Social and emotional support and its implication for health. Curr Opin Psychiatry 2008 Mar;21(2):201-205 [FREE Full text] [doi: 10.1097/YCO.0b013e3282f3ad89] [Medline: 18332671]
25. Strom JL, Egede LE. The impact of social support on outcomes in adult patients with type 2 diabetes: A systematic review. Curr Diab Rep 2012 Dec;12(6):769-781 [FREE Full text] [doi: 10.1007/s11892-012-0317-0] [Medline: 22949135]
26. Shippee ND, Shah ND, May CR, Mair FS, Montori VM. Cumulative complexity: A functional, patient-centered model of patient complexity can improve research and practice. J Clin Epidemiol 2012 Oct;65(10):1041-1051 [FREE Full text] [doi: 10.1016/j.jclinepi.2012.05.005] [Medline: 22910536]

XSL•FO
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27. Tran V, Montori VM, Ravaud P. Is my patient overwhelmed?: Determining thresholds for acceptable burden of treatment using data from the ComPaRe e-cohort. Mayo Clin Proc 2020 Mar;95(3):504-512. [doi: 10.1016/j.mayocp.2019.09.004] [Medline: 31619365]
28. National Institute of Mental Health. Chronic Illness and Mental Health: Recognizing and Treating Depression. Bethesda, MD: US Department of Health and Human Services, National Institutes of Health; 2021. URL: https://www.nimh.nih.gov/sites/default/files/documents/health/publications/chronic-illness-mental-health/21-mh-8015-chronicillness-mentalhealth_1.pdf [accessed 2021-11-21]
29. Kent EE, Rowland JH, Northouse L, Litzelman K, Chou WS, Shelburne N, et al. Caring for caregivers and patients: Research and clinical priorities for informal cancer caregiving. Cancer 2016 Jul 01;122(13):1987-1995 [FREE Full text] [doi: 10.1002/cncr.29939] [Medline: 26991807]
30. Pitman A, Suleman S, Hyde N, Hodgkiss A. Depression and anxiety in patients with cancer. BMJ 2018 Apr 25;361:k1415. [doi: 10.1136/bmj.k1415] [Medline: 29695476]
31. Riba MB, Donovan KA, Andersen B, Braun I, Breitbart WS, Brewer BW, et al. Distress Management, Version 3.2019, NCCN Clinical Practice Guidelines in Oncology. J Natl Compr Canc Netw 2019 Oct 01;17(10):1229-1249 [FREE Full text] [doi: 10.6004/jnccn.2019.0048] [Medline: 31590149]
32. Korotkin BD, Hoerger M, Voorhees S, Allen CO, Robinson WR, Duberstein PR. Social support in cancer: How do patients want us to help? J Psychosoc Oncol 2019;37(6):699-712. [doi: 10.1080/07347332.2019.1580331] [Medline: 30929593]
33. Cipolletta S, Simonato C, Faccio E. The effectiveness of psychoeducational support groups for women with breast cancer and their caregivers: A mixed methods study. Front Psychol 2019;10:288 [FREE Full text] [doi: 10.3389/fpsyg.2019.00288] [Medline: 30833920]
34. Okati-Aliabad H, Ansari-Moghadam A, Mohammadi M, Kargar S, Shahraki-Sanavi F. The prevalence of anxiety and depression and its association with coping strategies, supportive care needs, and social support among women with breast cancer. Support Care Cancer 2022 Jan;30(1):703-710. [doi: 10.1007/s00520-021-06477-2] [Medline: 34365523]
35. Bright EE, Stanton AL. Prospective investigation of social support, coping, and depressive symptoms: A model of adherence to endocrine therapy among women with breast cancer. J Consult Clin Psychol 2018 Mar;86(3):242-253. [doi: 10.1037/ccp0000272] [Medline: 29265835]
36. Cutler RL, Fernandez-Llimos F, Frommer M, Benrimoj C, Garcia-Cardenas V. Economic impact of medication non-adherence by disease groups: A systematic review. BMJ Open 2018 Jan 21;8(1):e016982 [FREE Full text] [doi: 10.1136/bmjopen-2017-016982] [Medline: 29358417]
37. Kadambi S, Soto-Perez-de-Celis E, Garg T, Loh KP, Krok-Schoen JL, Battisti NML, et al. Social support for older adults with cancer: Young International Society of Geriatric Oncology review paper. J Geriatr Oncol 2020 Mar;11(2):217-224 [FREE Full text] [doi: 10.1016/j.jgo.2019.09.005] [Medline: 31628066]
38. Pinquart M, Duberstein PR. Associations of social networks with cancer mortality: A meta-analysis. Crit Rev Oncol Hematol 2010 Aug;75(2):122-137 [FREE Full text] [doi: 10.1016/j.critrevonc.2009.06.003] [Medline: 19604706]
39. Kroenke CH, Kwan ML, Neugut AI, Ergas IJ, Wright JD, Caan BJ, et al. Social networks, social support mechanisms, and quality of life after breast cancer diagnosis. Breast Cancer Res Treat 2013 Jun;139(2):515-527 [FREE Full text] [doi: 10.1007/s10549-013-2477-2] [Medline: 23657404]
40. Bertucci F, Le Corroller-Soriano A, Monneur-Miramon A, Moulin J, Fluzin S, Maraninchi D, et al. Outpatient cancer care delivery in the context of e-oncology: A French perspective on "cancer outside the hospital walls". Cancers (Basel) 2019 Feb 14;11(2):219 [FREE Full text] [doi: 10.3390/cancers11020219] [Medline: 30769858]
41. Sullivan AB, Miller D. Who is taking care of the caregiver? J Patient Exp 2015 May;2(1):7-12 [FREE Full text] [doi: 10.1177/237437431500200103] [Medline: 28725810]
42. Schulz R, Beach SR. Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. JAMA 1999 Dec 15;282(23):2215-2219. [doi: 10.1001/jama.282.23.2215] [Medline: 10605972]
43. Nightingale CL, Curbow BA, Wingard JR, Pereira DB, Carnaby GD. Burden, quality of life, and social support in caregivers of patients undergoing radiotherapy for head and neck cancer: A pilot study. Chronic Illn 2016 Sep;12(3):236-245 [FREE Full text] [doi: 10.1177/1742395316644305] [Medline: 27068111]
44. Spiegel D. Cancer and depression. Br J Psychiatry Suppl 1996 Jun(30):109-116. [Medline: 8864156]
45. Walker J, Hansen CH, Martin P, Symeonides S, Ramessur R, Murray G, et al. Prevalence, associations, and adequacy of treatment of major depression in patients with cancer: A cross-sectional analysis of routinely collected clinical data. Lancet Psychiatry 2014 Oct;1(5):343-350 [FREE Full text] [doi: 10.1016/S2215-0366(14)70313-X] [Medline: 26360998]
46. National Academies of Sciences, Engineering, and Medicine, Division of Behavioral and Social Sciences and Education, Health and Medicine Division, Board on Behavioral, Cognitive, and Sensory Sciences, Board on Health Sciences Policy, Committee on the Health and Medical Dimensions of Social Isolation and Loneliness in Older Adults. Social Isolation and Loneliness in Older Adults: Opportunities for the Health Care System. Washington, DC: National Academies Press; 2020.
47. Gudina AT, Cheruvu VK, Gilmore NJ, Kleckner AS, Arana-Chicas E, Kehoe LA, et al. Health related quality of life in adult cancer survivors: Importance of social and emotional support. Cancer Epidemiol 2021 Oct;74:101996. [doi: 10.1016/j.canep.2021.101996] [Medline: 34333220]

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48. Aoun SM, Breen LJ, Howting D. The support needs of terminally ill people living alone at home: A narrative review. Health Psychol Behav Med 2014 Jan 01;2(1):951-969 [FREE Full text] [doi: 10.1080/21642850.2014.933342] [Medline: 25750828]
49. Essue BM, Iragorri N, Fitzgerald N, de Oliveira C. The psychosocial cost burden of cancer: A systematic literature review. Psychooncology 2020 Nov;29(11):1746-1760 [FREE Full text] [doi: 10.1002/pon.5516] [Medline: 32783287]
50. Turner J, Kelly B. Emotional dimensions of chronic disease. West J Med 2000 Feb;172(2):124-128 [FREE Full text] [doi: 10.1136/ewjm.172.2.124] [Medline: 10693376]
51. Coravos A, Khozin S, Mandl KD. Developing and adopting safe and effective digital biomarkers to improve patient outcomes. NPJ Digit Med 2019;2(1):14 [FREE Full text] [doi: 10.1038/s41746-019-0090-4] [Medline: 30868107]
52. Place S, Blanch-Hartigan D, Rubin C, Gorrostieta C, Mead C, Kane J, et al. Behavioral indicators on a mobile sensing platform predict clinically validated psychiatric symptoms of mood and anxiety disorders. J Med Internet Res 2017 Mar 16;19(3):e75 [FREE Full text] [doi: 10.2196/jmir.6678] [Medline: 28302595]
53. Jacobson NC, Weingarden H, Wilhelm S. Digital biomarkers of mood disorders and symptom change. NPJ Digit Med 2019;2:3 [FREE Full text] [doi: 10.1038/s41746-019-0078-0] [Medline: 31304353]
54. Akechi T, Okuyama T, Sagawa R, Uchida M, Nakaguchi T, Ito Y, et al. Social anxiety disorder as a hidden psychiatric comorbidity among cancer patients. Palliat Support Care 2011 Mar;9(1):103-105. [doi: 10.1017/S1478951510000581] [Medline: 21352622]
55. Goodday SM, Friend S. Unlocking stress and forecasting its consequences with digital technology. NPJ Digit Med 2019;2:75 [FREE Full text] [doi: 10.1038/s41746-019-0151-8] [Medline: 31372508]
56. Shulman LN, Sheldon LK, Benz EJ. The future of cancer care in the United States-Overcoming workforce capacity limitations. JAMA Oncol 2020 Mar 01;6(3):327-328. [doi: 10.1001/jamaoncol.2019.5358] [Medline: 31971546]
57. Anderson-Lewis C, Darville G, Mercado RE, Howell S, Di Maggio S. mHealth technology use and implications in historically underserved and minority populations in the United States: Systematic literature review. JMIR Mhealth Uhealth 2018 Jun 18;6(6):e128 [FREE Full text] [doi: 10.2196/mhealth.8383] [Medline: 29914860]
58. Patel R, Chang T, Greysen SR, Chopra V. Social media use in chronic disease: A systematic review and novel taxonomy. Am J Med 2015 Dec;128(12):1335-1350. [doi: 10.1016/j.amjmed.2015.06.015] [Medline: 26159633]
59. Badr H, Carmack CL, Diefenbach MA. Psychosocial interventions for patients and caregivers in the age of new communication technologies: Opportunities and challenges in cancer care. J Health Commun 2015;20(3):328-342 [FREE Full text] [doi: 10.1080/10810730.2014.965369] [Medline: 25629218]
60. Attai DJ, Sedrak MS, Katz MS, Thompson MA, Anderson PF, Kesselheim JC, Collaboration for Outcomes on Social Media in Oncology (COSMO). Social media in cancer care: highlights, challenges & opportunities. Future Oncol 2016 Jul;12(13):1549-1552. [doi: 10.2217/fon-2016-0065] [Medline: 27025657]

Abbreviations

HCP: health care provider
QoL: quality of life

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Original Paper

Making National Cancer Institute–Designated Comprehensive Cancer Center Knowledge Accessible to Community Oncologists via an Online Tumor Board: Longitudinal Observational Study

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Abstract

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Background: Expert knowledge is often shared among multidisciplinary academic teams at tumor boards (TBs) across the country, but these conversations exist in silos and do not reach the wider oncology community.

Objective: Using an oncologist-only question and answer (Q&A) website, we sought to document expert insights from TBs at National Cancer Institute–designated Comprehensive Cancer Centers (NCI-CCCs) to provide educational benefits to the oncology community.

Methods: We designed a process with the NCI-CCCs to document and share discussions from the TBs focused on areas of practice variation on theMednet, an interactive Q&A website of over 13,000 US oncologists. The faculty translated the TB discussions into concise, non–case-based Q&As on theMednet. Answers were peer reviewed and disseminated in email newsletters to registered oncologists. Reach and engagement were measured. Following each Q&A, a survey question asked how the TB Q&As impacted the readers' practice.

Results: A total of 23 breast, thoracic, gastrointestinal, and genitourinary programs from 16 NCI-CCC sites participated. Between December 2016 and July 2021, the faculty highlighted 368 questions from their TBs. Q&As were viewed 147,661 times by 7381 oncologists at 3515 institutions from all 50 states. A total of 277 (75%) Q&As were viewed every month. Of the 1063 responses to a survey question on how the Q&A affected clinicians' practices, 646 (61%) reported that it confirmed their current practice, 163 (20%) indicated that a Q&A would change their future practice, and 214 (15%) reported learning something new.

Conclusions: Through an online Q&A platform, academics at the NCI-CCCs share knowledge outside the walls of academia with oncologists across the United States. Access to up-to-date expert knowledge can reassure clinicians' practices, significantly impact patient care in community practices, and be a source of new knowledge and education.

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KEYWORDS

National Cancer Institute–designated Comprehensive Cancer Centers; NCI-CCC; tumor boards; TBs; knowledge sharing; cancer; digital health; oncology; health websites; health education

Introduction

Cancer is the second leading cause of death in the United States [1]. The field of oncology is rapidly evolving, and it is difficult to stay up-to-date with the changing treatment paradigms. In 2017, the Food and Drug Administration (FDA) issued 58 new approval notifications in hematology/oncology—more than in any other field of medicine [2]. In 2019, 13 of the 48 novel drugs approved by the FDA were in the field of hematology/oncology [3]. As a result of the rapidly changing treatment practices, clinicians often have questions regarding the management of specific clinical scenarios [4]. However, clinical trials and clinical practice guidelines often do not answer questions on complex and nuanced clinical situations [5-7]. When clinicians search current resources and do not find an answer, they are often faced with having to make difficult clinical judgments without sufficient expertise in the particular clinical scenario [6]. Therefore, more than half of the questions go unanswered, which may result in inconsistent and poor quality of patient care [4-7]. Additionally, there is a lost opportunity for knowledge gaps to be identified and targeted.

In oncology, difficult clinical scenarios are often discussed within a multidisciplinary tumor board (TB). The TBs at the National Cancer Institute–designated Comprehensive Cancer Centers (NCI-CCCs) serve as excellent opportunities for experts to share their knowledge. These discussions can play a crucial role in impacting patient care and survival [8,9]. Unfortunately, the TB insights from experts at the NCI-CCCs are not systematically documented and disseminated in a way that is easily accessible to physicians in the community. This represents a lost opportunity to capture and share real-world questions, thoughtful discussions, and clinical expertise that can impact patient care in community centers. This paradigm can change using social networks, which have long been acknowledged as critical for the diffusion and adaptation of new information and experiential physician knowledge.

In other industries, social question and answer (Q&A) databases have become a method of knowledge creation and storage, which can be ranked via a search engine and discovered by all internet users. The most well-known examples of such databases are Stack Overflow and Quora, which owe their success to having significant user bases with deep expertise in their domains [10]. Building on the utility of Q&A databases, theMednet was developed in 2014 as a physician-only online platform with a mission to facilitate knowledge sharing from academic to community physicians in order for patients to get high-quality care despite where they are treated. It was designed for community oncologists to ask non–case-based clinical questions from experts and for the expert answers to be part of a large and searchable Q&A database that would be accessible at any time to physicians with similar questions. In effect, this would bring the Q&A process in medicine to an online platform and expose community clinicians to strong expert networks. It was started among radiation oncologists across the United States and then expanded to involve medical, surgical, and pediatric oncologists. Experts and community oncologists join theMednet through individual outreach, invitations from users, and word of mouth. All members are reviewed to ensure that they are US-based practicing oncologists. The platform is moderated by a team of deputy and associate editors who review every question, answer, and comment posted. TheMednet now contains over 10,000 clinical questions that cannot be easily answered based on a review of the literature, textbooks, or guidelines. Over 13,000 US radiation oncologists, medical oncologists, surgical oncologists, gynecologic oncologists, and

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pediatric oncologists are registered members, with 50% of registered physicians using the website at least once a month.

Having both an established community of academic and community oncologists and a content management system that routes questions to the appropriate experts and routes answers for appropriate peer review, theMednet is uniquely suited to capture and disseminate knowledge from the NCI-CCCs to community oncologists. We sought to use theMednet to document, discuss, and disseminate clinical knowledge from the TBs at the NCI-CCCs to the oncology community, using technology and best practices from online social networks.

Methods

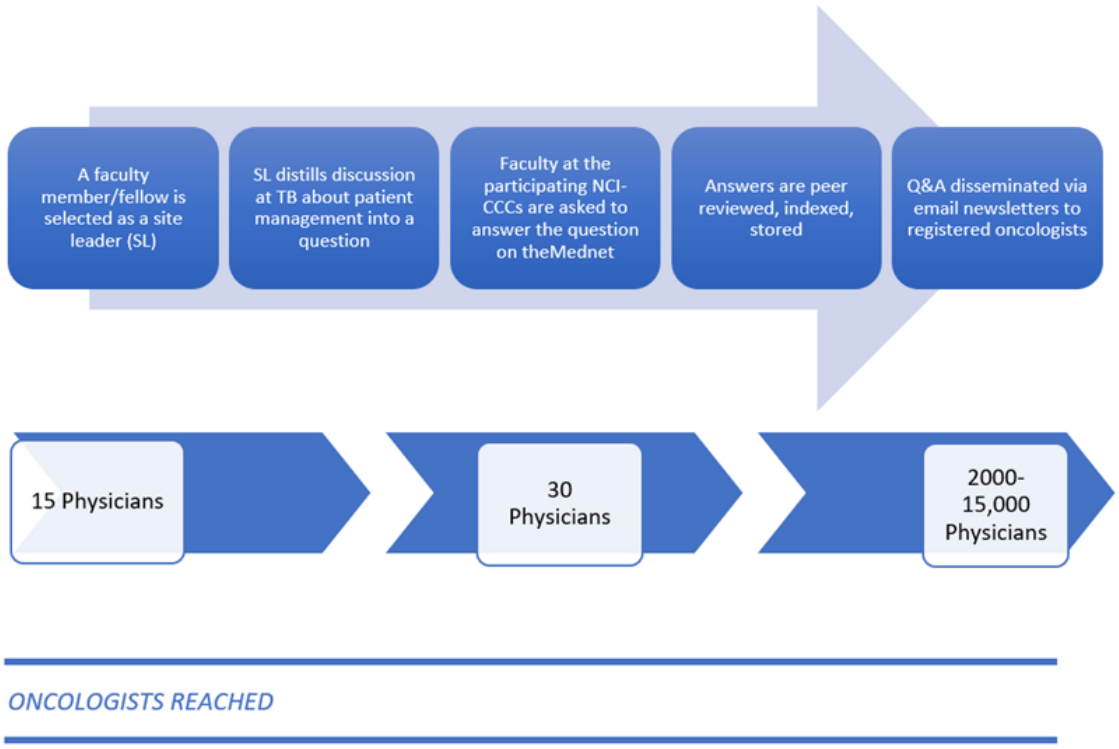
Overview

We hypothesized that the experts at the NCI-CCCs can systematically document and share experiential knowledge and best practices into actionable information in the form of searchable Q&As on theMednet. We also hypothesized that the Q&As from the TBs, in addition to the clinical Q&As from the community, have a long-lasting value to future users who will have similar questions, which may have otherwise gone unanswered. While the term "expert" may have many connotations and definitions, in the context of this application we define "expert" as an oncology specialist (medical, radiation, surgical, etc) with an academic appointment at a US university, who has published original research in his or her subspecialty (eg, breast cancer, prostate cancer, etc) or participates in clinical trials related to that specialty.

The program was initiated at a single site as a pilot program with the University of Texas MD Anderson Cancer Center (MDACC). In the pilot, we collaborated with the breast cancer faculty at the MDACC, an NCI-CCC treating over 135,000 patients with cancer a year, to jointly develop a process that distills, documents, and distributes important information from the TBs via theMednet. In this process, a junior faculty member was assigned as a "site leader" to post 1 question per week from the TB. The question would be routed to a physician editor who would then invite experts from the NCI-CCC and other academic cancer centers to answer the question. The answers would then be distributed to additional faculty for peer review. By the end of the week, the Q&A would be included in a weekly email newsletter and distributed to the physician members of theMednet. Through this process, a discussion among 15 to 20 physicians at a single time and place becomes part of a searchable repository of knowledge that provides long-lasting value to 500 times more physicians (Figure 1).

Once the program was successfully launched and running at the MDACC, further expansion was focused on breast cancer sites at NCI-CCCs across the country. Institutions designated as NCI-CCCs with a high level of engagement on theMednet were selected. In the next phase, the program was expanded to 5 sites in thoracic oncology, followed by 4 sites in gastrointestinal oncology and 4 sites in genitourinary oncology. At each site, a site leader was selected to distill discussions about patient management from the TB meetings into questions to be posted on theMednet. Experts from medical oncology, radiation oncology, and surgical oncology were invited to participate as experts from each site. Web- or phone-based training sessions for site leaders and expert physicians were held prior to each launch with further details provided below.

Figure 1. Methodology and potential reach. NCI-CCCs: National Cancer Institute–designated Cancer Centers; Q&A: question and answer, TB: tumor board.



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Information Creation and Quality Review

Site leaders were instructed to distill conversations about a patient case into one or more questions to be posted on theMednet. A training manual was provided to each site leader to explain how to write questions in a way that concisely addresses the clinical situation being discussed and not the specific patient case. Writing the questions in this manner facilities search queries and encourages the answer to be written in a way that applies to a broad range of patients, providing guidance and educational value to a greater number of physicians. It also removes any information that would violate the Health Insurance Portability and Accountability Act standards. Additionally, questions were required to be focused on nuanced clinical discussions, where there were no clear answers based on existing research and guidelines. If a similar question already existed in theMednet database, that old question was tagged as the "tumor board question" and then sent to the TB experts for updated answers as responses may have changed based on evolving data.

Once a question was posted on theMednet, it was sent to 3 or 4 physicians participating in the TB program via email to be answered. Answers were then shared with other experts nationwide for peer review. This process either built consensus around a course of action for a clinical situation or created a dialogue around best practices when there was no clear answer. The pool of experts for peer review included academic medical oncologists at the participating NCI-CCCs and academic medical oncologists across the country who had previously been recruited to answer questions from community oncologists. Q&As were reviewed and indexed by physician editors for easy search retrieval.

Information Dissemination and Ongoing Engagement

A customized email, highlighting new answers from the TB conference, was sent biweekly to oncologists registered on theMednet. Because of the increased volume of the Q&As over time, a daily digest was also created for users who opted to receive a daily, rather than a biweekly, email. The newsletter went out daily to 5617 medical and radiation oncologists. It was sent biweekly to 5018 medical and radiation oncologists. Questions were also included in weekly newsletters to 1277 pediatric and gynecologic oncologists if relevant to those specialists.

To provide feedback to experts answering questions and highlight their impact, a bimonthly custom report was created detailing the number of times their answers were read, the number of physicians their answers reached, and the number and names of the institutions their answers reached. The site leaders received an automated email just before their TB meeting every week to remind them to post a question, with the expectation of posting 1 question a month. A TB project manager individually contacted site leaders at each site at the end of a month if at least 1 question had not been received from them that month.

Target Audience and Dynamic Feedback

To help actively capture the opinions and real-world practices of oncologists using theMednet, 1-question polls were created for a number of TB questions. Community physicians also provided feedback by marking a question as a "good question" or indicating whether they "agree" with or find answers "helpful." An additional survey also captured whether the information in the Q&A had changed their practice or confirmed their current practice. Both the total views and the views per unique physicians for each individual Q&A were tracked over time.

Ethics Approval

This analysis was exempt from IRB review as it does not include human subjects research and involves secondary analysis of published online data. Impact surveys were issued by site personnel for the intent and purposes of improving services and programs for members. The privacy of users was protected, and confidentiality of individual responses was maintained throughout data collection and review. Results from data analysis are being presented in aggregate.

Results

The NCI-CCC Sites

The NCI-CCC breast cancer TB program was initially launched in December 2016 with the MDACC and expanded to include the University of Pittsburg Medical Center and the University of California, Los Angeles by April 2017. Between April 2017 and July 2021, the program was expanded to include a total of 23 breast, thoracic, and gastrointestinal programs at 16 NCI-CCCs indicated in Table 1. A total of 22 out of 23 TB programs were retained at the time of this publication. Only 1 program declined further participation because of the inability of a site leader to participate. The program grew from 38 involved academic physicians in 2017 (6 faculty members asked questions that were answered by 32 experts) to 131 academic physicians by July 2021 (16 faculty members asked questions that were answered by 69 experts.)

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Table 1. The National Cancer Institute–designated Comprehensive Cancer Center tumor board (TB) participating sites.

TB program	Participating sites
Breast cancer	MD Anderson Cancer Center; University of California, Los Angeles; Yale Cancer Center; University of Utah; University of Wisconsin; Columbia University Medical Center; The Ohio State University Medical Center; Moffitt Cancer Center; University of Iowa
Thoracic malignancies	Indiana University, The Ohio State University Medical Center, Yale Cancer Center, Vanderbilt University Medical Center, University of Michigan
Gastrointestinal malignancies	University of Wisconsin, Yale Cancer Center, Indiana University, Rutgers Health
Genitourinary malignancies	Duke University Medical Center; Vanderbilt University Medical Center; The Sidney Kimmel Comprehensive Cancer Center, Johns Hopkins University; University of California, San Francisco

Q&A Reach

Between December 2016 and July 2021, a total of 534 answers to 368 questions have been posted from these 23 programs from 16 NCI-CCC sites. Answers came from 123 academic physicians and were peer reviewed by 93 academic physicians. A total of 127 (35%) questions had more than 1 answer. Figure 2 shows a typical format of how a TB question, asked from a site leader, is answered by an expert from a different site and then peer reviewed by another expert in the field. These Q&As were viewed 147,661 times by the oncologists at 3515 institutions from all the 50 states of the United States, including 5131 community oncologists (Figure 3). A total of 227 (75%) Q&As were viewed every month. Answers to 22 questions were updated at least 6 months after the initial answers due to evolving data in the field.

A total of 431 clinicians agreed with the answers 1773 times, and 545 physicians found them helpful 1321 times. Editors created 88 (24%) real-world practice poll questions out of these Q&As. These poll questions asked for the clinical opinion of the oncologists about a particular scenario (Figure 4). A total of 2116 clinicians voted in these polls with 7789 votes.

A total of 231 (43%) answers cited published data with 328 publications cited. Nearly 303 (60%) of the answers cited clinical experience, highlighting the frequency with which oncologists encounter scenarios not adequately addressed by the current evidence. Customized emails with new Q&As resulted in a visit to the website an average of 15% of the time (7 times the industry average) [11].

Figure 2. Example of a question asked in the breast cancer tumor board program with an expert response and peer review. ER: estrogen positive; PR: progesterone positive.

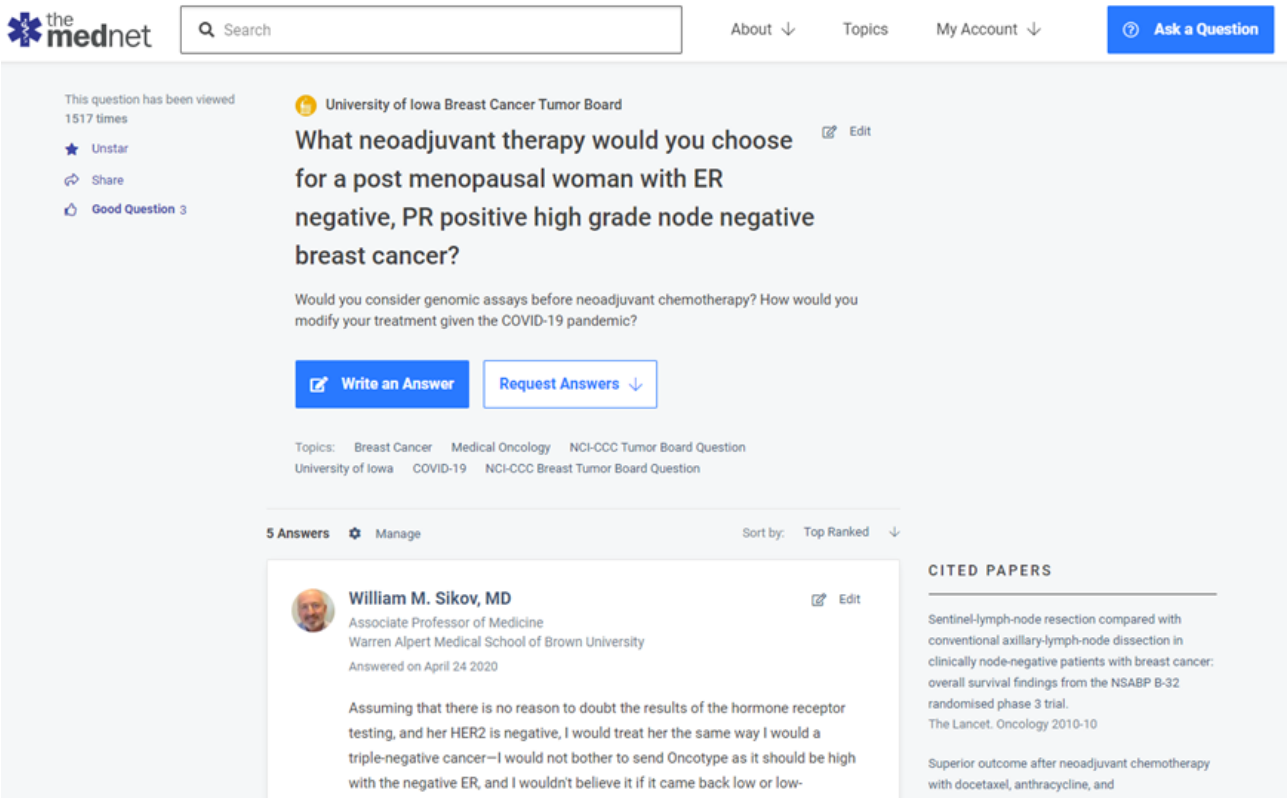

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Figure 3. Map of the United States showing the reach of tumor board program.

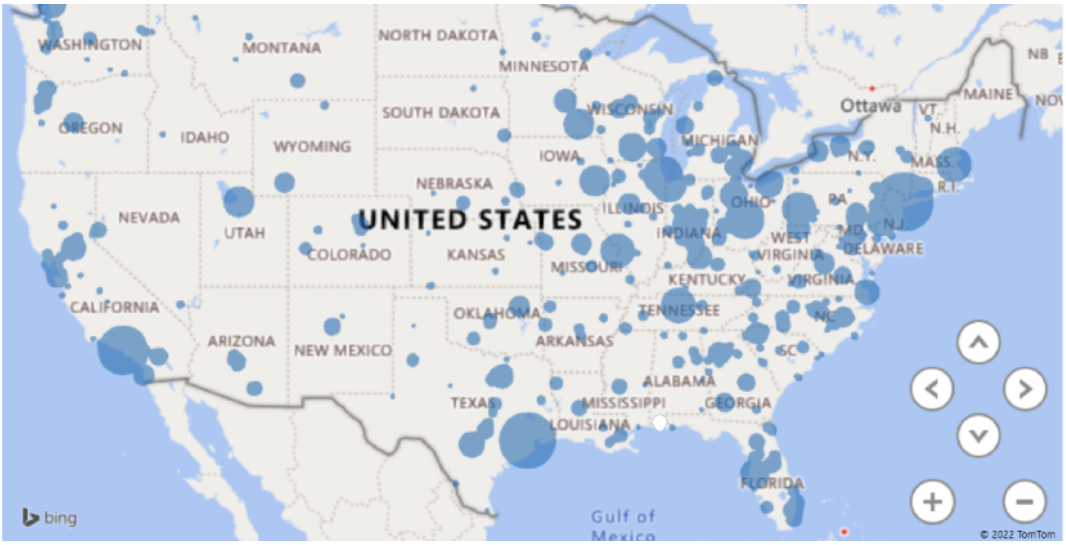
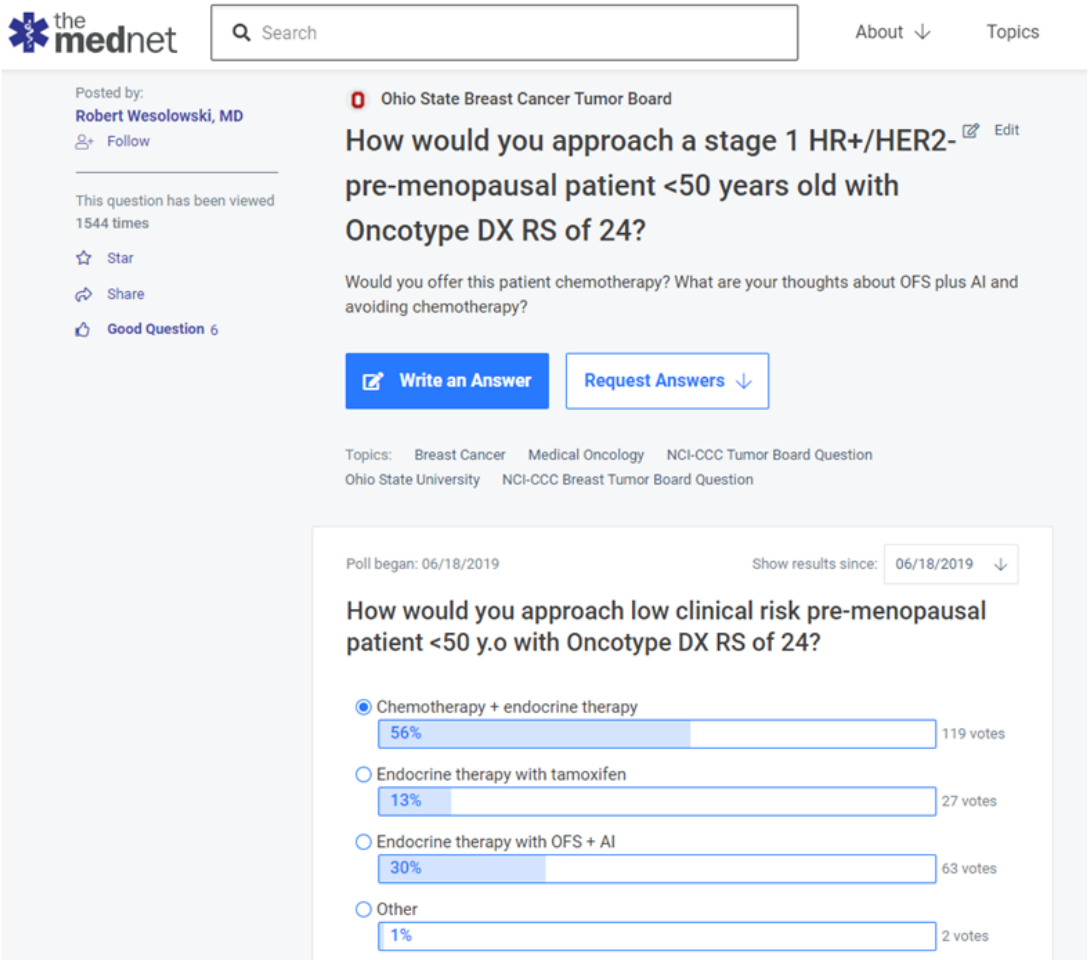


Figure 4. Example of a real-world practice poll question with responses. HER2: human epidermal growth factor receptor 2; HR: hormone receptor; oncotype DX; 21 gene recurrence score; RS: recurrence score.



Dynamic Feedback

We conducted a short survey on how the Q&As impacted the clinicians' practice. The survey questions were posted at the end of each Q&A page and were open to response by the viewers. The impact survey questions are listed in Figure 5. Of the 1063 responses to a survey on how the Q&As affected clinicians' practice, 646 (61%) reported that it confirmed their current practice, 163 (20%) indicated that a Q&A would change their future practice, 214 (15%) reported learning something new, 20 (2%) indicated that their practice differs, and 20 (2%) chose "other" as their response. Multimedia Appendix 1 shows a pie graph of all the impact survey question responses.

Table 2 summarizes the number of views and the number of oncologists engaged over time. We have found that both the

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Q&A views and the number of oncologists viewing the TB Q&As increased over time. A total of 277 (75%) of all the TB Q&As were viewed every month.

In February 2020, qualitative feedback was sought from 8 site leaders. Standardized questions were developed and focused on process improvement. Sample questions included "Would you recommend this program to other NCI-CCC sites? Why or why not?" and "What are some barriers to posting questions?" Eight out of the 8 site leaders stated they would recommend this program to other NCI-CCCs. Some of the feedback was that the program "opened up conversations at our institution"; "has helped expand my knowledge base"; "helps hearing what is going on at other sites"; and "some answers don't have the strongest evidence but it is good to know who agrees." The most common barriers to posting a question routinely were (1) the time to distill a clinical scenario into a broad-based question and (2) not being able to identify a good question from the TB. Of the 8 site leaders, 7 found automated email reminders useful to remember to think of a question to share during the TB discussions.

Figure 5. Impact survey questions.

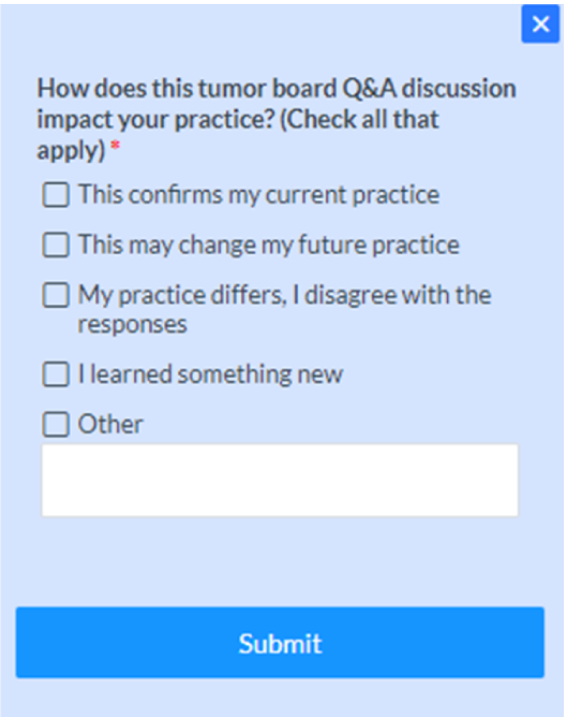

Table 2. Community oncologists' engagement over time.

Year	Oncologists viewing the TB[a] Q&As[b], n	TB Q&A views, n
2016	172	361
2017	844	4792
2018	3010	24,886
2019	3616	39,550
2020	4749	49,941

[a]TB: tumor board.

[b]Q&A: question and answer.

Discussion

Oncology is a constantly evolving field of medicine, and oncologists deal with complex patients and clinical scenarios every day due to increased patient comorbidities and age, rapidly evolving changes in care standards, and the emergence of complex genome-guided, personalized therapies [12,13]. As a result of increasing patient complexity, current evidence and practice guidelines may not be directly applicable to many patients [12]. Physicians cite expert authorities as the best source for questions on complex clinical situations [6,7]. Questions to experts tend to be about nuanced patient situations and often require guidance, affirmation, judgment, and feedback [14]. However, expert insights are often not readily accessible to community physicians who treat 80% of patients with cancer in the United States [15]. Additionally, while there is a systematic process of documenting the best research evidence in journals and textbooks, there exists no centralized way of documenting and disseminating clinical expertise; it is found in conversations in conferences, hospital hallways, emails, and on the telephone. This valuable experiential knowledge is shared

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socially among colleagues, but it never makes its way to the greater community through an indexed and searchable database.

In most cancer centers, difficult clinical questions are discussed at multidisciplinary TBs in which peer expertise is shared. TBs are the central forums for decision-making in situations where there is limited evidence and in which patients have confounding factors. At the NCI-CCC, the TBs are more than a place for decision-making. They are acknowledged as a place for disseminating knowledge [16], generating ideas that lead to research projects, raising awareness of clinical trials [17], highlighting nuances in diagnostic approaches and treatment, educating oncology teams, and discussing existing controversies in treatments [8].

TheMednet has emerged as a novel physician-only website that has given oncologists a platform to ask and search answers to complex clinical questions. In collaboration with the TBs at the NCI-CCC, academics have shared knowledge outside the walls of 23 academic programs with oncologists across the United States. Over the course of 4+ years, discussions from these TBs have reached over 7000 oncologists across all 50 states of the United States. It is exemplary of how technology is helping to break down health disparities and achieve health equity. The discussions happening at major academic institutions have helped oncologists treat patients in rural settings, without the need for those patients to travel across the country. The observation that more than three quarters of these Q&As were viewed every month indicates that these clinically relevant Q&As provide value for weeks, months, and even years after they are posted. Answers are frequently updated as practices evolve, and new data become available. Our data indicate a high level of engagement from community oncologists and a high retention rate among the participating NCI-CCCs, with direct feedback from academic site leaders indicating high satisfaction with continued learning and professional growth. Additionally, when asked about the impact of the TB Q&As, 1 in 5 responses indicate that these Q&As may change oncologists' future practice.

This program has been unique as it involves active participation and interaction of academic and community oncologists. Additionally, the answers display how academic physicians incorporate current guidelines and evidence into their clinical practice based on their years of experience and research in the field. This access to up-to-date expert knowledge helps community oncologists with clinical decision-making by affirming their current practices, teaching them new information they did not previously know, and changing clinical practices. To our knowledge, this represents the only searchable repository of expert knowledge on areas of controversy in oncology, accessible to oncologists throughout the United States.

This program has gained unprecedented prominence and popularity in the 4 years since its launch, and engagement continues to increase over time. Future efforts will be focused on involving more NCI-CCCs in the program, expanding to additional disease sites such as pediatric and gynecologic oncology, in addition to malignant hematology, and international expansion to reach non–US-based physicians. Additionally, qualitative and quantitative studies will investigate how regular exposure to knowledge at the NCI-CCCs impacts patient care in community settings.

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Authors' Contributions

MK and NH conceptualized and designed the project. MK wrote the manuscript, and NH reviewed the manuscript. MK, NH, KM, MSK, JGA, AP, RW, MW, SSM, GAD, AQ, CS, MST, AJA, FHW, WTI, AAT, PV, MC, SL, P Pathak, KS, HS, VSK, MKL, CHM, KEB, DT, DLH, GAO, BR, DC, SJ, N Hanna, KK, AT, GH, CHB, KW, ML, LH, KDC, DHO, BL, BA, P Peddi, JL, PRH, SG, NLH, SSB, AC, NU, MS, AB, and SH contributed to the implementation of the project. MK, VH, and SH conducted data analysis. EH reviewed the manuscript and the data. The following authors are a part of theMednet.org NCI-CCC Tumor Board Program Collaborative Group. They were involved in providing their expert opinions during the Tumor Boards at the various NCI-CCC sites: Hatem Soliman, Debasish Tripathy, Dawn L Hershman, Gregory A Otterson, Bhuvaneswari Ramaswamy, David Carbone, Shadia Jalal, Nasser Hanna, Kevin Kalinsky, Amye Tevaarwerk, Carlos H. Barcenas, Kari Wisinski, Maryam Lustberg, Leora Horn, Katherine D Crew, Dwight H Owen, Bora Lim, Banu Arun, Parvin Peddi, Jill Lacy, Paul R Helft, Shirish Gadgeel, N Lynn Henry, Saundra S Buys, Anne Chiang, and Naoto Ueno.

Conflicts of Interest

NH and SH are the cofounders of theMednet website. NH is also the chief medical officer of theMednet and had support from theMednet to present preliminary findings at the American Society of Clinical Oncology (ASCO) Quality Care Symposium in 2019. MK had support from theMednet to present preliminary findings at the ASCO annual research meeting. AB received a monthly stipend as theMednet's deputy editor of medical oncology. EH receives support from theMednet to attend education sessions such as the ASCO, and is an employee of theMednet. VH receives a monthly stipend from theMednet, Inc. FHW reports personal fees from Loxo Oncology and grants from Agios outside the submitted work. MC reports receive honoraria from Eisai

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Inc, Agios Pharmaceuticals, AstraZeneca, GRAIL, Aptitude Health, and DAVA Oncology. MC also holds equity in Parthenon Therapeutics Inc, and receives salary support on a National Cancer Institute Career Development Award (1K08CA255465-01A1). CHM receives fees from Obseva, Astellas, Bayer, Dendreon, and McGraw-Hill (outside the scope of this work). ACB is the Deputy Editor of Medical Oncology for theMednet. Other authors do not have any relevant conflicts of interest to report. MSK is consulting with Gilead and Lily.

Multimedia Appendix 1
Responses to impact survey questions.
[PNG File , 67 KB - cancer_v8i2e33859_app1.png]

References

1. Siegel RL, Miller KD, Jemal A. Cancer statistics, 2019. CA A Cancer J Clin 2019 Jan 08;69(1):7-34. [doi: 10.3322/caac.21551]
2. Oncology (cancer)/ hematologic malignancies approval notifications. FDA. URL: https://www.fda.gov/drugs/resources-information-approved-drugs/oncology-cancer-hematologic-malignancies-approval-notifications [accessed 2018-07-24]
3. New drug therapy approvals 2019. FDA. URL: https://www.fda.gov/drugs/new-drugs-fda-cders-new-molecular-entities-and-new-therapeutic-biological-products/new-drug-therapy-approvals-2019 [accessed 2022-03-31]
4. Del Fiol G, Workman TE, Gorman PN. Clinical questions raised by clinicians at the point of care: a systematic review. JAMA Intern Med 2014 May 01;174(5):710-718. [doi: 10.1001/jamainternmed.2014.368] [Medline: 24663331]
5. Bennett N, Casebeer LL, Zheng S, Kristofco R. Information-seeking behaviors and reflective practice. J Contin Educ Health Prof 2006;26(2):120-127. [doi: 10.1002/chp.60] [Medline: 16802313]
6. Cook DA, Sorensen KJ, Wilkinson JM, Berger RA. Barriers and decisions when answering clinical questions at the point of care: a grounded theory study. JAMA Intern Med 2013 Dec 25;173(21):1962-1969. [doi: 10.1001/jamainternmed.2013.10103] [Medline: 23979118]
7. Ely J, Osheroff JA, Maviglia SM, Rosenbaum ME. Patient-care questions that physicians are unable to answer. J Am Med Inform Assoc 2007;14(4):407-414 [FREE Full text] [doi: 10.1197/jamia.M2398] [Medline: 17460122]
8. Gatcliffe T, Coleman R. Tumor board: more than treatment planning—a 1-year prospective survey. J Cancer Educ 2008;23(4):235-237. [doi: 10.1080/08858190802189014] [Medline: 19058072]
9. Bristow RE, Chang J, Ziogas A, Campos B, Chavez LR, Anton-Culver H. Impact of national cancer institute comprehensive cancer centers on ovarian cancer treatment and survival. J Am Coll Surg 2015 May;220(5):940-950 [FREE Full text] [doi: 10.1016/j.jamcollsurg.2015.01.056] [Medline: 25840536]
10. Anderson AH. Discovering value from community activity on focused question answering sites: a case study of stack overflow. 2012 Presented at: KDD '12: Proceedings of the 18th ACM SIGKDD International Conference on Knowledge Discovery and Data Mining; August 12-16; Beijing, China p. 850-858. [doi: 10.1145/2339530.2339665]
11. Richardson M, Dominowska E, Robert R. Predicting clicks: estimating the click-through rate for new ads. 2007 Presented at: WWW '07: Proceedings of the 16th International Conference on World Wide Web; May 8-12; Banff, AB p. 521-530. [doi: 10.1145/1242572.1242643]
12. Sarfati D, Koczwara B, Jackson C. The impact of comorbidity on cancer and its treatment. CA Cancer J Clin 2016 Jul 17;66(4):337-350 [FREE Full text] [doi: 10.3322/caac.21342] [Medline: 26891458]
13. Meric-Bernstam F, Johnson A, Holla V, Bailey AM, Brusco L, Chen K, et al. A decision support framework for genomically informed investigational cancer therapy. J Natl Cancer Inst 2015 Jul;107(7) [FREE Full text] [doi: 10.1093/jnci/djv098] [Medline: 25863335]
14. Smith R. What clinical information do doctors need? BMJ 1996 Oct 26;313(7064):1062-1068 [FREE Full text] [doi: 10.1136/bmj.313.7064.1062] [Medline: 8898602]
15. Pfister DG, Rubin DM, Elkin EB, Neill US, Duck E, Radzyner M, et al. Risk adjusting survival outcomes in hospitals that treat patients with cancer without information on cancer Stage. JAMA Oncol 2015 Dec 01;1(9):1303-1310 [FREE Full text] [doi: 10.1001/jamaoncol.2015.3151] [Medline: 26448610]
16. Siderits R, Yates S, Rodriguez A, Lee T, Rimmer C, Roche M. Embedding QR codes in tumor board presentations, enhancing educational content for oncology information management. J Registry Manag 2011;38(4):209-211. [Medline: 23270096]
17. Coe K, Wilson C, Eisenberg M, Attakai A, Lobell M. Creating the environment for a successful community partnership. Cancer 2006 Oct 15;107(8 Suppl):1980-1986 [FREE Full text] [doi: 10.1002/cncr.22156] [Medline: 16929483]

Abbreviations

ASCO: American Society of Clinical Oncology
FDA: Food and Drug Administration
MDACC: MD Anderson Cancer Center

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NCI-CCC: National Cancer Institute–designated Comprehensive Cancer Center
Q&A: question and answer
TB: tumor board

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Original Paper

Identifying Themes for Assessing Cancer-Related Cognitive Impairment: Topic Modeling and Qualitative Content Analysis of Public Online Comments

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Abstract

Background: Cancer-related cognitive impairment (CRCI) is a common and significant adverse effect of cancer and its therapies. However, its definition and assessment remain difficult due to limitations of currently available measurement tools.

Objective: This study aims to evaluate qualitative themes related to the cognitive effects of cancer to help guide development of assessments that are more specific than what is currently available.

Methods: We applied topic modeling and inductive qualitative content analysis to 145 public online comments related to cognitive effects of cancer.

Results: Topic modeling revealed 2 latent topics that we interpreted as representing internal and external factors related to cognitive effects. These findings lead us to hypothesize regarding the potential contribution of locus of control to CRCI. Content analysis suggested several major themes including symptoms, emotional/psychological impacts, coping, “chemobrain” is real, change over time, and function. There was some conceptual overlap between the 2 methods regarding internal and external factors related to patient experiences of cognitive effects.

Conclusions: Our findings indicate that coping mechanisms and locus of control may be important themes to include in assessments of CRCI. Future directions in this field include prospective acquisition of free-text responses to guide development of assessments that are more sensitive and specific to cognitive function in patients with cancer.

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KEYWORDS

cognitive; natural language processing; cancer; oncology

Introduction

A condition known colloquially as *chemobrain*, cancer-related cognitive impairment (CRCI) affects an estimated 60% or more of patients with cancer [1,2]. CRCI is an interesting illustration of the significant effects that systemic disease or its therapies can have on brain function. Cognitive deficits decrease quality of life in patients with cancer and are independent predictors of survival [3-5]; however, assessment of CRCI remains challenging. Specifically, despite the significant and widespread brain changes observed in neuroimaging studies of CRCI, behavioral assessments show less consistent effects [6-8].

Objectively, CRCI is primarily assessed using standardized neuropsychological testing. However, these measures tend to have poor ecological validity [9-11] and may lack adequate sensitivity and specificity for CRCI [12]. Self-report measures tend to be more sensitive to CRCI, but have their own set of disadvantages in terms of administration and interpretation [13] and also do not always detect CRCI [14]. Most existing assessments are not cancer specific, and therefore, they may

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not sufficiently include themes or domains that are important to cancer survivors. Qualitative research is best suited for uncovering such themes but has been limited to date in this field.

The aim of this study was to elucidate qualitative themes surrounding the cognitive effects of cancer to better inform development of cancer-specific self-report assessments. We employed 2 text analysis approaches: topic modeling and traditional content analysis. Both methods use unstructured, free-text responses to assess symptoms and functioning. Topic modeling is a text mining technique that seeks to interpret the rich data inherent in written language using machine learning algorithms to identify important themes, or topics [15]. This method removes some of the labor-intensive aspects of traditional qualitative analysis by automatically quantifying subjective information. However, the meaning and relevance of the generated topics must be deduced, and therefore, some qualitative aspects remain. Topic modeling has been used to evaluate depression, anxiety, and other symptoms from public comments in social media posts [16,17]. Importantly, public online comments have also been used to detect early signs of cognitive decline [18]. We sought to evaluate a similar approach for investigating CRCI given the advantages that it affords, including access to a large data set that is without cost, representation of a wide variety of individuals, and reduced bias related to assessment context [16].

Traditional qualitative content analysis is used to describe phenomena and generate evidence for larger quantitative descriptive studies or for theory generation [19]. Researchers code narrative data to determine the existence and frequency of concepts within the text. This is an inductive process as broad categories are generalized from the specific content that is identified in the data. Qualitative content analysis has been employed in a few prior studies of CRCI [9,20-24], but studies employing quantitative methods are far more common. Further, previous qualitative studies were not used to guide development of CRCI assessments. We aimed to demonstrate how qualitative themes can provide novel insights regarding patient experiences with CRCI that could potentially inform the development of cancer-specific assessments in the future.

Methods

Topic Modeling

We identified 10 public online forums by conducting internet searches with the terms *chemobrain*; *cancer*; *cognition*; *survivorship*; and *supportive care*. These forums consisted largely of group discussions/conversations regarding cancer survivorship–related topics but also included responses to online articles about *chemobrain*. We extracted comments using automated data scraping functions in the R Statistical Package version 4.0.2 (R Foundation). Comments were cleaned (removed contractions, symbols, links, stop words [eg, *the*, *has*, *this*]) and converted to a document-term matrix for topic modeling, again using automated functions in R. Latent topics were discovered using latent Dirichlet allocation [25] with Gibbs sampling. This yielded a probability that a forum comment belonged to a particular latent topic. Topics, in this context, are groups of words that are related to each other. There is no standard for determining the optimal number of topics to look for. Therefore, we examined the rate of perplexity change across a range of topic values to estimate the optimal number of topics [26]. Latent Dirichlet allocation was conducted in R using the *topicmodels* library.

Content Analysis

The forum responses were aggregated into a single transcript and reviewed independently by 2 of the coauthors (AMH and WT) using an inductive qualitative content analysis approach [19,27,28]. This approach allows for the distillation of words into fewer content-related categories, which is done manually [28]. Each coauthor read through the entire transcript at least once to become familiar with the data, then initiated the line-by-line coding process. The units of analysis were words and phrases. Codes were inductively grouped into larger categories that emerged directly from the data, without an organizing framework, noting quotes from participants illustrating the categories [28]. The coauthors then met to compare and collapse categories and complete the abstraction process. Abstraction involves forming general descriptions and meanings of the final categories [28]. AMH and WT were kept blinded to the topic modeling results so that their findings would not be influenced by the topic modeling.

Ethics Approval

This study utilized public data that do not require institutional review board approval.

Results

Overview

We identified 145 online forum comments. Comments were posted by single online usernames, and all included first-person pronouns (eg *I*, *my*). Thus, comments were assumed to represent 145 individuals. Comments had a mean word count of 146 (SD 65).

Topic Modeling

As shown in Figure 1, topic modeling identified 2 latent topics that we qualitatively interpreted, by consensus, as representing *external* (topic 1) and *internal* (topic 2) factors related to individuals' concerns about cognitive functioning. These findings lead us to hypothesize regarding the potential contribution of locus of control to CRCI.

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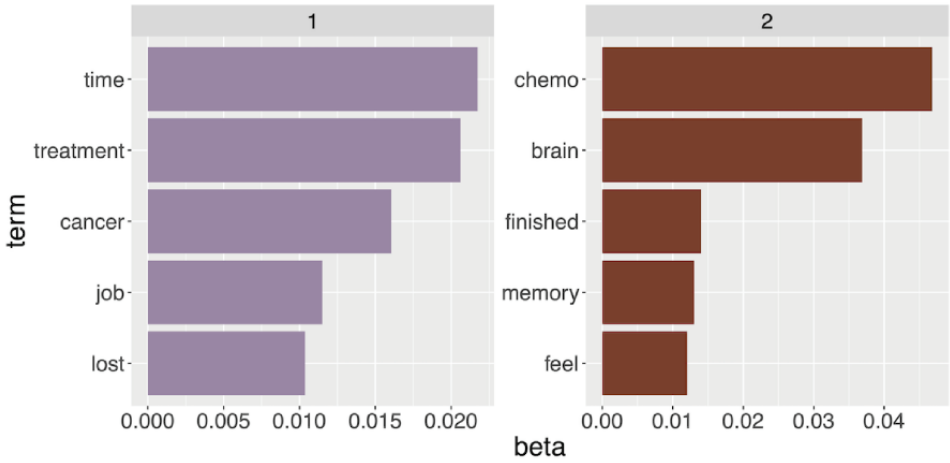
Figure 1. Topic modeling of free-text comments. Latent Dirichlet allocation (LDA) analysis of online comments identified 2 topics related to cognitive effects of cancer and its treatments. Beta = probability that the term belongs to that topic. We interpreted topic 1 as reflecting external factors and topic 2 as indicating internal factors leading us to hypothesize regarding potential contribution of locus of control to subjective cognitive impairment. Figure created using ggplot in the R Statistical Package.



Content Analysis

Major Categories

The following major categories were identified: *symptoms*, *emotional/psychological impacts*, *coping*, *"chemobrain" is real*, *change over time*, and *function*.

Symptoms

The online comments largely described cognitive symptoms along with related physical symptoms (eg, fatigue, neuropathy). The most common cognitive symptom discussed was impaired memory, specifically trouble with short-term memory or remembering things "on the fly." One person described, a "Total inability to cope with remembering things" and another said, "My mind couldn't remember things that used to be easy for me." Other comments frequently mentioned word-finding problems, difficulty concentrating, and a slowness or lack of mental sharpness/speed. People also suggested explanations other than chemotherapy for their symptoms such as other cancer treatments (eg, tamoxifen, radiation), having too much on their plates (ie, information overload), getting older, or developing dementia.

Emotional/Psychological Impact

Throughout the online comments, many people discussed the strong emotional and psychological impacts of their cognitive symptoms and changes. These were sometimes described in the context of feeling worried, upset, anxious, or scared of their cognitive symptoms. Other times symptoms were described in the context of extreme frustration, feelings of anger, and being overly stressed. One person said, "It's a total frustration" and another said, "I am really suffering." Additionally, many described feelings of embarrassment, loss of confidence or self-reliance, or even feeling nervous about their own cognitive performance. One person illustrated this point by saying, "Cancer and memory loss can corrode my intellectual self-esteem and only compound the problem."

Coping

Many people referenced ways of coping with their cognitive changes by engaging in brain-healthy behaviors such as exercise, stress reduction, or puzzles. Others referenced using different medications such as Ritalin, or supplements (eg, CoQ10) to improve their cognitive stamina and function. Others talked about utilizing compensatory strategies for better functioning in their everyday lives such as making lists, using smartphone capabilities, slowing down, and planning more.

"Chemobrain" Is Real

Most of the online comments related to the idea of validating that chemobrain, or cognitive changes related to cancer and cancer treatment, are very real. Different words were used to describe the phenomenon such as "chemo haze," "chemo fog," a "scrambled brain," and "brain is total mush." Some people voiced frustration with lack of awareness or validation from their providers and noted that, "it would have helped if there had been more awareness [about chemobrain]". Similarly, people made sure to emphasize that those suffering from chemobrain are not alone. For example, one person said, "Don't feel you have to cope with this on your own" and another said, "we are with you".

Change Over Time

A common theme that emerged from the online comments was the experience of cognitive function changing over time. For instance, many people described ongoing cognitive difficulties since the end of their treatments and in some cases declining or getting worse over time. By contrast, others described improvements in cognitive difficulties since their treatments ended, saying they are "doing better with time". Others described cognitive symptoms as getting worse throughout individual days, with better functioning in the morning and dysfunction in the evenings or when they were tired.

Function

Finally, many of the online comments centered around the theme of functioning in their everyday lives—from social and interpersonal interactions to occupational performance and in

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many cases debilitation, or lack of function. One person said, "I can sit and listen to someone talk and then it's like I feel thick, like I just don't understand what's being said." Others talked about slow returns to work, workload reduction, and lack of ability to do the work they did prior to their cancer. Several people described losing their jobs due to their cognitive problems and inability to function at previous levels. Some talked about an inability to do the things they wanted to in their lives, or a loss of the person they were prior to their treatments. One person said, "I wish I could be my old self."

Discussion

Principal Findings

We evaluated public online comments regarding CRCI for qualitative themes using both topic modeling and content analysis. The goal of this study was to demonstrate how qualitative themes can provide novel insights regarding patient experiences with CRCI that could potentially inform the development of cancer-specific self-report assessments. Topic modeling identified 2 topics from online comments that we interpreted as representing "internal" and "external" factors related to CRCI. Taken together, these topics suggested the potential importance of locus of control when considering CRCI symptoms.

A previous qualitative study regarding CRCI also identified perceived control as a major theme derived from interviews with 12 participants [29]. Locus of control regarding health has been shown to be important for cancer survivorship [30] and quality of life [31], and is correlated with self-management behaviors [32,33]. Importantly, locus of control has been shown to be a modifiable factor in cognitive function [34]. One study found a correlation between internal locus of control and self-reported cognitive function in patients with colorectal cancer [35]. Internal locus of control is associated with adaptive coping [36], likely because it engenders a greater sense of agency and mastery over one's situation. However, no studies have examined the relationship between locus of control, coping mechanisms, and cognitive impairment in patients with cancer.

A total of 6 categories were identified using content analysis including symptoms, emotional/psychological impacts, coping, "chemobrain" is real, change over time, and function. Our findings support themes identified in previous qualitative studies of CRCI such as cognitive symptoms, negative emotional reactions to cognitive changes, major negative effects on quality of life, trying different coping strategies, and a need for validation [9,20-24]. However, our sample was much larger as most previous qualitative studies have been conducted with samples of 10-25 participants. The largest study to date involved a total of 74 breast cancer survivors [9]. Our study findings summarize experiences of approximately 145 individuals, representing the largest qualitative study on *chemobrain* to our knowledge. Second, content analysis is typically used to analyze data collected through individual interviews or small focus groups. Our use of content analysis to evaluate a large volume of public comments is novel.

Our results indicated that each text analysis method provides unique information and insights. Topic modeling indicated 2 topics, or categories, while content analysis indicated 6 categories. While the number of categories is different, there was conceptual overlap in the categories. For example, the content analysis categories *symptoms*, *emotional/psychological impacts*, and *coping* could align with the *internal* topic, while *"chemobrain" is real*, *change over time*, and *functioning* could align with the *external* topic. In fact, both techniques pointed to the importance of coping mechanisms as a significant theme.

As content analysis is used to develop an understanding of the meaning of the intentions, consequences, and contexts of the words [19,27,28], the findings are inherently richer and can be considered more "macroscopic" than topic modeling, which focuses on the more "microscopic," word level of narratives. Topic modeling allowed for latent analysis of the forum comments, which the content analysis did not. The locus of control theme suggested by topic modeling was not readily apparent from the online comments and thus this technique provided increased depth of understanding.

Based on our findings, it would be important to include questions regarding coping mechanisms and locus of control when assessing patients for CRCI. The ways in which patients must adjust their approach to cognitive demands in real-world situations may be a more sensitive measure of their cognitive status than performance on a cognitive test. In fact, CRCI was historically controversial due to normal performance on cognitive tests by patients reporting cognitive deficits [12]. Some have suggested that patients are able to compensate for or adapt to cognitive effects, masking the underlying deficit [37]. However, compensation is effortful and the lengths that one must go to adapt would be reflective of the masked deficit. Currently, there are no standardized self-report measures for CRCI that include evaluation of coping mechanisms. However, the Compensatory Cognitive Strategies Scale was developed and validated in persons with multiple sclerosis to measure the frequency of using 24 cognitive strategies [38]. This scale could easily be adapted and validated for use in cancer populations.

We would expect that patients with internal locus of control would have greater tendency to utilize compensatory strategies when dealing with cognitive effects. A focus on locus of control could also have implications for treating CRCI partly by changing individual attributions regarding cognitive failures [39]. Mindfulness-based interventions for CRCI [40] may work via locus of control by exploring the way one thinks about successes and failures. We previously suggested that cognitive training may operate in part by increasing locus of control [41]. Currently, there are no standardized self-report measures for CRCI that include evaluation of locus of control. However, there are several existing locus of control measures, including within the public domain, that could be used or adapted for the evaluation of CRCI (eg, [42])

Limitations

The reliability of topic modeling is affected by the sizes of the corpus and its individual documents. While there are no set benchmarks for these, larger samples are typically better for distinguishing topics, and therefore, we may have lacked the

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ability to find additional latent topics. Even though content analysis is commonly used in health sciences research to characterize phenomena and generate theories, individual interpretations can influence or bias the results of content analysis [19]. The interpretation of latent topics is similarly subjective.

Conclusions

Our results suggest that analysis of free-text narratives may provide unique insights regarding subjective experience of cognitive function that could guide development of new CRCI assessments. Although this is not the first study to reveal important qualitative themes related to CRCI, little has been done thus far in terms of incorporating these themes into actual CRCI assessments. This may be due in part to the inherent difficulty in acquiring large samples of data from traditional qualitative methods or a lack of qualitative researchers invested in this field. Applying topic modeling would also be advantageous in terms of increased analytical efficiency given that it is largely automated. Although some advanced computational and computer science expertise is often required for such analyses, many user-friendly resources are currently available, such as Amazon Comprehend (Amazon Web Services, Inc.), MonkeyLearn (MonkeyLearn, Inc.), RapidMiner (RapidMiner, Inc.), and Google Cloud Natural Language (Google, Inc.), which require little if any expertise.

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Authors' Contributions

SRK contributed to the concept, design, supervision, data acquisition/analysis, and writing. AMH and WT performed data analysis and writing. VR performed data acquisition and analysis.

Conflicts of Interest

None declared.

References

1. Janelsins MC, Kesler SR, Ahles TA, Morrow GR. Prevalence, mechanisms, and management of cancer-related cognitive impairment. Int Rev Psychiatry 2014 Feb;26(1):102-113 [FREE Full text] [doi: 10.3109/09540261.2013.864260] [Medline: 24716504]
2. Kesler SR, Rao A, Blayney DW, Oakley-Girvan IA, Karuturi M, Palesh O. Predicting long-term cognitive outcome following breast cancer with pre-treatment resting state fMRI and random forest machine earning. Front Hum Neurosci 2017;11:555 [FREE Full text] [doi: 10.3389/fnhum.2017.00555] [Medline: 29187817]
3. Robb C, Boulware D, Overcash J, Extermann M. Patterns of care and survival in cancer patients with cognitive impairment. Crit Rev Oncol Hematol 2010 Jun;74(3):218-224. [doi: 10.1016/j.critrevonc.2009.07.002] [Medline: 19709899]
4. Stilley CS, Bender CM, Dunbar-Jacob J, Sereika S, Ryan CM. The impact of cognitive function on medication management: three studies. Health Psychol 2010 Jan;29(1):50-55 [FREE Full text] [doi: 10.1037/a0016940] [Medline: 20063935]
5. Krull KR, Hardy KK, Kahalley LS, Schuitema I, Kesler SR. Neurocognitive outcomes and interventions in long-term survivors of childhood cancer. J Clin Oncol 2018 Jul 20;36(21):2181-2189 [FREE Full text] [doi: 10.1200/JCO.2017.76.4696] [Medline: 29874137]
6. Feng Y, Zhang XD, Zheng G, Zhang LJ. Chemotherapy-induced brain changes in breast cancer survivors: evaluation with multimodality magnetic resonance imaging. Brain Imaging Behav 2019 Dec;13(6):1799-1814. [doi: 10.1007/s11682-019-00074-y] [Medline: 30937827]
7. Kesler SR. Default mode network as a potential biomarker of chemotherapy-related brain injury. Neurobiol Aging 2014 Sep;35 Suppl 2:S11-S19 [FREE Full text] [doi: 10.1016/j.neurobiolaging.2014.03.036] [Medline: 24913897]
8. Li M, Caeyenberghs K. Longitudinal assessment of chemotherapy-induced changes in brain and cognitive functioning: A systematic review. Neurosci Biobehav Rev 2018 Sep;92:304-317. [doi: 10.1016/j.neubiorev.2018.05.019] [Medline: 29791867]
9. Boykoff N, Moieni M, Subramanian SK. Confronting chemobrain: an in-depth look at survivors' reports of impact on work, social networks, and health care response. J Cancer Surviv 2009 Dec;3(4):223-232 [FREE Full text] [doi: 10.1007/s11764-009-0098-x] [Medline: 19760150]
10. Hutchinson AD, Hosking JR, Kichenadasse G, Mattiske JK, Wilson C. Objective and subjective cognitive impairment following chemotherapy for cancer: a systematic review. Cancer Treat Rev 2012 Nov;38(7):926-934. [doi: 10.1016/j.ctrv.2012.05.002] [Medline: 22658913]
11. Howieson D. Current limitations of neuropsychological tests and assessment procedures. Clin Neuropsychol 2019 Feb;33(2):200-208. [doi: 10.1080/13854046.2018.1552762] [Medline: 30608020]

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12. Horowitz TS, Suls J, Treviño M. A call for a neuroscience approach to cancer-related cognitive impairment. Trends Neurosci 2018 Aug;41(8):493-496. [doi: 10.1016/j.tins.2018.05.001] [Medline: 29907436]
13. Gibbons C, Bower P, Lovell K, Valderas J, Skevington S. Electronic quality of life assessment using computer-adaptive testing. J Med Internet Res 2016 Sep 30;18(9):e240 [FREE Full text] [doi: 10.2196/jmir.6053] [Medline: 27694100]
14. Amidi A, Christensen S, Mehlsen M, Jensen AB, Pedersen AD, Zachariae R. Long-term subjective cognitive functioning following adjuvant systemic treatment: 7-9 years follow-up of a nationwide cohort of women treated for primary breast cancer. Br J Cancer 2015 Sep 01;113(5):794-801 [FREE Full text] [doi: 10.1038/bjc.2015.243] [Medline: 26171932]
15. Yau C, Porter A, Newman N, Suominen A. Clustering scientific documents with topic modeling. Scientometrics 2014 May 6;100(3):767-786. [doi: 10.1007/s11192-014-1321-8]
16. Liu D, Feng XL, Ahmed F, Shahid M, Guo J. Detecting and measuring depression on social media using a machine learning approach: systematic review. JMIR Ment Health 2022 Mar 01;9(3):e27244 [FREE Full text] [doi: 10.2196/27244] [Medline: 35230252]
17. Guntuku SC, Yaden DB, Kern ML, Ungar LH, Eichstaedt JC. Detecting depression and mental illness on social media: an integrative review. Current Opinion in Behavioral Sciences 2017 Dec;18:43-49. [doi: 10.1016/j.cobeha.2017.07.005]
18. Thakur N, Han CY. A multimodal approach for early detection of cognitive impairment from tweets. In: Human Interaction, Emerging Technologies and Future Systems V. Cham, Switzerland: Springer; 2022 Presented at: International Conference on Human Interaction and Emerging Technologies (IHIET 2021); August 27-29, 2021; France p. 11-19. [doi: 10.1007/978-3-030-85540-6_2]
19. Sandelowski M. Whatever happened to qualitative description? Res Nurs Health 2000 Aug;23(4):334-340. [doi: 10.1002/1098-240x(200008)23:4<334::aid-nur9>3.0.co;2-g] [Medline: 10940958]
20. Selamat MH, Loh SY, Mackenzie L, Vardy J. Chemobrain experienced by breast cancer survivors: a meta-ethnography study investigating research and care implications. PLoS One 2014;9(9):e108002 [FREE Full text] [doi: 10.1371/journal.pone.0108002] [Medline: 25259847]
21. Bolton G, Isaacs A. Women's experiences of cancer-related cognitive impairment, its impact on daily life and care received for it following treatment for breast cancer. Psychol Health Med 2018 Dec;23(10):1261-1274. [doi: 10.1080/13548506.2018.1500023] [Medline: 30048158]
22. Becker H, Henneghan A, Mikan SQ. When do I get my brain back? Breast cancer survivors' experiences of cognitive problems. Clin J Oncol Nurs 2015 Apr;19(2):180-184. [doi: 10.1188/15.CJON.180-184] [Medline: 25840383]
23. Player L, Mackenzie L, Willis K, Loh SY. Women's experiences of cognitive changes or 'chemobrain' following treatment for breast cancer: a role for occupational therapy? Aust Occup Ther J 2014 Aug;61(4):230-240. [doi: 10.1111/1440-1630.12113] [Medline: 24499127]
24. Rust C, Davis C. Chemobrain in underserved African American breast cancer survivors: a qualitative study. Clin J Oncol Nurs 2013 Apr;17(2):E29-E34. [doi: 10.1188/13.CJON.E29-E34] [Medline: 23538262]
25. Blei DM, Ng AY, Jordan MI. Latent Dirichlet allocation. J Mach Learn Res 2003;3:993-1022 [FREE Full text]
26. Zhao W, Chen JJ, Perkins R, Liu Z, Ge W, Ding Y, et al. A heuristic approach to determine an appropriate number of topics in topic modeling. BMC Bioinformatics 2015;16 Suppl 13:S8 [FREE Full text] [doi: 10.1186/1471-2105-16-S13-S8] [Medline: 26424364]
27. Sandelowski M. When a cigar is not just a cigar: alternative takes on data and data analysis. Res Nurs Health 2011 Aug;34(4):342-352. [doi: 10.1002/nur.20437] [Medline: 21480296]
28. Elo S, Kyngäs H. The qualitative content analysis process. J Adv Nurs 2008 Apr;62(1):107-115. [doi: 10.1111/j.1365-2648.2007.04569.x] [Medline: 18352969]
29. Henderson FM, Cross AJ, Baraniak AR. 'A new normal with chemobrain': Experiences of the impact of chemotherapy-related cognitive deficits in long-term breast cancer survivors. Health Psychol Open 2019;6(1):2055102919832234 [FREE Full text] [doi: 10.1177/2055102919832234] [Medline: 30873289]
30. Kulpa M, Ziętalewicz U, Kosowicz M, Stypuła-Ciuba B, Ziółkowska P. Anxiety and depression and cognitive coping strategies and health locus of control in patients with ovary and uterus cancer during anticancer therapy. Contemp Oncol (Pozn) 2016;20(2):171-175 [FREE Full text] [doi: 10.5114/wo.2016.60074] [Medline: 27358598]
31. Toscano A, Blanchin M, Bourdon M, Bonnaud Antignac A, Sébille V. Longitudinal associations between coping strategies, locus of control and health-related quality of life in patients with breast cancer or melanoma. Qual Life Res 2020 May;29(5):1271-1279. [doi: 10.1007/s11136-019-02401-8] [Medline: 31894505]
32. Musich S, Wang SS, Slindee L, Kraemer S, Yeh CS. The impact of internal locus of control on healthcare utilization, expenditures, and health status across older adult income levels. Geriatr Nurs 2020;41(3):274-281 [FREE Full text] [doi: 10.1016/j.gerinurse.2019.10.008] [Medline: 31727348]
33. Náfrádi L, Nakamoto K, Schulz PJ. Is patient empowerment the key to promote adherence? A systematic review of the relationship between self-efficacy, health locus of control and medication adherence. PLoS One 2017;12(10):e0186458 [FREE Full text] [doi: 10.1371/journal.pone.0186458] [Medline: 29040335]
34. Anderson E, Cochrane A, Golding J, Nowicki S. Locus of control as a modifiable risk factor for cognitive function in midlife. Aging (Albany NY) 2018 Jul 12;10(7):1542-1555 [FREE Full text] [doi: 10.18632/aging.101490] [Medline: 30001219]

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35. Wilson C, Giles K, Nettelbeck T, Hutchinson A. Locus of control, optimism, and recollections of depression and self-reported cognitive functioning following treatment for colorectal cancer. Psychooncology 2018 Feb;27(2):676-682. [doi: 10.1002/pon.4567] [Medline: 29047197]
36. Groth N, Schnyder N, Kaess M, Markovic A, Rietschel L, Moser S, et al. Coping as a mediator between locus of control, competence beliefs, and mental health: A systematic review and structural equation modelling meta-analysis. Behav Res Ther 2019 Oct;121:103442. [doi: 10.1016/j.brat.2019.103442] [Medline: 31430689]
37. Reuter-Lorenz PA, Cimprich B. Cognitive function and breast cancer: promise and potential insights from functional brain imaging. Breast Cancer Res Treat 2013 Jan;137(1):33-43. [doi: 10.1007/s10549-012-2266-3] [Medline: 23053652]
38. Becker H, Stuifbergen AK, Henneghan A, Morrison J, Seo EJ, Zhang W. An initial investigation of the reliability and validity of the Compensatory Cognitive Strategies Scale. Neuropsychol Rehabil 2019 Jun;29(5):739-753 [FREE Full text] [doi: 10.1080/09602011.2017.1329154] [Medline: 28552019]
39. Kucherer S, Ferguson RJ. Cognitive behavioral therapy for cancer-related cognitive dysfunction. Curr Opin Support Palliat Care 2017 Mar;11(1):46-51 [FREE Full text] [doi: 10.1097/SPC.0000000000000247] [Medline: 27898511]
40. Cifu G, Power MC, Shomstein S, Arem H. Mindfulness-based interventions and cognitive function among breast cancer survivors: a systematic review. BMC Cancer 2018 Nov 26;18(1):1163 [FREE Full text] [doi: 10.1186/s12885-018-5065-3] [Medline: 30477450]
41. Wefel JS, Kesler SR, Noll KR, Schagen SB. Clinical characteristics, pathophysiology, and management of noncentral nervous system cancer-related cognitive impairment in adults. CA Cancer J Clin 2015 Mar 05;65(2):123-138 [FREE Full text] [doi: 10.3322/caac.21258] [Medline: 25483452]
42. Wallston KA. Multidimensional health locus of control scales. In: Gellman MD, editor. Encyclopedia of Behavioral Medicine. Cham, Switzerland: Springer; 2020.

Abbreviations

CRCI: cancer-related cognitive impairment

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Original Paper

Timing and Motivations for Alternative Cancer Therapy With Insights From a Crowdfunding Platform: Cross-sectional Mixed Methods Study

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Abstract

Background: Alternative cancer therapy is associated with increased mortality, but little is known about those who pursue it.

Objective: We aimed to describe individuals' motivations for using alternative cancer therapies and determine whether motivations differ based on individuals' timing of seeking alternative therapies.

Methods: We used data from 649 campaigns posted on the website GoFundMe between 2011 and 2019 for beneficiaries with cancer pursuing alternative therapy. The data were analyzed using a mixed methods approach. Campaigns were categorized by timing of alternative therapy (either before or after experiencing conventional therapy). Qualitative analysis identified motivational themes. Chi-square tests of independence and Fisher tests (all 2-sided) determined significant differences in the presence of motivational themes between groups.

Results: The expression of concerns about the efficacy of conventional therapy was significantly more likely in campaigns for individuals who used conventional therapy first than in campaigns for individuals who started with alternative therapy (63.3% vs 41.7%; $P<.001$). Moreover, on comparing those who started with alternative therapy and those who switched from conventional to alternative therapy, those who started with alternative therapy more often expressed natural and holistic values (49.3% vs 27.0%; $P<.001$), expressed an unorthodox understanding of cancer (25.5% vs 16.4%; $P=.004$), referenced religious or spiritual beliefs (15.1% vs 8.9%; $P=.01$), perceived alternative treatment as efficacious (19.1% vs 10.2%; $P=.001$), and distrusted pharmaceutical companies (3.2% vs 0.5%; $P=.04$).

Conclusions: Individuals sought treatments that reflected their values and beliefs, even if scientifically unfounded. Many individuals who reported prior conventional cancer therapy were motivated to pursue alternative treatments because they perceived the conventional treatments to be ineffective.

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KEYWORDS

internet; health misinformation; online crowdfunding; alternative medicine; internet research ethics

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Introduction

Alternative cancer therapy (ACT) is a subcategory of complementary and alternative medicine, a broad term defined by the National Cancer Institute to comprise the multitude of cancer treatment modalities outside the medical mainstream [1]. Among these treatment modalities are mind-body therapies, herbal supplements, special diets, and vitamin infusions. Complementary therapies are used alongside the standard of care as part of an integrative therapy plan created by a multidisciplinary care team, while ACT is used in place of the standard of care [1]. In other words, the same nonstandard treatment modality may be defined as either a complementary or an alternative therapy depending on whether it is applied as a complement to the standard of care (ie, complementary therapy) or as a replacement for it (ie, ACT) [2].

Research suggests that ACT use is common throughout the world and is seen by many patients as a curative form of cancer treatment [3-12]. Results from the 2018 American Society of Clinical Oncology Cancer Opinions Survey found that nearly 40% of adults surveyed in the United States believe that cancer can be cured through ACT alone [11]. These data are worrying because the efficacy of ACT for the treatment of cancer is either unproven or disproven and ACT use is linked to increased mortality among cancer patients who abandon conventional medical treatment [12]. Additionally, the high cost of ACT procedures and associated travel, surpassing US $50,000 per year for some cancer patients in the United States, may cause financial harm to patients and their families [13-15].

Studies on ACT use are challenging, since cancer patients may be hesitant to disclose ACT use to their providers [16]. This is particularly true in terms of studies on treatment decision making, since those who use ACT are often disconnected from standard medical systems that conduct qualitative research. Despite these challenges, research that improves the understanding of the complicated and multiphasic ways in which cancer patients decide to pursue ACT, including the timing and motivations for the decision, is necessary to improve health care providers' ability to care for an already vulnerable patient population [17]. Online crowdfunding sites, such as GoFundMe, offer a novel approach for studying cancer patients' treatment decisions [14,18,19]. Such sites are frequently used by cancer patients to raise money to pay for medical expenses, including both conventional and alternative therapies.

While previous studies have used data from crowdfunding sites to study individuals who use both classifications of unconventional therapy, we have focused our study on those individuals who state that they have chosen to pursue ACT exclusively [18,19]. This group is at the greatest risk for increased mortality and, therefore, warrants special attention [12]. The purposes of this study were to (1) describe individuals' motivations for using ACT and (2) explore whether individuals who seek ACT before using the standard of care or conventional cancer therapy (CCT) differ from individuals who pursue ACT after using CCT. Addressing these questions will generate informative data that may help medical providers identify individuals likely to seek ACT, anticipate when they may be considering this decision, and proactively address potential motivations prior to an individual foregoing or abandoning CCT.

Methods

Design

This was a cross-sectional mixed methods study of GoFundMe campaigns created between 2011 and 2019 to raise money for ACT for individuals with cancer.

Ethical Considerations

Special ethical concerns were considered as part of this internet-based research. This study did not involve an interaction or intervention with human subjects and was therefore exempt from institutional review board review [20]. Study data were extracted from publicly available campaigns in accordance with the GoFundMe terms of service, which states that "any information that is disclosed in [public campaigns] becomes public information for both us [GoFundMe] and other users to use and share" [21].

Despite the public nature of the data, we recognized the need to put additional protections in place, given the vulnerable position of individuals represented in the GoFundMe campaigns. Presenting qualitative data that were both publicly accessible and deeply personal created a unique challenge for the preservation of patient privacy, since any direct campaign quotes presented in this publication could be used to identify the organizers and beneficiaries, using internet search engine tools. Contacting each campaign organizer or beneficiary, some of whom were likely deceased, to obtain informed consent was not feasible. Considering these challenges and out of an abundance of caution, we opted to paraphrase the exemplary quotes presented in the qualitative results in a manner that removed identifiable characteristics (geography, age, cancer type, and gender, including replacing gender-specific pronouns with they/their/theirs) while retaining the sentiments and themes of the originals. Each paraphrased quote was queried by JP and TW using Google Search to ensure the campaigns could not be identified.

Data Source and Selection

A custom web scraping code was developed and used to search GoFundMe for English language campaigns, using the term "alternative cancer" (Multimedia Appendix 1). The search was conducted on October 25, 2019, and yielded 795 campaigns that were initiated between 2011 and 2019. Each campaign was reviewed for eligibility according to the following criteria: written in English, inclusion of a campaign description, and raising of funds for an individual with cancer seeking ACT. To select campaigns that were seeking uniquely alternative rather than complementary therapies, the text of the campaigns was analyzed to determine whether the patients were using unconventional therapies simultaneously with conventional care or in place of conventional care. In cases where the patient had previously used CCT but had since stopped, the campaign was classified as ACT. If the described therapy was complementary or if the intent was ambiguous, the campaign was omitted. If a campaign was found to be a duplicate of another, only 1 version

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was included in the study. Among the 795 campaigns, 17 did not meet these criteria and were excluded. The remaining 778 campaigns were reviewed to determine the timing of the beneficiary's decision to pursue ACT. A campaign was only included if it could be determined that the beneficiary sought ACT either before or after experiencing CCT. Among the 778 campaigns, 129 did not contain sufficient details to determine timing and were excluded, leaving 649 campaigns in the final analysis.

Statistical Analysis

Clinical, demographic, and treatment data were extracted for the 649 campaigns. Variables included the individual's gender, nation of residence, primary cancer type, cancer stage, and ACT modality. Each campaign was categorized by the timing of the individual's decision to pursue ACT. "ACT first" included individuals who had started their treatment with ACT, and "ACT after CCT" included individuals who had used CCT prior to seeking ACT. Campaigns were categorized into the "ACT after CCT" group if the patients had ever received CCT prior to seeking ACT, including for an earlier occurrence of the same cancer or a different cancer. To categorize cases for timing, 50 cases were dually classified by 2 independent coders (κ=0.750), discordant cases were discussed, and procedures were clarified before commencing independent classification of the remaining campaigns.

The text of the campaign description was analyzed in ATLAS.ti 9 using applied thematic analysis techniques [22]. First, a subset of 100 cases was inductively coded by 2 independent analysts to identify themes related to motivations for using ACTs. Themes were considered "motivational" if they initiated, guided, or informed the decisions of beneficiaries to pursue ACT. They may not have been the sole rationale, but they were prominent enough that the beneficiaries felt they were important to include in their calls for donations. The codes were discussed in the larger research team, and consensus was reached on a set of codes that best captured themes across the campaigns. A codebook was developed that included parent and child codes, with definitions and exemplary quotes. The 2 analysts then dually coded 50 transcripts (Krippendorff α=.745). Discordant codes were discussed for consensus, and modifications were made to the codebook to clarify code definitions. The remaining campaigns were thereafter coded individually by the 2 analysts. Code reports were generated to synthesize the text associated with each code and to quantify the number of campaigns in which each code appeared.

Statistical analyses were performed using Stata, version 16.1 (Stata Corp). The demographic, clinical, and treatment characteristics of the campaigns were described, and associations with treatment timing (ACT first vs ACT after CCT) were examined using chi-square tests of independence (for variables with frequencies ≥5) and Fisher exact tests (for variables with frequencies <5). Each code representing a motivational theme was transformed into a variable, and campaigns were assigned as having that theme present in the text or not. Chi-square tests of independence or Fisher exact tests were used to assess whether the presence of each motivational theme was associated with treatment timing. All statistical tests were 2-sided.

Results

Demographic and Clinical Characteristics of the Sample

The demographic and clinical characteristics of the individuals represented by the 649 campaigns are shown in Table 1. Details about the ACT modalities individuals pursued are shown in Table 2. Of the 649 individuals represented by the campaigns, 371 (57.2%) sought ACT after using CCT and 278 (42.8%) pursued ACT first.

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Table 1. Demographics and clinical breakdown of the sample by timing of the decision to use alternative cancer therapy.

Variable	Total campaigns (N=649), n (%)	ACT[a] first (N=278), n (%)	ACT after CCT[b] (N=371), n (%)	*P* value[c]
Gender				.47
Female	417 (64.3)	183 (65.8)	234 (63.1)	
Male	232 (35.7)	95 (34.2)	137 (36.9)	
Cancer type				<.001
Breast	171 (26.3)	82 (29.5)	89 (24.0)	
Colorectal	70 (10.8)	24 (8.6)	46 (12.6)	
Lung	36 (5.5)	15 (5.4)	21 (5.7)	
Head and neck	35 (5.4)	25 (9.0)	10 (2.7)	
Brain	30 (4.6)	8 (2.9)	22 (5.9)	
Esophagus/gastric	28 (4.3)	16 (5.8)	12 (3.2)	
Ovarian	28 (4.3)	7 (2.5)	21 (5.7)	
Pancreas	26 (4.0)	5 (1.8)	21 (5.7)	
Bone and soft tissue	24 (3.7)	9 (3.2)	15 (4.0)	
Lymphoma	22 (3.4)	11 (4.0)	11 (3.0)	
Other[d]	179 (27.6)	76 (27.3)	103 (27.8)	
Cancer stage[e]				.03
I, II, or III	76 (20.8)	38 (26.6)	38 (17.1)	
IV	289 (79.2)	105 (73.4)	184 (82.9)	
Primary residence				.06
United States	524 (80.7)	235 (84.5)	289 (77.9)	
Europe	57 (8.8)	23 (8.3)	34 (9.2)	
Canada	43 (6.6)	15 (5.4)	28 (7.5)	
Other	25 (3.9)	5 (1.8)	20 (5.4)	

[a]ACT: alternative cancer therapy.

[b]CCT: conventional cancer therapy.

[c]From chi-square tests comparing patients in the “ACT first” and “ACT after CCT” groups.

[d]Other cancers include anal, cervix, endometrial, leukemia, melanoma, nonmelanoma skin, liver and biliary, kidney, multiple myeloma, prostate, bladder, neuroendocrine, thyroid, testicular, vulvar, and unspecified.

[e]Cancer stage was reported in 365 campaigns, with 143 in the “ACT first” group and 222 in the “ACT after CCT” group. These numbers were used as the denominators for each cancer stage timing category.

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Table 2. Details of alternative cancer therapies pursued by the timing of the decision to use alternative cancer therapy.

Proposed ACT[a]	Total campaigns (N=649), n (%)	ACT first (N=278), n (%)	ACT after CCT[b] (N=371), n (%)	*P* value
Special diets	187 (28.8)	92 (33.1)	95 (25.6)	.04
Vitamins and minerals	155 (23.9)	77 (27.7)	78 (21.0)	.05
Supplements	128 (19.7)	70 (25.2)	58 (15.6)	.003
Intravenous infusions	119 (18.3)	55 (19.8)	64 (17.3)	.41
Herbs and botanicals	101 (15.6)	53 (19.1)	48 (12.9)	.03
Heat/light/sauna	65 (10.0)	39 (14.0)	26 (7.0)	.003
Oxygen therapy (hyperbaric, etc)	62 (9.6)	32 (11.5)	30 (8.1)	.14
Unknown injections	51 (7.9)	29 (10.4)	22 (5.9)	.04
Homeopathy and naturopathy	44 (6.8)	20 (7.2)	24 (6.5)	.72
Ozone therapy (topical, intravenous, intramuscular)	40 (6.2)	20 (7.2)	20 (5.4)	.34
Enemas	35 (5.4)	14 (5.0)	21 (5.7)	.73
Prayer	32 (4.9)	17 (6.1)	15 (4.0)	.23
Yoga or exercise	30 (4.6)	15 (5.4)	15 (4.0)	.42
Insulin potentiation therapy	27 (4.2)	17 (6.1)	10 (2.7)	.03
Electromagnetic therapies[c]	25 (3.9)	11 (4.0)	14 (3.8)	.90
Massage	17 (2.6)	9 (3.2)	8 (2.2)	.39
Acupuncture	14 (2.2)	8 (2.9)	6 (1.6)	.27
Meditation	14 (2.2)	6 (2.2)	8 (2.2)	>.99
Other	19 (2.9)	14 (5.0)	5 (1.3)	.006

[a]ACT: alternative cancer therapy.

[b]CCT: conventional cancer therapy.

[c]Includes pulsed electromagnetic frequency therapy, Rife, electrocancer therapy, and galvanotherapy.

Motivational Themes

On examining the stated motivations for pursuing ACT, 4 primary themes ("Dissatisfaction with CCT," "Compatibility with belief system," "Desire for greater personal control," and "Perceived efficacy of ACT") were identified. Subthemes emerged under "Dissatisfaction with CCT" ("Perceived inefficacy," "Adverse effects," and "Financial concerns") and "Compatibility with belief system" ("Natural and holistic values," "Unorthodox understanding of cancer and/or therapy," "Distrust of medical professionals and hospitals," "Religious/spiritual reasons," and "Distrust of pharmaceutical companies"). The 4 most common motivational themes were "Perceived inefficacy" of CCT (n=351, 54.1%), "Adverse effects" of CCT (n=281, 43.3%), "Natural and holistic values" (n=237, 36.5%), and "Unorthodox understanding of cancer and/or therapy" (n=132, 20.3%). Multimedia Appendix 2 provides a summary of all themes and subthemes, exemplary quotations, and frequencies of campaigns in which these themes occurred.

Comparison Between the Timing Groups

Most cancer types seen in this study were found to be significantly more represented among campaigns for beneficiaries who were seeking ACT after CCT (*P*<.001) (Table 1). Only beneficiaries reporting head and neck cancers or esophageal/gastric cancers were more represented among campaigns that sought ACT first (9.0% vs 2.7% and 5.8% vs 3.2%, respectively; *P*<.001). All other cancers (breast, colorectal, lung, brain, ovarian, pancreatic, bone and soft tissue, and lymphoma) were more common among campaigns that reported seeking ACT after CCT (*P*<.001) (Table 1). Cancer stage was reported in 365 (56.2%) campaigns analyzed. Among these campaigns, stage IV cancers were significantly more common in individuals who were seeking ACT after CCT than ACT first (82.9% vs 73.4%; *P*=.03), while those reporting stage I, II, and III cancers were more often seeking ACT first than ACT after CCT (26.6% vs 17.1%; *P*=.03) (Table 1).

The campaigns for beneficiaries who pursued ACT as first-line treatment were significantly more likely to seek the following 8 of 19 classes of ACT modalities identified in this study (Table 2): special diets (33.1% vs 25.6%; *P*=.04); vitamins and minerals (27.7% vs 21.0%; *P*=.05); supplements (25.2% vs 15.6%; *P*=.003); herbs and botanicals (19.1% vs 12.9%; *P*=.03); heat, light, and sauna therapies (14.0% vs 7.0%; *P*=.003); unknown injections (10.4% vs 5.9%; *P*=.04); insulin potentiation therapy (6.1% vs 2.7%; *P*=.03); and other therapies, including electrical therapies such as galvanotherapy and Rife therapy (5.0% vs 1.3%; *P*=.006).

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Campaigns for individuals who started with ACT were significantly more likely to express natural and holistic values (49.3% vs 27.0%; $P<.001$), demonstrate an unorthodox understanding of cancer or cancer treatment (25.5% vs 16.4%; $P=.004$), cite their religious or spiritual beliefs (15.1% vs 8.9%; $P=.01$), mention distrust of pharmaceutical companies (3.2% vs 0.5%; $P=.01$), and make claims about the efficacy of the chosen ACT (19.1% vs 10.2%; $P=.001$) (Multimedia Appendix 2). Campaigns for individuals who pursued ACT after CCT were significantly more likely to perceive CCT to be ineffective (63.3% vs 41.7%; $P<.001$) (Multimedia Appendix 2).

Discussion

Principal Findings

This study highlights the diversity of motivations for choosing to pursue ACT present among a small sample of English-speaking GoFundMe users. Most individuals featured in the GoFundMe campaigns had prior experience with CCT and pursued ACT primarily because of their perception that CCT was not effective. Not surprisingly, metastatic disease and concerns about the inefficacy of CCT were both significantly more common among the same class of campaigns. The limited treatment options available to these individuals may have prompted an interest in ACT as a last resort. This may seem acceptable to maintain hope and preserve patient autonomy; however, improved communication between physicians and patients is needed to discuss the physical and financial risks of unproven treatments. When patients have exhausted all options for evidence-based therapies, shared decision-making and coordination with supportive oncology services, palliative care, and other necessary providers should be prioritized and initiated early in their care to improve their care experience and maintain quality of life.

The role that beliefs and values play in guiding the decisions regarding cancer care can be seen in the campaigns for individuals in our sample, who chose to pursue ACT as their first mode of treatment. Campaigns for these individuals were more likely to express a desire for care that was consistent with their personal beliefs, particularly a value-based preference for natural healing. In some campaigns the desire for a more “natural” therapy was closely tied to an incorrect understanding of cancer biology, often surrounding the immune system’s capacity to fight cancer. A total of 132 (20.3%) campaigns cited pseudoscientific information as the reason for pursuing ACT, underscoring the impact of medical misinformation, often from online sources, in persuading individuals to use cancer treatments that are not evidence-based [23]. Frequently, seeking natural care was conveyed as a mark of faith. Rather than putting their confidence in secular science, the beneficiaries stated that they were manifesting their trust in God’s ability to heal by refusing CCT. The beliefs that motivated individuals to use ACT as a first-line therapy commonly drew from multiple sources, blending in a way that was deeply personal and grounded in one’s identity and core values.

These results highlight the dilemma faced by medical providers who strive to respect patient autonomy while encouraging patients to pursue evidence-based treatment [24]. Despite these challenges, medical communication research offers some guidance on facilitating open goal-concordant and patient-centered care conversations in these situations. A medical provider’s ability to actively listen, express compassion, and build a relationship with his or her patients has been shown to increase trust and counter false medical information [2,25]. Establishing a strong therapeutic alliance may make it easier for patients who lack trust in mainstream medicine or hold unorthodox medical beliefs to discuss their concerns more freely with medical providers.

It remains unclear why certain ACT modalities, such as supplements and herbal remedies, were more represented among campaigns seeking ACT first. It is possible that this is a product of the selection bias generated by gathering information from English-speaking individuals, most of whom are US residents with internet access. A larger more diverse sample might have produced different results. The relative frequency of these modalities is similar to the findings of previous research using GoFundMe data. In their 2018 investigation into complementary and alternative cancer treatment use, Song et al found special diets, herbal remedies, oral vitamin and mineral supplements, and vitamin injections to be among the top 10 most frequently used modalities [19]. The results of this paper, while limited to alternative cancer treatments, nonetheless also found special diets, oral vitamins and minerals, supplements, herbal remedies, and intravenous vitamins to be the most sought-after forms of ACT. An additional study is warranted to understand why these therapies are consistently desirable. Furthermore, as research expands the number of evidence-based options available to patients, the list of therapies that are considered CCTs will continue to evolve. It may be valuable to monitor how emerging therapeutic approaches, including immunotherapy, nanostructures, and tumor-selective delivery of chemotherapy, will impact trends in the use of ACT modalities [26,27].

Internet Research Ethics

In conducting this study, we carefully weighed the ethical considerations of using social media data and took steps to protect the identity of vulnerable individuals who created GoFundMe campaigns. In recent years, internet research has highlighted the importance of protecting the agency and privacy of online research subjects [28-30]. The descriptive approach taken in this study yielded insights into medical decision-making without interacting or providing an intervention with human subjects [20]. Multimedia Appendix 2 provides examples of how public, but potentially sensitive, qualitative data can be presented in a way that preserves both its meaning and the sources’ privacy [29].

Limitations

This novel approach to conducting research with a particularly difficult-to-study cancer population provides important descriptive information about individuals who pursue ACT. Nevertheless, the study’s findings must be considered in light of its limitations, primarily the reliance on campaign texts that were written for the purpose of soliciting financial support for individuals seeking ACT. Here, we attempted to identify motivational themes among those using only alternative therapies. The term “alternative cancer” was used to potentially

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exclude those patients who are using reiki, homeopathy, Gerson therapy, or other specific therapies with their CCTs, or are otherwise defined as complementary medicine users. We acknowledge that in an effort to exclude those receiving complementary medicines, we may have underascertained some users of ACTs. However, this term is highly specific and still resulted in the largest qualitative study, known to date, of patients receiving alternative medicines for cancer. Information content was inconsistent across campaigns, and some campaign descriptions were written by close friends and family rather than directly by the individuals living with cancer. We felt that it was still appropriate to include these campaigns authored by close friends and family because they were often intimately involved throughout the diagnosis and medical decision-making process. Additionally, we did not want to exclude campaigns for patients whose health condition or technological literacy may have prevented them from independently writing and organizing their GoFundMe campaigns. Moreover, we acknowledge the possibility that fraudulent campaigns were inadvertently included in this study and acknowledge our dependence on the GoFundMe fraud detection system to minimize this risk. To mitigate the possibility of including fraudulent campaigns, we excluded campaigns that did not include text or information detailed enough to determine the timing of alternative therapy [21]. Some characteristics of the data may limit their generalizability. Not all ACT users utilize crowdfunding, and our data likely excluded individuals with limited access to the internet, individuals without broad social networks, and individuals who could afford to self-fund their treatments. Though the sample size of 649 campaigns is in line with other studies performed using GoFundMe data, the inclusion criterion of English language presents a bias toward an English-speaking US-based population, which limits the generalizability of these results to a broader population. Finally, the individuals represented by the campaigns were not contacted, and thus, the information provided about their treatment and diagnosis was not verifiable. Notwithstanding these issues, this research yielded a large amount of data that could serve as a starting place for future important investigations into larger and more generalizable populations.

Conclusions

Individuals represented by the GoFundMe campaigns in our sample chose to pursue ACT at different points in time during their treatment course, and the sequence of their decisions is associated with specific clinical profiles and motivations. The results of this study emphasize the importance of providers having candid and compassionate discussions with their patients throughout the course of treatment, starting at diagnosis and continuing as the disease and treatment progress. Just as individuals' motivations differed depending on when they chose to pursue ACT, so too should providers' responses. By learning what makes ACT an attractive option, medical providers can better respond to patients' beliefs and values, and advocate for evidence-based treatment.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Web scraping code.
[TXT File , 3 KB - cancer_v8i2e34183_app1.txt]

Multimedia Appendix 2
Description of key elements of patients' reasons for pursuing alternative cancer therapy either before or after using conventional cancer therapy.
[DOCX File , 20 KB - cancer_v8i2e34183_app2.docx]

References

1. Complementary and Alternative Medicine. National Cancer Institute. 2021. URL: https://www.cancer.gov/about-cancer/treatment/cam [accessed 2021-08-20]
2. Peterson JS, Swire-Thompson B, Johnson SB. What is the alternative? Responding strategically to cancer misinformation. Future Oncol 2020 Sep;16(25):1883-1888. [doi: 10.2217/fon-2020-0440] [Medline: 32564627]
3. Kemppainen LM, Kemppainen TT, Reippainen JA, Salmenniemi ST, Vuolanto PH. Use of complementary and alternative medicine in Europe: Health-related and sociodemographic determinants. Scand J Public Health 2018 Jun;46(4):448-455 [FREE Full text] [doi: 10.1177/1403494817733869] [Medline: 28975853]

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4. Anderson JG, Taylor AG. Use of complementary therapies for cancer symptom management: results of the 2007 National Health Interview Survey. J Altern Complement Med 2012 Mar;18(3):235-241 [FREE Full text] [doi: 10.1089/acm.2011.0022] [Medline: 22420737]
5. Barnes P, Bloom BFNR, Nahin R. Complementary and alternative medicine use among adults and children: United States, 2007. Natl Health Stat Report 2008 Dec 10(12):1-23 [FREE Full text] [Medline: 19361005]
6. Clarke TC, Black LI, Stussman BJ, Barnes PM, Nahin RL. Trends in the use of complementary health approaches among adults: United States, 2002-2012. Natl Health Stat Report 2015 Feb 10(79):1-16. [Medline: 25671660]
7. Horneber M, Bueschel G, Dennert G, Less D, Ritter E, Zwahlen M. How many cancer patients use complementary and alternative medicine: a systematic review and metaanalysis. Integr Cancer Ther 2012 Sep;11(3):187-203 [FREE Full text] [doi: 10.1177/1534735411423920] [Medline: 22019489]
8. Johnson SB, Park HS, Gross CP, Yu JB. Complementary Medicine, Refusal of Conventional Cancer Therapy, and Survival Among Patients With Curable Cancers. JAMA Oncol 2018 Oct 01;4(10):1375-1381 [FREE Full text] [doi: 10.1001/jamaoncol.2018.2487] [Medline: 30027204]
9. Reid R, Steel A, Wardle J, Trubody A, Adams J. Complementary medicine use by the Australian population: a critical mixed studies systematic review of utilisation, perceptions and factors associated with use. BMC Complement Altern Med 2016 Jun 11;16:176 [FREE Full text] [doi: 10.1186/s12906-016-1143-8] [Medline: 27289517]
10. Cano-Orón L. Correlación entre las búsquedas sobre terapias complementarias en Google y su uso por parte de la población española. Panace 2016;17(44):124-132 [FREE Full text]
11. Cavallo J. Findings From ASCO's Second National Cancer Opinion Survey. The ASCO Post. 2019. URL: https://ascopost.com/issues/january-25-2019/findings-from-asco-s-second-national-cancer-opinion-survey/ [accessed 2022-05-12]
12. Johnson SB, Park HS, Gross CP, Yu JB. Use of Alternative Medicine for Cancer and Its Impact on Survival. J Natl Cancer Inst 2018 Jan 01;110(1):10.1093/jnci/djx145. [doi: 10.1093/jnci/djx145] [Medline: 28922780]
13. Snyder J, Adams K, Chen YY, Birch D, Caulfield T, Cohen IG, et al. Navigating physicians' ethical and legal duties to patients seeking unproven interventions abroad. Can Fam Physician 2015 Jul;61(7):584-6, e295 [FREE Full text] [Medline: 26175363]
14. Snyder J, Zenone M, Caulfield T. Crowdfunding for complementary and alternative medicine: What are cancer patients seeking? PLoS One 2020 Nov 20;15(11):e0242048 [FREE Full text] [doi: 10.1371/journal.pone.0242048] [Medline: 33216790]
15. John GM, Hershman DL, Falci L, Shi Z, Tsai W, Greenlee H. Complementary and alternative medicine use among US cancer survivors. J Cancer Surviv 2016 Oct 26;10(5):850-864 [FREE Full text] [doi: 10.1007/s11764-016-0530-y] [Medline: 26920872]
16. Davis EL, Oh B, Butow PN, Mullan BA, Clarke S. Cancer patient disclosure and patient-doctor communication of complementary and alternative medicine use: a systematic review. Oncologist 2012;17(11):1475-1481 [FREE Full text] [doi: 10.1634/theoncologist.2012-0223] [Medline: 22933591]
17. Weeks L, Balneaves LG, Paterson C, Verhoef M. Decision-making about complementary and alternative medicine by cancer patients: integrative literature review. Open Med 2014;8(2):e54-e66 [FREE Full text] [Medline: 25009685]
18. Cohen AJ, Brody H, Patino G, Ndoye M, Liaw A, Butler C, et al. Use of an Online Crowdfunding Platform for Unmet Financial Obligations in Cancer Care. JAMA Intern Med 2019 Dec 01;179(12):1717-1720 [FREE Full text] [doi: 10.1001/jamainternmed.2019.3330] [Medline: 31498408]
19. Song S, Cohen AJ, Lui H, Mmonu NA, Brody H, Patino G, et al. Use of GoFundMe to crowdfund complementary and alternative medicine treatments for cancer. J Cancer Res Clin Oncol 2020 Jul 26;146(7):1857-1865. [doi: 10.1007/s00432-020-03191-0] [Medline: 32219517]
20. Considerations and Recommendations Concerning Internet Research and Human Subjects Research Regulations, with Revisions. U.S. Department of Health & Human Services. 2013. URL: https://www.hhs.gov/ohrp/sites/default/files/ohrp/sachrp/mtgings/2013%20March%20Mtg/internet_research.pdf [accessed 2022-05-24]
21. GoFundMe Terms of Service. GoFundMe. URL: https://www.gofundme.com/terms [accessed 2022-05-24]
22. Guest G, MacQueen K, Namey E. Introduction to Applied Thematic Analysis. In: Applied Thematic Analysis. Thousand Oaks, CA: SAGE Publications, Inc; 2012:3-20.
23. Johnson SB, Parsons M, Dorff T, Moran MS, Ward JH, Cohen SA, et al. Cancer Misinformation and Harmful Information on Facebook and Other Social Media: A Brief Report. J Natl Cancer Inst 2021 Jul 22:460-2105. [doi: 10.1093/jnci/djab141] [Medline: 34291289]
24. Clark PA. The ethics of alternative medicine therapies. J Public Health Policy 2000;21(4):447-470. [doi: 10.2307/3343283] [Medline: 11214376]
25. Hillen MA, de Haes HCJM, Smets EMA. Cancer patients' trust in their physician-a review. Psychooncology 2011 Mar;20(3):227-241. [doi: 10.1002/pon.1745] [Medline: 20878840]
26. Gu W, Meng F, Haag R, Zhong Z. Actively targeted nanomedicines for precision cancer therapy: Concept, construction, challenges and clinical translation. J Control Release 2021 Jan 10;329:676-695. [doi: 10.1016/j.jconrel.2020.10.003] [Medline: 33022328]

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27. Oliveira C, Reis RL, Martins A, Silva TH. Marine-derived polymeric nanostructures for cancer treatment. Nanomedicine (Lond) 2021 Sep;16(22):1931-1935. [doi: 10.2217/nnm-2021-0175] [Medline: 34369828]
28. Flick C. Informed consent and the Facebook emotional manipulation study. Research Ethics 2015 Aug 11;12(1):14-28. [doi: 10.1177/1747016115599568]
29. Selinger E, Hartzog W. Facebook's emotional contagion study and the ethical problem of co-opted identity in mediated environments where users lack control. Research Ethics 2015 May 13;12(1):35-43. [doi: 10.1177/1747016115579531]
30. Internet Research Ethics. Methaphysics Research Lab, Stanford University. 2012. URL: https://plato.stanford.edu/entries/ethics-internet-research/ [accessed 2021-03-28]

Abbreviations

ACT: alternative cancer therapy
CCT: conventional cancer therapy

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Original Paper

Convenient Access to Expert-Reviewed Health Information via an Alexa Voice Assistant Skill for Patients With Multiple Myeloma: Development Study

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Abstract

Background: Patients with multiple myeloma (MM) have high information needs due to the complexity of the disease and variety of treatments. Digital voice assistants provide support in daily life and can be a convenient tool that even older patients can use to access health information. Voice assistants may therefore be useful in providing digital health services to meet the information needs of patients with MM.

Objective: We aim to describe and report on the development, content, and functionality of the first Amazon Alexa voice assistant skill for patients with MM in Germany with the goal of empowering and educating patients. Further, we share data on skill usage and first learnings.

Methods: In a cocreation workshop with MM patient organizations and MM medical experts in Germany, Takeda Oncology discussed the development and content of the Alexa skill *Multiple Myeloma*. Patient information on MM disease, diagnostics, and therapy was presented in a question-and-answer format, reviewed by experts, and programmed into the skill. Additionally, a search function for finding patient support groups within a perimeter of 200 km around the users and a myeloma quiz functionality with multiple-choice questions were integrated into the skill. Aggregated retrospective data on the total number of skill installations and skill usage were retrieved from an Amazon Alexa developer account, and a web-based patient survey was conducted on the Takeda Oncology website.

Results: The Alexa skill *Multiple Myeloma* was launched in September 2019. It was available free of charge on the German Amazon Alexa skill store between September 2019 and March 2022 and could be used with devices featuring the Amazon Alexa voice assistant. Since the launch in September 2019 and up to July 2021, a total of 141 users have installed the skill. Between July 2020 and July 2021, a total of 189 skill sessions with 797 utterances were analyzed. The most popular inquiries were searches for patient support groups near the users (58/797, 7.3%), followed by inquiries about information on MM disease (53/797, 6.6%) and the quiz (43/797, 5.4%). The web-based survey on voice assistant usage and the feedback on the Alexa skill *Multiple Myeloma* were collected from 24 participants and showed that 46% (11/24) of participants would recommend the Alexa skill. Nonusers of voice assistants (11/24, 46%) stated that data protection concerns (7/11, 64%) and a lack of need (6/11, 55%) were the most important factors of not using voice assistants.

Conclusions: The Alexa skill *Multiple Myeloma* offers patient-friendly and expert-reviewed answers and explanations for medical terms related to MM disease, diagnostics, and therapy, as well as connections to patient support groups and a quiz functionality. In the future, the skill can be extended with new content and functionalities, such as medication adherence support.

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KEYWORDS

Alexa voice assistant; Alexa; voice assistant; virtual assistant; multiple myeloma; cancer; oncology; medical education; patient support group; digital health; patient support; support group; Europe; German; mobile phone

Introduction

Multiple myeloma (MM) is a malignant disease that is characterized by the presence of monoclonal plasma cells in bone marrow [1]. It is the second most frequent hematologic malignancy and accounts for 2% of all cancers [2]. As MM is diagnosed at a median age of 69 years, MM typically affects older individuals [1]. Despite advances in diagnostics and treatment that have resulted in the more than doubling of the median overall survival rate, MM remains largely incurable [3]. Patients frequently survive ≥10 years with the disease but require repeated treatment courses and ultimately enter a refractory state. Further, significant morbidity, which limits patients' quality of life, is related to MM-induced bone damage and impaired kidney function, anemia, and hypercalcemia, as well as treatment-related toxicities [1]. The awareness of being diagnosed with an incurable disease further adds to the heavy burden on psychological well-being [4].

The complexity of the disease; the plethora of diagnostic and follow-up tests; and the various treatment options, including autologous stem cell transplantation, have resulted in a high, continuous information need in affected patients [5-7]. Receiving a diagnosis of MM and being confronted with specialized medical terms can be very overwhelming, and patients, as well as their caregivers, are often unable to address all of their questions directly to a health care professional when they occur. In addition, they may also be concerned about asking "stupid" questions or wasting the time of health care providers (HCPs). Thus, there is a need for patients and their families to have easy access to basic and accurate information at the time they need it and not at their next formal appointment [6,8]. Patient brochures or information on the internet might not be easily accessible for all patients, trustful sources on the internet are not easy to select due to the overflow of search engine results upon information retrieval, and older patients might have difficulties with reading or using a computer. With regard to bridging the gap between information needs and easy access to validated information, voice assistants may play an important role [9].

The Amazon Alexa voice assistant offers education and support in daily life and a new opportunity for providing convenient access to health information that can be delivered in a patient's home [10]. The assistant has the potential to reach patient populations, especially older patients and patients living in rural areas, who otherwise might not engage with education and support. Alexa skills are small programs that are similar to apps; people can use them to obtain validated and expert-reviewed content instead of searching for such content via search engines. Alexa skills can be used with devices featuring Amazon Alexa (eg, Amazon smart speakers or smart televisions [TVs]) or with any smartphone that has the Amazon Alexa app and the integrated Alexa voice assistant. In 2019, the United Kingdom's National Health Service (NHS) announced a partnership with Amazon Alexa, which aims to provide reliable health information from the NHS website through voice-assisted technology. The partnership claims to be a "world first" and aims to aid patients, especially older patients and patients with blindness, who cannot easily search for advice on the internet. The NHS expects voice-assisted technology to reduce the pressure on the NHS and HCPs by providing information for common illnesses [11,12]. In Germany, several health insurance programs have started to launch Alexa skills. Techniker Krankenkasse ("TK health insurance") offers meditation training, mindfulness training, and relaxation exercises with the Alexa skill *TK Smart Relax* [13,14]. Deutsche Angestellten-Krankenkasse ("DAK health insurance") offers exercises for people with dementia via the Alexa skill *Erinnerungs-Coach* [15]. The Alexa skill *Knappschaft Babyglück* offers weekly information and health advice during pregnancy [16]. However, although some Alexa health skills are available, there are none for MM (or oncology) in Germany yet.

We therefore developed the first Alexa voice assistant skill for MM in collaboration with patient organizations and HCPs, with the aim of educating and empowering patients with MM and their families.

Methods

Ethical Considerations

No application for an ethics review board assessment was submitted. As the retrieval of Amazon Alexa usage data was covered by data protection regulations and the data were made available by Amazon only in aggregated form, no individual user data were analyzed.

Participants

The participants included Takeda Oncology, MM patient organizations (Myelom Deutschland e.V., Leukaemiehilfe Rhein-Main [LHRM] e.V., and Arbeitsgemeinschaft Multiples Myelom [AMM]-Online), and MM medical experts (office-based and hospital-based experts).

Procedure

In June 2019, a cocreation workshop with 3 patient organizations (Myelom Deutschland e.V., LHRM e.V., and AMM-Online) and MM medical experts was organized by the pharmaceutical company Takeda Pharma Vertrieb GmbH & Co. KG, Berlin, Germany, to discuss the development and content of the Alexa skill *Multiple Myeloma*. Patient information on MM disease, diagnostics, and therapy was presented in a question-and-answer format (Alexa intents), reviewed by experts, and then programmed into the skill. The Alexa skill is able to answer questions that vary in terms of wording but have the same intent as long as it recognizes similar keywords. For example, a user can ask "what are myeloma cells" or "what do you know about plasma cells" and receive the same expert-reviewed answer for explaining that myeloma cells are abnormal plasma cells. In alignment with German laws on advertising health-related

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products and services (*Heilmittelwerbegesetz*) [17], no information on specific medications was added, and patient-friendly language was used. Changes in information on MM disease, diagnostics, and therapy, as well as new information (eg, MM-related information on COVID-19 pandemic), could be rapidly programmed into the skill as new intents at any time. Additionally, a search function for finding patient support groups within a perimeter of 200 km around the users, which is based on publicly available data from patient organizations, was integrated in the skill. Further, to enrich interactivity, an MM quiz functionality with multiple-choice questions was added. The Alexa skill *Multiple Myeloma* was launched in September 2019, and it was available at no cost on the German Amazon Alexa store between September 2019 and March 2022. It can be used on different devices, including smart speakers, smart TVs, and smartphones by using the Amazon Alexa app with the integrated Alexa voice assistant. The skill is activated with the easy and intuitive keywords *Alexa, start/open Multiple Myeloma*.

Usage Data

Usage data were retrieved retrospectively and in aggregated form, in accordance with data protection standards, from an Amazon Alexa developer account. These data included the total number of skill installations (user enablements) since the skill's launch, as well as the number of sessions and inquiries (utterances) that were conducted from July 1, 2020, through July 1, 2021, and the topics (intents) that were the most popular during the same time frame.

Patient Survey

To collect data on users' first experiences with the Alexa skill, a web-based patient survey was conducted on the Takeda Oncology website. The survey consisted of 6 questions regarding the usage of voice assistants and experiences with the Alexa skill *Multiple Myeloma*, which were answered in a multiple-choice or free-text format. The survey was promoted by Takeda and via patient organization communication channels. The results were analyzed by using descriptive statistics in Microsoft Excel.

Promotion

By performing multichannel promotion via a Google AdWords campaign, web-based banners, print advertisements, and flyers, we aimed to reach as many patients as possible. A website with an educational video on how to use the skill should additionally empower and motivate patients to use the skill [18].

Results

Skill Features

The Alexa skill *Multiple Myeloma* was launched in September 2019 to empower and educate patients with MM and their families by offering easy access to validated information. The primary features of the skill are answering frequently asked questions and explaining medical terms related to MM disease, diagnostics, and therapy based on underlying expert-reviewed content. The skill currently contains over 30 intents for answering questions regarding MM disease, diagnostics, and therapy (Multimedia Appendix 1). With regard to myeloma disease, questions like "what are myeloma cells" and "what are typical symptoms" can be answered. Further, the skill answers questions regarding myeloma diagnosis, such as "how is myeloma diagnosed" and "what do you know about cytogenetics," and questions regarding myeloma therapy, such as "how is myeloma treated," "why are combination therapies used," and "what is a stem cell transplantation?" Sample questions and answers are shown in Figure 1.

A search function for 29 local German support groups for patients with myeloma was integrated into the skill. This function searches for patient support groups within the perimeter of 200 km around the users (eg, "What patient support groups are near me?") or in a specific city (eg, "Is there a patient support group in Berlin?") based on publicly available data from patient organizations (Multimedia Appendix 1). The algorithm of the search function is shown in Figure 2.

An interactive feature—an MM quiz functionality that provides multiple-choice questions that change on a weekly basis—was added to the skill. The quiz functionality can be actively started either by users asking for the quiz or by users waiting until they are asked if they want to answer the weekly quiz question after starting the skill. Alexa then provides the questions and 3 possible answers—"a," "b," and "c" (Multimedia Appendix 1). The users choose an answer and receive feedback on the answer. Thereafter, the skill offers the option for additional educational information ("Do you want to learn more on this?"). A sample question is shown in Figure 3. The quiz algorithm is shown in Figure 4.

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Figure 1. Examples of question-and-answer content from the Alexa skill “Multiple Myeloma." The original German content was translated for this publication.

Question from user: What are myeloma cells?

Answer Alexa: In multiple myeloma, the plasma cells are degenerated – this means that they are different from healthy cells. The degenerated plasma cells are called myeloma cells. They divide uncontrollably and produce vast quantities of functionless antibodies even without a pathogen. Physicians refer to these antibodies as monoclonal or M-proteins.

Question from user: What do you know about cytogenetics?

Answer Alexa: Determining cytogenetics in multiple myeloma is important because myeloma cells can become more aggressive due to certain mutations. Typical examples in multiple myeloma are the translocation t(4/14) or the deletion del(17p). This may have an impact on therapy selection.

Question from user: What is autologous stem cell transplantation?

Answer Alexa: Autologous stem cell transplantation is the transplantation of the patient's own stem cells. High-dose chemotherapy followed by transplantation of the patient's own stem cells is standard therapy for patients with good general health, even at an older age. Do you want to know more?

(If yes) In order to destroy as many tumor cells as possible, a very high dose of chemotherapy is administered. This destroys the so-called hematopoietic bone marrow, i.e. also the healthy cells. Therefore, before the start of the high-dose chemotherapy, stem cells are taken from the patient's blood, then the high-dose chemotherapy is administered and then stem cells are returned after completion of the treatment.

Figure 2. The algorithm of the search function for finding support groups for patients with multiple myeloma.

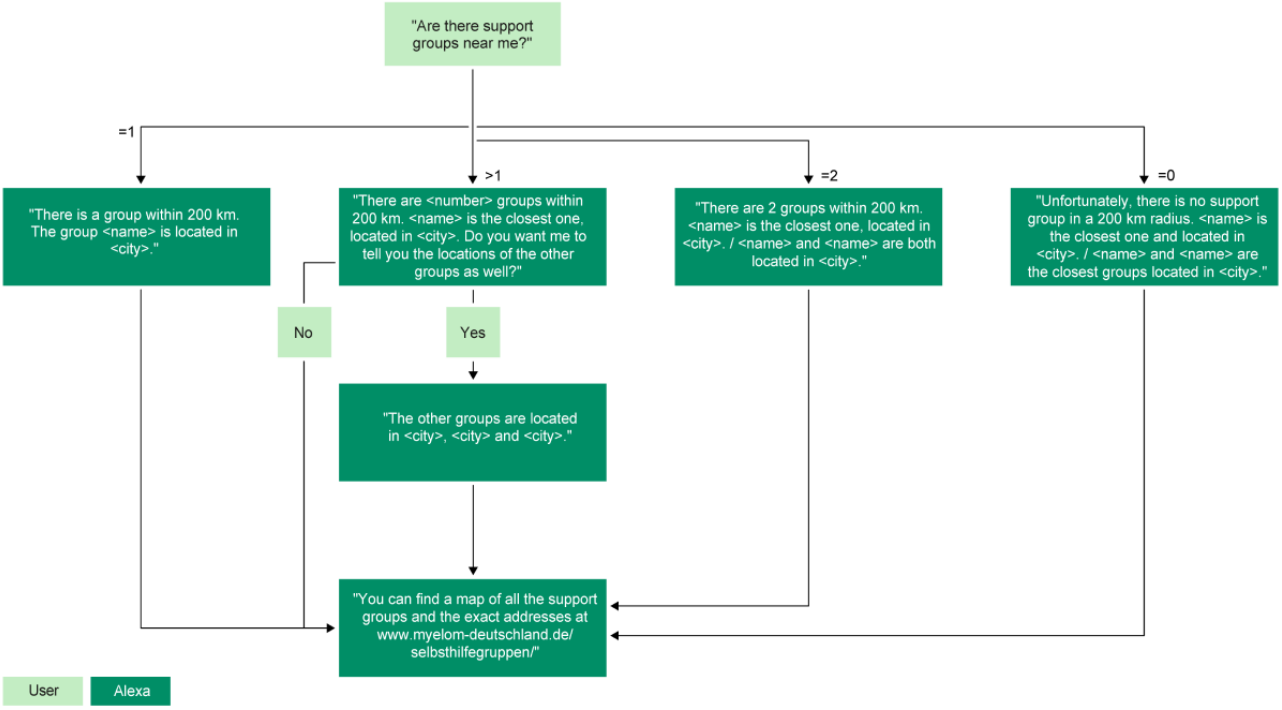

Figure 3. Sample question from the quiz in the Alexa skill “Multiple Myeloma”.

Myeloma cells are malignant plasma cells. What is the function of normal/healthy plasma cells in the body?

A *– Normal plasma cells produce antibodies* (correct answer)

B *– Normal plasma cells produce blood plasma*

C *– Normal plasma cells build bones*

Do you want to learn more?

Plasma cells are part of the immune system. Normal healthy plasma cells produce antibodies to fight infections and release them into the bloodstream.

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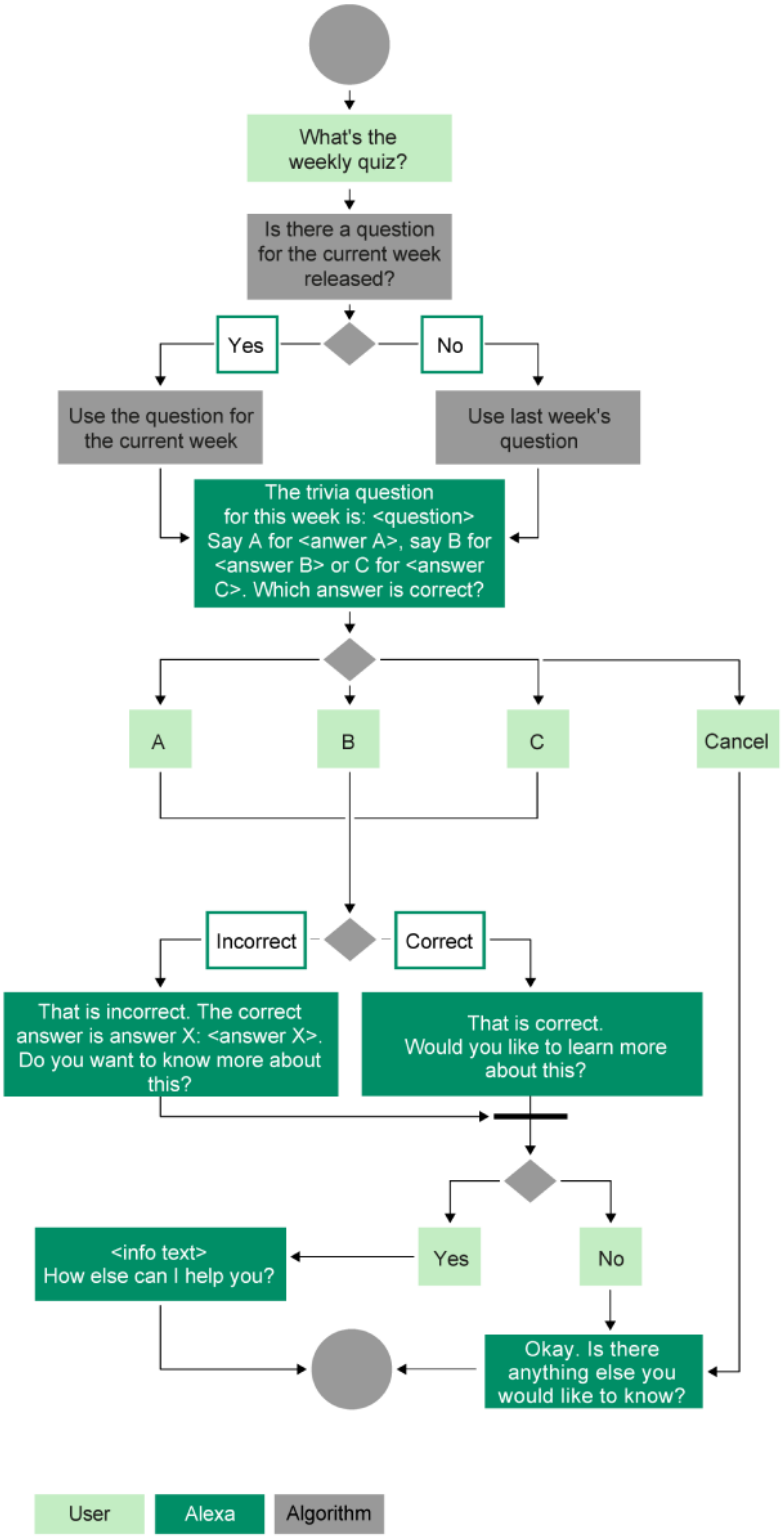
Figure 4. The algorithm of the multiple myeloma quiz functionality.



Usage Data

A total of 141 users (user enablements) have installed the skill since its launch (September 18, 2019, through July 1, 2021). In the time frame of the last 12 months (July 1, 2020, through July 1, 2021), a total of 189 skill sessions were retrospectively analyzed, which included 797 inquiries (utterances), indicating approximately 4 interactions per session. The most popular skill topics during this time frame were patient support groups near the users (58/797, 7.3%), information on MM (53/797, 6.6%), and the weekly quiz function (43/797, 5.4%). The average user retention rate in the analyzed time frame (3 users/week) decreased from 100% at its first use to 18.3% in week 1, 12.9% in week 2, and 1.3% in week 5. This was expectable, since we did not provide new content or news each week. Due to the limited number of total users and sessions in the analyzed time frame, the available usage data were not suitable for a more detailed analysis that would allow for useful interpretations.

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The web-based survey on voice assistant usage and the feedback on the Alexa skill *Multiple Myeloma* were collected from 24 participants. These were patients and patient representatives (15/24, 63%), caregivers (6/24, 25%), HCPs (2/24, 8%), and other types of participants (1/24, 4%). Further, 54% (13/24) of the survey participants reported the prior usage of voice assistants (ie, mainly for listening to music or the radio and searching for information). Nonusers of voice assistants (11/24, 46%) stated that data protection concerns (7/11, 64%) and a lack of need (6/11, 55%) were the most important factors of not using voice assistants in general. Additionally, 50% (12/24) of participants had tested 1 or more functions of the Alexa skill *Multiple Myeloma*, and 46% (11/24) of participants would recommend the Alexa skill.

Discussion

Principal Findings

At MM diagnosis and during the MM disease course, patients with MM and their families are confronted with a lot of information and medical terms related to MM disease, diagnostics, and therapy, generating many questions. Often, patients and their families are not able to address their questions to an HCP directly when they occur. Hence, there is a need for patients and their families to have easy access to accurate, expert-reviewed information at the time they need it and in between formal appointments [6,8]. Further, patients with cancer are more vulnerable to the COVID-19 pandemic, which can impact their psychological health as well as their access to clinics [19,20]. As patient brochures or information on the internet might not be easily accessible for all patients and as older patients might have difficulties with reading or using a computer, voice assistants could offer a new opportunity to patients and their families. The Alexa skill *Multiple Myeloma* can be used with different devices, including smart speakers and smart TVs, and with smartphones by using the Amazon Alexa app with the integrated Alexa voice assistant. As all content of the *Multiple Myeloma* Alexa skill has been reviewed by cross-functional experts, the information is validated and is explained in patient-friendly language.

Although many questions can currently be answered by the skill, the content does not cover all possible questions, leaving room for future improvement. Furthermore, there are restrictions on content that pharmaceutical companies provide to patients based on laws and regulations in Germany; therefore, for example, no information on medications can be provided. The data on participants' first use of the skill, although limited, show that the most popular skill features are directing patients to local patient support groups (58/797, 7.3%), followed by information on MM disease (53/797, 6.6%) and the weekly quiz function (43/797, 5.4%). The usage data, our patient survey, and personal feedback from medical experts and patient support groups have brought to light key challenges in using a medical voice assistant skill. As the median age of patients with MM at diagnosis is 69 years [1], this patient group may be difficult to reach via digital advertisement, and there are often technical obstacles that need to be overcome to install and use voice assistant skills. Therefore, we have added step-by-step instructions on how to use the skill for different devices, and our advertisements for the skill highlight the facts that no smart speaker is needed and that the skill can also be used with any smartphone that has the Alexa app. As we have identified data privacy concerns (7/11, 64%) as obstacles that limit more widespread adoption, especially since it was made public that an Amazon team listened to Alexa recordings to train its speech recognition and natural language understanding systems in 2019 [21], we further educated patients (via our advertisement of the skill) on questions regarding general data privacy concerns with voice assistants. We highlighted that users can change the Alexa privacy settings in the Alexa app if they do not want their voice recordings to be listened to by Amazon employees to improve Alexa's services. Patient support groups suggested offering training to their local groups to introduce the skill and more effectively inform the patient populations in need of such a skill. Ideally, the initial installation and settings (including data privacy settings) are set up under the supervision of an experienced user (eg, in the context of patient support groups). Further limitations include the lack of experience with and use of voice assistants in daily life.

The speech recognition and interpretation of the questions are critical to the quality of the answers given by Alexa, even more so since specialized medical terms are being used. A failure to correctly understand or interpret the users' questions was reported when using the skill. To improve these limitations, the skill's content base could be expanded to cover more topics that are of interest to the users. Also, the addition of further utterances (wording variations of questions) to the existing intents would help users easily find their desired content. Generally, the more frequent use of the Alexa skill could improve its understanding and interpretation abilities through Amazon Alexa's artificial intelligence engine. Further, training Alexa to respond to a user's voice can also contribute to the skill's improvement.

Discussions about the future usage of Alexa skills and voice assistants for patients with MM among HCPs and patient organizations indicated that digital assistants and companions could be useful for promoting and supporting patients' medication adherence. Proactive daily notifications, which can possibly be delivered via Alexa skill "routines," for asking patients about their well-being, documenting side effects, and providing medication reminders could be useful additional features of an extended skill, thereby offering patients a more holistic "companion" during therapy. Medication adherence reminder systems for digital home assistants are currently being evaluated by investigators [22]. Side effects could possibly be documented in a diary function for patients' next visit with a health care professional, and the voice assistant could ask patients to talk to their physician and offer to make a call if the algorithm detects side effects that should be looked at immediately. Functions that provide news on MM advancements in research and patient care could also be interesting features, especially if they can be made to adhere to data compliance and *Heilmittelwerbegesetz* regulations. Finally, voice assistants could also be useful in myeloma clinical studies, as they can be used to collect patient-reported outcomes via voice commands to make data collection easier and more comfortable for patients.

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Conclusions

The Alexa skill *Multiple Myeloma* answers frequently asked questions, explains medical terms, identifies nearby patient support groups, and includes a quiz with the goal of educating and empowering patients with MM.

Acknowledgments

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Authors' Contributions

MAB and LP contributed to the technical concept, skill development, the acquisition of data, the drafting of the manuscript, the critical revision of intellectual content, and the approval of the final version. SD, SJ and, HB drafted the manuscript, critically revised intellectual content, and approved the final version. HS and FF contributed to the technical concept, skill development, the acquisition of data, the critical revision of intellectual content, and the approval of the final version.

Conflicts of Interest

SD, LP, SJ, HB are full-time employees of Takeda Pharma Vertrieb GmbH & Co. KG, Berlin, Germany. This publication is not directly related to and does not deal with any marketed product of Takeda or any product of Takeda in development; the work on the manuscript was carried out without any fiscal support from the company. MAB consults for Takeda and Novartis; receives honoraria from Takeda (except for the work on this manuscript); receives research funding from Novartis; and receives travel grants from Celgene, Amgen, and Janssen. HS receives honoraria from Janssen Cilag, Takeda, Amgen, Bristol Myers Squibb (BMS), Celgene, Sanofi, Oncopeptides, Abbvie, Glaxo Smith Kline (GSK), Chugai, and Pfizer. HS also receives travel grants, accommodations, and expenses from Janssen, Takeda, Amgen, BMS, Celgene, Sanofi, and GSK. FF consults for and receives honoraria from AstraZeneca, Roche, Pfizer, Takeda, Medac, Incyte, BMS, GSK, Janssen, Novartis, Amgen, Servier, and Kedrion.

Multimedia Appendix 1
Overview of the content in the Alexa skill "Multiple Myeloma" (eg, frequently asked questions and a quiz).
[DOCX File , 34 KB - cancer_v8i2e35500_app1.docx]

References

1. Röllig C, Knop S, Bornhäuser M. Multiple myeloma. Lancet 2015 May 30;385(9983):2197-2208. [doi: 10.1016/S0140-6736(14)60493-1] [Medline: 25540889]
2. Cancer stat facts: Myeloma. National Cancer Institute Surveillance, Epidemiology, and End Results Program. URL: https://seer.cancer.gov/statfacts/html/mulmy.html [accessed 2020-09-24]
3. Landgren O, Iskander K. Modern multiple myeloma therapy: deep, sustained treatment response and good clinical outcomes. J Intern Med 2017 Apr;281(4):365-382 [FREE Full text] [doi: 10.1111/joim.12590] [Medline: 28205262]
4. Seitzler S, Finley-Oliver E, Simonelli C, Baz R. Quality of life in multiple myeloma: considerations and recommendations. Expert Rev Hematol 2019 Jun;12(6):419-424. [doi: 10.1080/17474086.2019.1613886] [Medline: 31091117]
5. Puts MTE, Papoutsis A, Springall E, Tourangeau AE. A systematic review of unmet needs of newly diagnosed older cancer patients undergoing active cancer treatment. Support Care Cancer 2012 Jul;20(7):1377-1394. [doi: 10.1007/s00520-012-1450-7] [Medline: 22476399]
6. Fagerlin A, Zikmund-Fisher BJ, Ubel PA. Helping patients decide: ten steps to better risk communication. J Natl Cancer Inst 2011 Oct 05;103(19):1436-1443 [FREE Full text] [doi: 10.1093/jnci/djr318] [Medline: 21931068]
7. Monterosso L, Taylor K, Platt V, Lobb E, Musiello T, Bulsara C, et al. Living with multiple myeloma: A focus group study of unmet needs and preferences for survivorship care. J Patient Exp 2018 Mar;5(1):6-15 [FREE Full text] [doi: 10.1177/2374373517715011] [Medline: 29582005]
8. Pereira MG, Vilaça M, Pereira M, Ferreira G, Monteiro S, Coelho H, et al. The mediator role of unmet needs on quality of life in myeloma patients. Qual Life Res 2020 Oct;29(10):2641-2650. [doi: 10.1007/s11136-020-02511-8] [Medline: 32356277]
9. Jagannath S, Mikhael J, Nadeem O, Raje N. Digital health for patients with multiple myeloma: An unmet need. JCO Clin Cancer Inform 2021 Oct;5:1096-1105 [FREE Full text] [doi: 10.1200/CCI.20.00145] [Medline: 34735265]
10. Hoy MB. Alexa, Siri, Cortana, and more: An introduction to voice assistants. Med Ref Serv Q 2018;37(1):81-88. [doi: 10.1080/02763869.2018.1404391] [Medline: 29327988]

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11. Lake E. How we are talking to Alexa. NHS Digital. 2019 Jul 25. URL: https://digital.nhs.uk/blog/transformation-blog/2019/how-we-are-talking-to-alexa [accessed 2022-05-02]
12. NHS health information available through Amazon's Alexa. GOV.UK. 2019 Jul 10. URL: https://www.gov.uk/government/news/nhs-health-information-available-through-amazon-s-alexa [accessed 2022-05-02]
13. TK Smart Relax: Alexa Skills. Amazon. URL: https://www.amazon.de/Die-Techniker-TK-Smart-Relax/dp/B074QM4KKQ [accessed 2022-05-02]
14. TK Smart Relax sorgt für Entspannung - rund um die Uhr. TK Die Techniker. URL: https://www.tk.de/techniker/magazin/digitale-gesundheit/apps/alexa-tk-smart-relax-2009254?tkcm=aaus [accessed 2022-05-02]
15. DAK Erinnerungs-Coach: Alexa Skills. Amazon. URL: https://www.amazon.de/DAK-Gesundheit-DAK-Erinnerungs-Coach/dp/B07JJVK757 [accessed 2022-05-02]
16. KNAPPSCHAFT BabyGlück: Alexa Skills. Amazon. URL: https://www.amazon.de/KNAPPSCHAFT-BabyGl%C3%BCck/dp/B07HHCRTFR [accessed 2022-05-02]
17. Gesetz über die Werbung auf dem Gebiete des Heilwesens (Heilmittelwerbegesetz - HWG). Bundesministerium der Justiz. URL: https://www.gesetze-im-internet.de/heilmwerbg/BJNR006049965.html [accessed 2022-05-19]
18. Multiples Myelom Alexa Skill. Takeda Onkologie. URL: https://web.archive.org/web/20200810050417/https://www.takeda-onkologie.de/multiples-myelom/mm-alexa [accessed 2022-05-19]
19. Fadavi P, Houshyari M, Kashi ASY, Jarrahi AM, Roshanmehr F, Broomand MA, et al. Review on the oncology practice in the midst of COVID-19 crisis: The challenges and solutions. Asian Pac J Cancer Prev 2021 Jan 01;22(1):19-24 [FREE Full text] [doi: 10.31557/APJCP.2021.22.1.19] [Medline: 33507674]
20. Taghizadeh-Hesary F, Porouhan P, Soroosh D, PeyroShabany B, Shahidsales S, Keykhosravi B, et al. COVID-19 in cancer and non-cancer patients. Int J Cancer Manag 2021 Apr 13;14(4):e110907 [FREE Full text] [doi: 10.5812/ijcm.110907]
21. Parker N. ALEXA, STOP BEING A PERV Outrage as Amazon's Alexa listens to Brits having sex, rowing, swearing and sharing medical news. The Sun. 2019 Jul 29. URL: https://www.thesun.co.uk/tech/9611689/outrage-as-amazons-alexa-listens-to-brits-having-sex-rowing-swearing-and-sharing-medical-news/ [accessed 2022-05-02]
22. Corbett CF, Combs EM, Chandarana PS, Stringfellow I, Worthy K, Nguyen T, et al. Medication adherence reminder system for virtual home assistants: Mixed methods evaluation study. JMIR Form Res 2021 Jul 13;5(7):e27327 [FREE Full text] [doi: 10.2196/27327] [Medline: 34255669]

Abbreviations

AMM: Arbeitsgemeinschaft Multiples Myelom
BMS: Bristol Myers Squibb
GSK: Glaxo Smith Kline
HCP: health care provider
LHRM: Leukaemiehilfe Rhein-Main
MM: multiple myeloma
NHS: National Health Service
TV: television

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Original Paper

Self-monitoring of Physical Activity After Hospital Discharge in Patients Who Have Undergone Gastrointestinal or Lung Cancer Surgery: Mixed Methods Feasibility Study

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Abstract

Background: Self-monitoring of physical activity (PA) using an accelerometer is a promising intervention to stimulate PA after hospital discharge.

Objective: This study aimed to evaluate the feasibility of PA self-monitoring after discharge in patients who have undergone gastrointestinal or lung cancer surgery.

Methods: A mixed methods study was conducted in which 41 patients with cancer scheduled for lobectomy, esophageal resection, or hyperthermic intraperitoneal chemotherapy were included. Preoperatively, patients received an ankle-worn accelerometer and the corresponding mobile health app to familiarize themselves with its use. The use was continued for up to 6 weeks after surgery. Feasibility criteria related to the study procedures, the System Usability Scale, and user experiences were established. In addition, 6 patients were selected to participate in semistructured interviews.

Results: The percentage of patients willing to participate in the study (68/90, 76%) and the final participation rate (57/90, 63%) were considered good. The retention rate was acceptable (41/57, 72%), whereas the rate of missing accelerometer data was relatively high (31%). The mean System Usability Scale score was good (77.3). Interviewed patients mentioned that the accelerometer and app were easy to use, motivated them to be more physically active, and provided postdischarge support. The technical shortcomings and comfort of the ankle straps should be improved.

Conclusions: Self-monitoring of PA after discharge appears to be feasible based on good system usability and predominantly positive user experiences in patients with cancer after lobectomy, esophageal resection, or hyperthermic intraperitoneal chemotherapy. Solving technical problems and improving the comfort of the ankle strap may reduce the number of dropouts and missing data in clinical use and follow-up studies.

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KEYWORDS

mobile phone; physical activity; self-monitoring; fitness trackers; telemedicine; cancer; physical therapy

Introduction

Surgery is an essential curative treatment option for patients diagnosed with gastrointestinal or lung cancer; however, it has a major impact on daily functioning and quality of life [1-3]. Most patients experience incomplete or delayed recovery of physical functioning after major thoracic or abdominal surgery [2-4].

During hospitalization, stimulation of physical activity (PA) has been shown to enhance the recovery of physical functioning [2,4-6], reduce the postoperative risk of readmission, and shorten the length of hospital stay [7,8]. Therefore, PA promotion is integrated into Enhanced Recovery After Surgery (ERAS) programs [9]. The aim of ERAS programs is to reduce postoperative complications and improve postoperative recovery. However, ERAS programs are mainly limited to the period of hospitalization, whereas encouraging PA after hospital discharge is also important for improving functional recovery [10,11].

In their own environments, increasing PA levels and resuming daily activities can be challenging for patients. They may experience barriers such as physical symptoms, insecurity, lack of motivation, or social support in doing so [12]. The use of body-worn accelerometers can support patients in resuming their daily activities after cancer surgery [10,13]. Such devices enable self-monitoring of and feedback on PAs by quantifying the frequency and intensity of human movement [14].

Adequate use of accelerometers for PA self-monitoring is an important prerequisite for its potential positive effect on functional recovery. Several studies have shown the feasibility of PA self-monitoring in patients who have undergone major (oncological) surgery, each using a different device [15,16]. Qualitative data on experiences with PA self-monitoring in these patients are largely unknown [17], and these experiences may add to the knowledge about potential barriers to the use of this technology and may help resolve them [18].

Therefore, this study aimed to collect both quantitative and qualitative data to investigate the feasibility of self-monitoring of PA using accelerometers after hospital discharge in patients with cancer who have undergone gastrointestinal or lung cancer surgery.

Methods

Ethics Approval

The study was approved by the medical research ethics committee of the Amsterdam University Medical Centers, location Vrije Universiteit Medical Center (registration number 2018/112). All patients provided written informed consent.

Study Design

A feasibility study with a mixed methods design was performed between April 2019 and April 2020 in patients with gastrointestinal or lung cancer scheduled for surgery. The formal sample size was not calculated. Instead, a convenience sample with a 1-year inclusion period was chosen. Self-monitoring of PA after hospital discharge was evaluated using a questionnaire and interviews conducted in April 2020, and the study procedures were evaluated using administrative data during the course of the study.

Participants

The inclusion criteria were adult patients with gastrointestinal or lung cancer who were invited for preoperative physiotherapy screening between April 2019 and April 2020 at the outpatient clinic of our tertiary teaching hospital (Amsterdam University Medical Center, location Vrije Universiteit Medical Center), which included patients scheduled for a lobectomy, esophageal resection, or hyperthermic intraperitoneal chemotherapy (HIPEC). Exclusion criteria were <7 days between inclusion and surgery, emergency procedures, patients who are nonambulatory, and no access to or not able to use a smartphone or tablet.

Intervention

Potentially eligible patients were informed about the study by the treating physiotherapist during the preoperative consultation. Patients who were willing and eligible to participate received the Physical Activity Monitor (PAM) AM400 3-axis accelerometer (Pam BV Doorwerth) and were given access to the corresponding smartphone app called *Atris* (Peercode BV, Geldermalsen; Figures 1 and 2). The PAM was selected for this study as (1) the PAM AM400 was found to be a suitable movement sensor to validly measure activity minutes [19]; (2) the battery of the PAM lasts for approximately 1 year, eliminating the need for patients to recharge the device; (3) the data of the PAM can be synced directly to a web-based application, enabling remote monitoring by clinicians; and (4) the PAM can be worn around the ankle and is waterproof to allow 24/7 wearing. The PAM measures PA continuously and provides the total PA every 15 minutes. With the *Atris app*, patients were able to self-monitor their daily PA levels and received feedback on the number of active minutes per day. Patients were able to set personal activity goals in the app by themselves.

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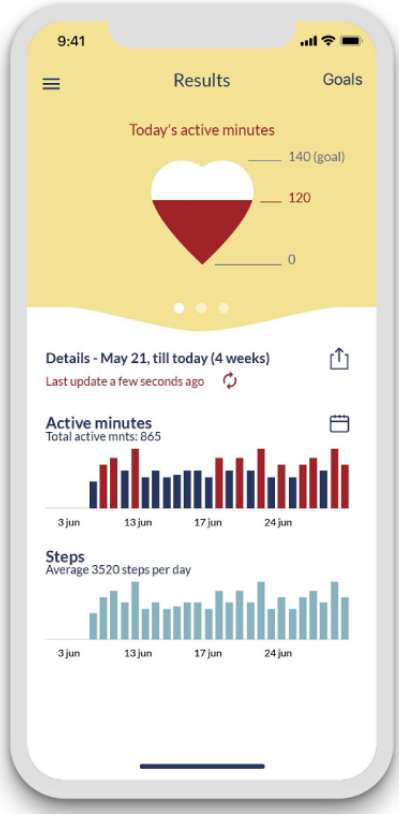
Figure 1. The Physical Activity Monitor.

Figure 2. Atris app.



All patients received the usual pre- and postoperative physiotherapy care. During the standard preoperative consultation, potential risk factors (eg, smoking or sedentary lifestyle) for delayed postoperative recovery were identified, leading to personalized advice for improving preoperative physical fitness. In addition, the patients were given instructions about the PAM and *Atris* app. The physiotherapist informed the patient that the app provided insights into the recovery of PA and advised them to use the app to resume their daily activities after surgery. Patients were asked to start wearing the PAM 24 hours a day in a strap around the ankle for at least 7 days before surgery to familiarize themselves with its use.

During hospitalization, patients received standard physiotherapy consultations and were stimulated to mobilize according to a daily mobilization goal following the ERAS protocol [20]. In addition, the physiotherapist guided the patients in using the PAM and *Atris* app.

Personalized rehabilitation recommendations were provided at discharge. If indicated by the physiotherapist, the patients were advised to continue physiotherapy in primary care after discharge. For this study, the patients were asked to wear the PAM 24 hours a day for 6 weeks. A period of 6 weeks was chosen as it was expected that patients would be able to gain sufficient experience using the PAM and *Atris* app to assess feasibility. A hospital physiotherapist provided insights into the activity levels of the patient on the corresponding web application and monitored the activity data of the patients weekly. In case the activity levels decreased or no data were available, the physiotherapist contacted the patient. In the case of technical problems, the physiotherapist helped resolve them if possible. In cases where patients had problems resuming their PA level by themselves, the physiotherapist advised them to contact a physiotherapist in primary care. The patients also had the opportunity to contact the physiotherapist themselves.

Outcome Measures

Study Procedures

Patients who were willing to participate (out of potentially eligible patients invited to the study), those who ultimately participated, and those who completed the study were recorded

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and described as percentages. Furthermore, the amount, type, and reasons for missing PAM data were identified. For exploration purposes, the PAM data were described as the number of active minutes per day (24 hours) from 1 week before surgery (baseline) to 6 weeks after surgery.

System Usability

System usability was assessed using the Dutch translation of the System Usability Scale (SUS). The SUS contains 10 statements about efficiency, learnability, and satisfaction and has been validated to assess the usability of electronic systems [21]. Patients can indicate the degree of agreement with each statement on a 5-point Likert scale. The total SUS score ranges from 0 to 100, with a score of ≥70 considered good. The patients received an email in April 2020 to complete the questionnaire on a secured web-based system (Castor Electronic Data Capture).

User Experiences

In addition to the SUS, the patients received 13 additional questions about the acceptability, satisfaction, and added value of the PAM and *Atris* app that was experienced (see Multimedia Appendix 1 for the questionnaire). In addition, the user experiences of the patients were assessed using semistructured qualitative interviews (see Multimedia Appendix 2 for the topic list). The responses to the SUS and additional questions were used as supplemental topics to the topic list. All patients were asked if they were willing to participate in the interviews. There were 2 groups, patients who did and patients who did not experience additional value. Of both groups, 3 patients were randomly selected for the interview. Interviews were conducted by VvV and MEdL via telephone and recorded using a voice recorder. Interviews were transcribed verbatim.

Descriptive Data

Demographic and clinical data were collected retrospectively from electronic medical records.

Feasibility Criteria

To evaluate the feasibility of self-monitoring of PA using the PAM and *Atris* app, we set feasibility criteria a priori based on cutoff points described in previous studies (Textbox 1) [21-25].

To better understand the feasibility, additional qualitative data on acceptability, satisfaction, and experienced additional value were collected to explore user experiences.

Textbox 1. Feasibility criteria based on cutoff points described in previous studies.

Willingness to participate

- Percentage of invited, potentially eligible, patients who were willing to participate in the study; a percentage of >70% was considered feasible

Participation rate

- Percentage of willing and eligible patients who intended to participate in the study; a percentage of >60% was considered feasible

Retention rate

- Percentage of included patients who completed the study (ie, these patients did not explicitly indicate their decision to stop); a retention rate of 80% was considered feasible

Data collection

- Percentage of missing Physical Activity Monitor data was determined to investigate whether physical activity data collection using the Physical Activity Monitor was feasible; complete data in at least 70% of all participants were considered feasible

System usability

- Measured with the System Usability Scale; a score of ≥70 was considered good

Data Analysis

SPSS (version 26; IBM Corp) was used for quantitative data analysis. Study population characteristics were presented descriptively as mean (SD), median (IQR), and percentage. Quantitative data were analyzed descriptively. The study procedures were presented as percentages. PAM data were considered missing if they were not available for ≥3 days in a given week. The available PAM data are presented as the median (IQR) of the total active minutes per day of each week and as a percentage of the preoperative PA baseline level. The mean (SD) SUS was calculated using the method described in the study by Brooke [21]. Additional questions about user experience are presented as percentages.

The research software ATLAS.ti (version 8) was used for qualitative analysis. Qualitative data analysis was performed following the steps of thematic analysis by 2 researchers (MvdL and MB) [26]. The interviews were read several times to familiarize with the data. Data were open coded line by line to segment them into the initial codes. Axial coding was used to define the definitive codes. Definitive codes were classified and described under different themes [26].

Results

Overview

A total of 90 potentially eligible patients were invited to participate between April 2019 and April 2020, of whom 68 (76%) were willing to participate. After the final eligibility check, of the 90 patients, 57 (63%) were included in the study, resulting in a participation rate of 63%. The retention rate was 72% (41/57); 28% (16/57) of patients dropped out during the

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study, of whom 44% (7/16) were related to the intervention. The reasons for nonparticipation, exclusion, and dropout are presented in the flowchart (Figure 3). Ultimately, 41 patients were included in the analysis. The median age of the patients in this study was 68 (IQR 60-73) years, and 58% (25/41) were male. The most common types of surgery were lobectomy (23/41, 56%) and HIPEC (10/41, 24%). The median length of hospital stay was 7 (IQR 6-11) days. Other relevant demographic and clinical data are presented in Table 1.

Approximately, 31% of the PAM data were missing. Missing value analysis suggested that the data were missing at random, as missing data increased during the time blocks of the postoperative phase. The amount of missing data increased during the 6 postoperative weeks: 27% of the PAM data were missing in the first postoperative week and 44% in the sixth postoperative week. Figure 4 shows an overview of the reasons for the missing data. The most common reasons for missing data were technical problems or withdrawal of wearing the PAM. Table 2 shows the median preoperative and postoperative PA levels in minutes per day and the median percentage of recovery in PA compared with the preoperative levels.

Figure 3. Flow of participants through the study. PA: physical activity.

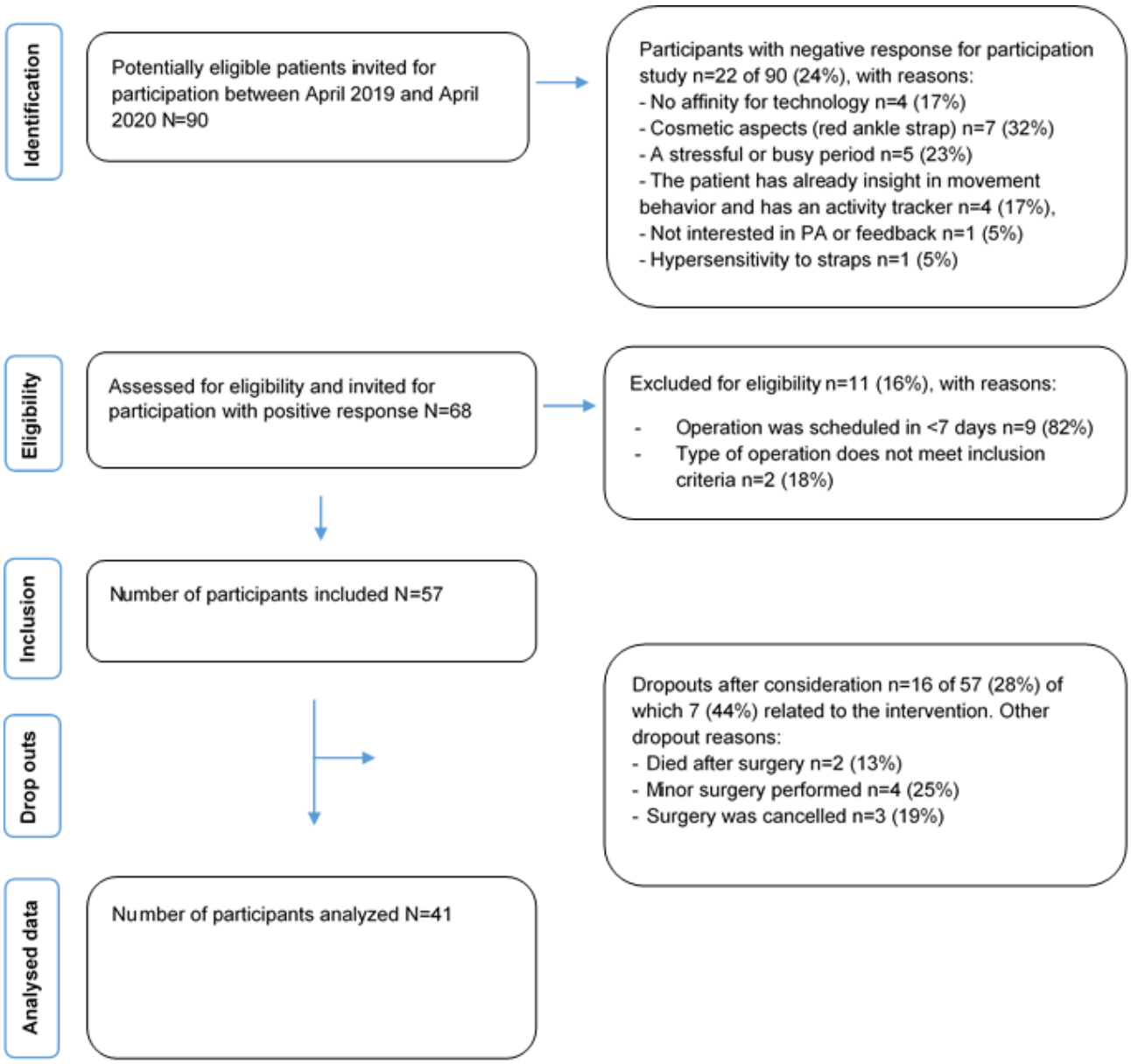

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Table 1. Patient characteristics (N=41).

Variable	Results
Patient characteristics	
Sex (male), n (%)	25 (58)
Age (years), median (IQR)	68 (60-73)
BMI, mean (SD)	26.1 (4.2)
Smoke status, n (%)	
Current	5 (12)
Past	24 (59)
Never	12 (29)
Primary diagnosis, n (%)	
Rectum cancer	1 (2)
Lung cancer	21 (51)
Esophagus cancer	8 (20)
Peritonitis carcinomatosa	8 (20)
Schwannoma	2 (5)
Thymoma	1 (2)
Tumor stage, n (%)	
1	7 (17)
2	8 (20)
3	6 (15)
4	18 (44)
Schwannoma	2 (5)
Comorbidities (ASA[a] score), n (%)	
Grade I	3 (7)
Grade II	27 (66)
Grade III	10 (24)
Grade IV	1 (2)
Type of treatment before surgery, n (%)	
Neoadjuvant chemotherapy	3 (7)
Neoadjuvant chemoradiotherapy	9 (22)
Neoadjuvant immunotherapy	1 (2)
Neoadjuvant hormone therapy	1 (2)
Sports ≥1 time per week, n (%)	15 (37)
Missing	1 (2)
Perioperative characteristics	
Type of surgery, n (%)	
Lobectomy	23 (56)
Esophagus resection	7 (17)
HIPEC[b] procedure	10 (24)
Schwannoma resection	1 (2)
Surgical approach, n (%)	
Video-assisted thoracic surgery	6 (15)

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Variable	Results
Open surgery	35 (85)
Type of treatment after surgery, n (%)	
Adjuvant chemoradiotherapy	2 (5)
Adjuvant chemotherapy	3 (7)
Adjuvant radiotherapy	1 (2)
Adjuvant hormonotherapy	1 (2)
Length of stay (days), median (IQR)	7 (6-11)
Complications (Clavien Dindo score), n (%)	
Grade I	26 (63)
Grade II	5 (12)
Grade IIIa	2 (5)
Grade IIIb	5 (12)
Grade IVa	3 (7)
Hospital readmission, n (%)	5 (12)
Duration of operation (minutes), median (IQR)	200 (128-336)

[a]ASA: American Society of Anesthesiologists.
[b]HIPEC: hyperthermic intraperitoneal chemotherapy.

Figure 4. Reasons for missing data. PAM: Physical Activity Monitor.

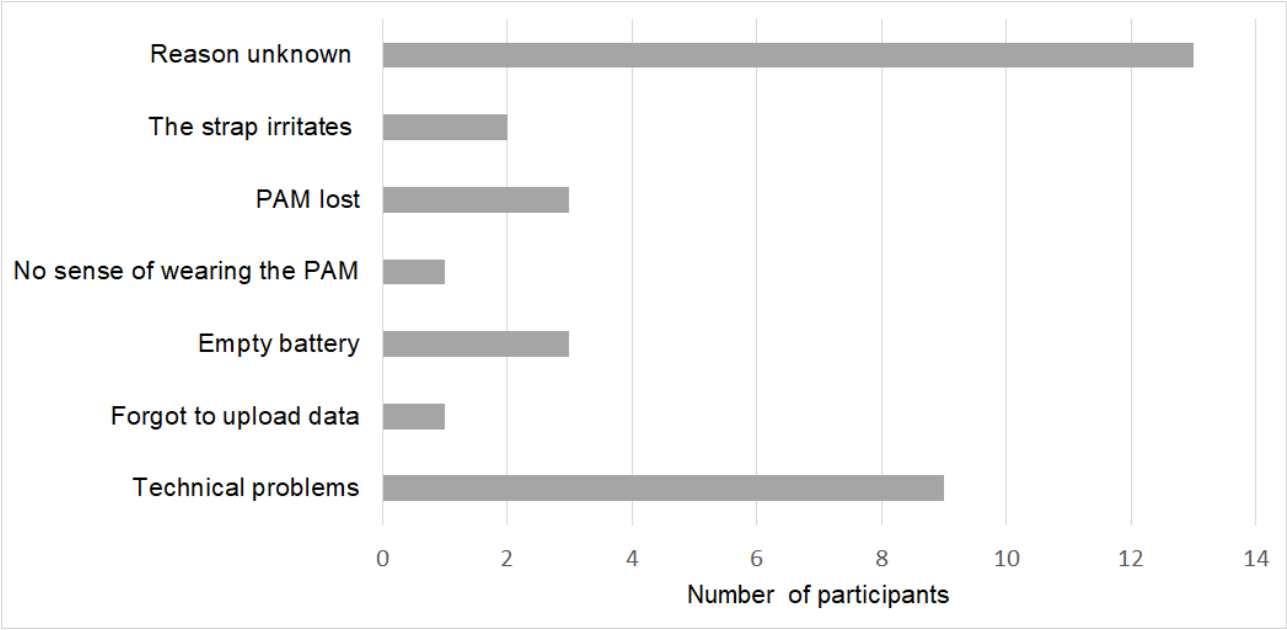

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Table 2. Median PA[a] (minutes per week) and percentage of PA compared with preoperative levels of PA (N=41)[b].

PA level	Preoperative	1 week[c]	2 weeks	3 weeks	4 weeks	5 weeks	6 weeks
PA (minutes)							
Values, median (IQR)	172 (114-213)	51 (26-82)	87 (54-138.5)	96 (68.5-171.5)	108 (78.3-170.5)	118.5 (80-196.5)	139 (81-184)
Values, n (%)	38 (93)	30 (73)	29 (71)	29 (71)	28 (68)	28 (68)	27 (66)
PA compared with preoperative level of PA (%)							
Values, median (IQR)	N/A[d]	29.4 (17.9-47.4)	55.7 (34.1-77.0)	65.0 (44.9-84.3)	67.2 (52.1-93.5)	78.0 (49.6-101.9)	80.3 (57.6-99.7)
Values, n (%)	N/A	29 (71)	27 (66)	26 (63)	25 (61)	25 (61)	25 (61)

[a]PA: physical activity.

[b]PA at baseline (preoperative; time point 0) and 1 to 6 weeks postoperative (time point 1 to time point 6).

[c]After surgery.

[d]N/A: not applicable.

Feasibility

Overview

The results of the feasibility criteria are presented in Table 3.

Table 3. Summary of results of feasibility criteria.

Feasibility criteria	Targets	Results	Conclusions
Study procedures			
Willingness to participate	Percentage of willing patients >70%	76% of the invited patients were willing to participate	Feasible
Participation rate	Participation rate >60%	The participation rate was 63%	Feasible
Retention rate	A retention rate of >80%	The number of dropouts during the study was 16; this resulted in a retention rate of 72%	Marginally feasible
Data collection	Complete outcome data of PA[a] in at least 70% of all participants at follow-up	Approximately 31% of the PA data were missing; the number of complete cases was 9, and 8 cases had <10% missing data	Not feasible
System usability			
Efficiency	SUS[b] score ≥70	Mean 79.6 (SD 24.2)	Feasible
Learnability	SUS score ≥70	Mean 74.0 (SD 27.5)	Feasible
Satisfaction	SUS score ≥70	Mean 75.0 (SD 25.2)	Feasible
User experience			
Study patients	Qualitative data about acceptability, satisfaction, and experienced added value	Wearing the PAM[c] was acceptable, patients were largely positive about the PAM and Atris app, and most patients experienced an added value; technical problems and the comfort of the ankle strap need to be improved	Feasible

[a]PA: physical activity.

[b]SUS: System Usability Score.

[c]PAM: Physical Activity Monitor.

SUS and Additional Questions

Of the 41 patients, the SUS and additional questionnaires were sent to 39 (95%) patients (n=2, 5% of patients died before April 2020). The mean number of weeks between the end of the self-monitoring period and receiving the questionnaire was 21.6 (SD 17.0). Approximately 85% (33/39) of patients responded to the questionnaire, of whom 5% (2/39) did not complete the entire questionnaire. System usability was feasible, with a mean SUS score of 77.3 (SD 20.7). Of all responding patients, 75% would recommend other patients to use the PAM and *Atris* app after surgery. Most patients (84%) indicated that they wore the PAM all day during the study period. The reasons for not wearing the PAM were poor comfort with the ankle strap or technical problems (eg, connection problems between the PAM

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and app). The other outcomes of the questionnaire are presented in Multimedia Appendix 3.

Interviews

Overview

Of the 39 patients, 8 (21%) patients did not respond to the interview invitation, and 4 (10%) were unwilling to participate in additional interviews. Of the remaining 27 patients who were willing to participate, 8 (30%) patients did not, and 19 (70%) patients found that the use of the PAM and *Atris* app added value. Approximately 15% (6/39) of patients were selected. The characteristics of the interviewed patients are shown in Table 4. The results are described by themes in the following paragraphs and supported by quotes (Table 5). The code tree is shown in Figure 5.

Table 4. Characteristics of interviewed patients.

Interviewee number	Gender	Age (years)	Type of surgery	ASA[a]	Length of hospital stay (days)	Missing data (%)	SUS[b] score
1	Male	69	HIPEC[c] (open)	1	11	69.4 (reason unknown)	70
2	Female	61	Lobectomy (VATS[d])	2	3	63.3 (PAM[e] lost)	90
3	Male	66	Lobectomy (VATS)	2	11	0	85
4	Male	77	Lobectomy (VATS)	2	4	34 (connection lost between PAM and smartphone)	97.5
5	Male	56	Lobectomy (open)	2	7	34.7 (no connection between PAM and smartphone)	67.5
6	Male	73	Lobectomy (open)	2	5	26.5 (low battery)	92.5

[a]ASA: American Society of Anesthesiologists.

[b]SUS: System Usability Scale.

[c]HIPEC: hyperthermic intraperitoneal chemotherapy.

[d]VATS: video-assisted thoracic surgery.

[e]PAM: Physical Activity Monitor.

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Table 5. Quotations of interviewed participants.

Quotation	Code	Interviewed participant number
User adherence		
"By the way, that bracelet was awful. Especially the closure. You have to invest a bit more in that. I don't know much else to improve. It weights nothing. You even forget it once in a while." (quote 1)	Comfort of the ankle strap	2
"Every morning and during the day I had to put the bracelet back on again, because it would be loose for a while, but that wasn't that bad...I don't have any complaints about it, that bracelet is a simple but good solution for wearing the sensor." (quote 2)	Comfort of the ankle strap	6
"In the beginning I had some trouble with updating. The connection wasn't always good. I have a certain brand of phone and apparently it doesn't work as well as other phones. Later I did a new update and then it worked better. I also had some contact with the VUmc about this." (quote 3)	Technical problems	4
"It didn't work well at all times. Then I called for a new battery. Then it worked again." (quote 4)	Technical problems	5
"And again about the technical problems. That really frustrated me. I called with the VUmc for help. They could often improve it remotely and the new battery helped in the end." (quote 5)	Technical problems	5
"I found the use of the app very friendly. Very easy, absolutely not unnecessarily complicated." (quote 6)	Easy to use	2
"It was a new experience for me. But I had no problems at all with it. It all went well." (quote 7)	Easy to use	6
"I have not thought for a moment of not using it because of my privacy. Only my active minutes were registered and I did not see any reason not to use it." (quote 8)	No privacy concerns	6
Experienced added value		
"I thought it was a phenominal item...You keep track of your active minutes in the app during the day. I do not use cell phones very often, because I am 63 years old, but this was a very nice challenge." (quote 9)	Provided insights into recovery	2
"I found it a nice application, I watched it every day." (quote 10)	Provided insights into recovery	6
"It had really became part of my lifestyle. When I went to sleep I took it off and put it on the bedside table. Before I took a shower I put it o, so every active minute would count. I had the feeling that the health professionals from the Vumc did everything they could, so I wanted to do that myself. This device helped me a lot with that." (quote 11)	Provided support	5
"Well if we look at the operation, especially my recovery, then it's very important to me that I have insight in and influence on my recovery. That you are able to see if you're making progress. When I just started I was 30 minutes active per day and at the end I was 4 to 5 hours active. It is very nice and important to have that insight." (quote 12)	Provided insights into recovery	3
"Well it worked really stimulating for me. Making movement goals gives direction in the rehabilitation proces. You can work towards that. It has really helped me and that's why I would recommend it to others." (quote 13)	Motivating effect	5
"You feel more co-responsible. Well then it's nice that you can show you are dowing well and that you try your best." (quote 14)	Motivating effect	3
"It's an addition to you health and life. It makes rehabilitation a little easier and more challenging. It focuses more on recovery than on your problems." (quote 15)	Provided support	2
"It's all very frightening and scary. What is going to happen? Will I wake up after the operation? Can I still do the same as I did? There is a lot going through you head and it's pretty scary, to be honest. At that moment, health profesionnals and such a motion sensor around you ankle helps enormously. You get feedback and it gives you something to hold on to." (quote 16)	Provided support	5
"I think it is a very good remedy. Only for myself it had not been necessary. For someone who has more difficulty with being active this is a completely different story. Then it can be a very nice support. If I speak for myself, it was just that I was curious about how much I walked that day." (quote 17)	Suitability	4
"I already moved a lot: I go to the gym twice a week and I also walk a lot and cycle a bit. Therefore, the PAM wasn't the reason I started being more active. But it was nice to see how active I was during the day." (quote 18)	Suitability	6

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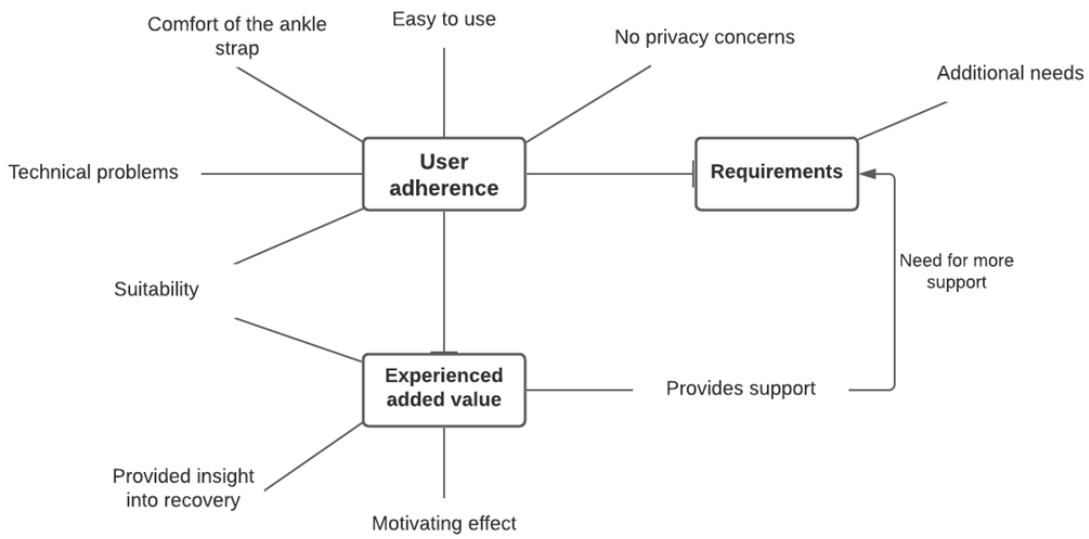
Quotation	Code	Interviewed participant number
Requirements		
"I would like to get a signal if I don't show good or abnormal activity behavior. Starting a conversation. That's also possible by telephone. I don't necessarily have to come to the VUmc more often. But such a conversation would be very nice." (quote 19)	Need for more support	1
"A sort of alarm or stimulating message. I think that also helps in creating awareness. People need to become aware of their activity behavior. A message when things are not going that well can help with that. It triggers you to think about it." (quote 20)	Need for more support	2
"I would like to get some more information as well. So besides the activity data. For example, about the heartrate and blood pressure. But anyway, it might also be difficult to integrate that into one application." (quote 21)	Additional needs	4
"Activity data should be more clearly displayed. Now you have a graph, but the activity data is only presented per day. You actually want to be able to see data and differences during the day. For example my difference in activity between an evening shift and day shift at work. I would have found that interesting to be able to see." (quote 22)	Additional needs	5
"I think it might work better if the goals are better tailored to the person." (quote 22)	Additional needs	5

Figure 5. Code tree.



User Adherence

Topics that may have had a negative impact on user adherence included problems experienced with the ankle straps and technical problems. All the interviewed patients experienced problems with the closure of the strap. They mentioned occasional loosening of the strap, as the closure did not function properly (quote 1; Table 5). Despite this problem, wearing the bracelet was an obstacle for none of the patients (quote 2; Table 5). In total, 67% (4/6) of patients mentioned technical problems; sometimes the connection between the sensor and the app did not work, disabling the update of the activity data (quote 3; Table 5). Of these 4 patients, 2 (50%) received a new sensor as the battery was depleted prematurely (quote 4; Table 5). One of the participants mentioned that the technical problems were frustrating (quote 5; Table 5).

Topics that may have had a positive effect on user adherence were ease of use of the *Atris* app (quotes 6 and 7; Table 5) and absence of privacy concerns (quote 8; Table 5).

Experienced Added Value

Most of the interviewed patients were positive about the use of the PAM and *Atris* app (quotes 9 and 10; Table 5). One of the participants mentioned that the use of the PAM had become a part of his lifestyle (quote 11; Table 5). All patients experienced having more insight into their recovery with the use of the PAM and *Atris* app as they were able to see if they were making progress (quote 12; Table 5). In addition, they mentioned that the PAM and *Atris* app had a motivating effect. They stimulated them to be more physically active as they were able to set goals and they felt more coresponsible for their recovery (quotes 13 and 14; Table 5). Moreover, patients experienced the PAM and *Atris* app as support during their recovery process. They

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mentioned that they provided more focus on recovery and provided something to hold on to (quotes 15 and 16; Table 5).

Approximately 33% (2/6) of patients did not experience additional values but were positive about the concept. They mentioned that they were already motivated to be physically active regardless of the PAM. They thought it would be more suitable for patients who needed more motivation to be physically active (quotes 17 and 18; Table 5).

Requirements

Overall, 67% (4/6) of patients highlighted the need for more support. They mentioned that it would be of additional value if they received messages or calls in situations of insufficient or abnormal activity behavior (quote 19; Table 5). Moreover, 33% (2/6) of patients also mentioned that motivational messages might serve as additional incentives (quote 20, Table 5). Additional requirements mentioned by 4 patients were the possibility to add additional measurements of data, such as heart rate or blood pressure (quote 21; Table 5). In addition, 33% (2/6) of patients wanted to gain more insight into the activity pattern during the day (quote 22; Table 5); 33% (2/6) of patients highlighted the need for more personalization (quote 23; Table 5).

Discussion

Principal Findings

Self-monitoring of PA after discharge appears to be feasible based on good system usability and predominantly positive user experiences in patients with cancer after lobectomy, esophageal resection, or HIPEC. These findings are consistent with those of other studies [15-17,22]. Wu et al [15] found good feasibility of self-monitoring using a wrist-worn accelerometer and an app in patients after gastric cancer surgery. Low et al [17] reported good usability of a real-time mobile technology–based sedentary behavior intervention for patients with abdominal cancer in the perioperative period using a smartwatch. However, feasibility was considered moderate in that study as adherence to wearing the smartwatch decreased significantly from before to after the surgery. In our study, adherence also seemed to decrease based on an increase in missing data during the intervention period. Solving technical problems and improving the comfort of the ankle strap may reduce the number of dropouts and missing data in clinical use and follow-up studies. In addition, improving self-efficacy and self-motivation and engaging in more social support could enhance user adherence, as suggested in a systematic review of predictors of adherence in home-based physical rehabilitation [27].

The system usability of the PAM and *Atris* app is similar to that of devices used in other studies [17,25]. Jonker et al [25] reported good system usability (mean SUS 73.1) for a wrist-worn activity tracker and mobile app in older adult patients after oncological surgery. In a study by Low et al [17], the system usability of a Fitbit smartwatch with an accompanying smartphone app during the perioperative period in patients scheduled for abdominal cancer surgery was also found to be good (mean SUS 83.8). The qualitative data, in addition to the quantitative data, provided insights into the facilitators of and barriers to the use of the *Atris* app and PAM. The user experiences were largely positive. The interviewed patients mentioned that the PAM and *Atris* app were easy to use, motivated them to be more physically active, and provided support after discharge. However, most of the patients recommended the design of a more comfortable ankle strap, and some were annoyed about technical problems. Only a few patients did not experience the added value of the PAM and *Atris* app as, in their opinion, they were already sufficiently active and, therefore, did not feel the need for additional support. In contrast, some other patients indicated the need for more support, such as through occasional telephone contact with a physiotherapist or motivational messages. Therefore, the tailoring of interventions to individual needs and preferences should be considered.

In this study, we explored the course of recovery in PA in the first 6 weeks after surgery. These results may be supportive in clinical practice to gain more objective insights into patient recovery and identify which patients may need more support in improving their PA levels. We found that most (19/25, 76%) of our study population did not return to baseline PA levels 6 weeks after surgery, although these results should be interpreted with caution, given the relatively large amount of missing PA data. In previous observational pilot studies using objective PA data after (cancer) surgery, most patients did not reach preoperative PA levels even at 3 months after surgery [28,29]. Similarly, a study using questionnaires to investigate the course of recovery in physical functioning 6 and 12 weeks after lung cancer surgery showed that patients were still recovering between 6 and 12 weeks after surgery [4]. The patients in our study underwent major surgeries, including HIPEC and major lung resections. These procedures are both associated with prolonged functional recovery compared with less invasive procedures such as minimally invasive segmental colectomies or video-assisted small lung resections. Therefore, it is suggested that for most of these patients, the period of supportive care to improve PA should be >6 weeks after surgery. However, to increase user adherence for longer-term use, the previously mentioned improvements to the ankle bracelet and resolution of technical problems are necessary. In addition, to better understand all dimensions of user adherence, an in-depth analysis of adherence to ambulant monitoring in this patient population should be performed, taking into account the 5 dimensions of adherence as described by the World Health Organization [30].

By conducting this feasibility study, barriers and enablers were identified for the use of the PAM and *Atris* app after hospital discharge in patients after cancer surgery. However, proper technical functioning and comfort in wearing are important prerequisites for all activity trackers. Moreover, the enablers found in our study, for example, that it motivates patients to be more physically active and that it provides more insight into PA recovery, are also generalizable to other activity trackers. The cost-effectiveness and effectiveness of interventions using PA self-monitoring during cancer treatment is largely unknown, and the conduct of randomized clinical trials is warranted [31]. In addition, not all patients seem to require the same amount of postoperative support. Further research should take into account

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the risk of functional decline after surgery, as well as the needs and preferences of individual patients.

Limitations

This study had some limitations. First, this feasibility study was conducted in a single hospital setting. In addition, not all diagnoses within gastrointestinal and lung cancer surgery were represented in our study population as preoperative physiotherapy screening was not part of the care pathway for all patients in our hospital. Therefore, the results of this study cannot be generalized to other diagnoses. Second, all patients were contacted to ask whether they were willing to participate in an interview after PA data collection had already ended. However, some patients did not respond or were unwilling to participate in the interviews. This could have caused a selection bias. To reduce selection bias among the patients interviewed, they were selected based on whether they perceived the PAM and *Atris* app as adding value. However, the selected interviewees had a somewhat higher mean SUS score than that of the entire study population (83.8 vs 77.3). Thus, this approach probably did not sufficiently eliminate the selection bias. To gain a full understanding of feasibility, future studies should also interview nonparticipants. In addition, data saturation may not have been achieved as the interviews were conducted in a small and partly selective sample. Third, for some patients, there was a period of several months between the end of the self-monitoring period and the completion of the questionnaires (and interviews), which may have led to recall bias. Finally, as the study was conducted in the usual care setting, the perioperative instructions from the physiotherapist were not strictly followed as per protocol, which hindered reproducibility. Our research group is currently working on a protocol to guide physiotherapists in using this intervention.

Conclusions

The results of our study showed good system usability and predominantly positive user experiences in patients with cancer after lobectomy, esophageal resection, or HIPEC. Most patients mentioned that the PAM and *Atris* app motivated them to be more physically active after discharge. The retention rate and amount of missing data need to be improved in follow-up studies. Solving technical problems and improving the comfort of ankle straps may enhance user adherence, thereby reducing the number of dropouts and missing data. Randomized clinical trials should be conducted to investigate whether interventions using accelerometers indeed improve the recovery of PA and physical functioning after surgery in this population.

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Authors' Contributions

EG, VvV, EEHvW, CD, JBT, MvdL, and MvdS conceived the study. EG included the patients for this study. EG, VvV, and MEdL collected the data. MEdL and MB analyzed the quantitative and qualitative data. MEdL and MB drafted the manuscript. MEdL, MB, MvdL, MvdS, and VdG drafted the final version of the manuscript. All authors reviewed, revised, and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Additional feasibility questions.
[DOCX File , 16 KB - cancer_v8i2e35694_app1.docx]

Multimedia Appendix 2
Topic list interviews.
[DOCX File , 12 KB - cancer_v8i2e35694_app2.docx]

Multimedia Appendix 3
Outcomes feasibility questionnaire.
[DOCX File , 15 KB - cancer_v8i2e35694_app3.docx]

References

1. Cabilan CJ, Hines S. The short-term impact of colorectal cancer treatment on physical activity, functional status and quality of life: a systematic review. JBI Database System Rev Implement Rep 2017 Feb;15(2):517-566. [doi: 10.11124/JBISRIR-2016003282] [Medline: 28178025]

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2. van Zutphen M, Winkels RM, van Duijnhoven FJ, van Harten-Gerritsen SA, Kok DE, van Duijvendijk P, et al. An increase in physical activity after colorectal cancer surgery is associated with improved recovery of physical functioning: a prospective cohort study. BMC Cancer 2017 Jan 25;17(1):74 [FREE Full text] [doi: 10.1186/s12885-017-3066-2] [Medline: 28122534]
3. Malmström M, Klefsgard R, Ivarsson B, Roman M, Johansson J. Quality of life measurements as an indicator for timing of support after oesophagectomy for cancer: a prospective study. BMC Health Serv Res 2015 Mar 12;15:96 [FREE Full text] [doi: 10.1186/s12913-015-0747-x] [Medline: 25890232]
4. van der Leeden M, Balland C, Geleijn E, Huijsmans RJ, Dekker J, Paul MA, et al. In-hospital mobilization, physical fitness, and physical functioning after lung cancer surgery. Ann Thorac Surg 2019 Jun;107(6):1639-1646. [doi: 10.1016/j.athoracsur.2018.12.045] [Medline: 30690020]
5. Campbell KL, Winters-Stone KM, Wiskemann J, May AM, Schwartz AL, Courneya KS, et al. Exercise guidelines for cancer survivors: consensus statement from international multidisciplinary roundtable. Med Sci Sports Exerc 2019 Nov;51(11):2375-2390 [FREE Full text] [doi: 10.1249/MSS.0000000000002116] [Medline: 31626055]
6. Brown JC, Winters-Stone K, Lee A, Schmitz KH. Cancer, physical activity, and exercise. Compr Physiol 2012 Oct;2(4):2775-2809 [FREE Full text] [doi: 10.1002/cphy.c120005] [Medline: 23720265]
7. Low CA, Bovbjerg DH, Ahrendt S, Choudry MH, Holtzman M, Jones HL, et al. Fitbit step counts during inpatient recovery from cancer surgery as a predictor of readmission. Ann Behav Med 2018 Jan 05;52(1):88-92 [FREE Full text] [doi: 10.1093/abm/kax022] [Medline: 29538623]
8. Hoyer EH, Friedman M, Lavezza A, Wagner-Kosmakos K, Lewis-Cherry R, Skolnik JL, et al. Promoting mobility and reducing length of stay in hospitalized general medicine patients: a quality-improvement project. J Hosp Med 2016 May;11(5):341-347. [doi: 10.1002/jhm.2546] [Medline: 26849277]
9. Kehlet H, Wilmore DW. Multimodal strategies to improve surgical outcome. Am J Surg 2002 Jun;183(6):630-641. [doi: 10.1016/s0002-9610(02)00866-8] [Medline: 12095591]
10. Van der Walt N, Salmon LJ, Gooden B, Lyons MC, O'Sullivan M, Martina K, et al. Feedback from activity trackers improves daily step count after knee and hip arthroplasty: a randomized controlled trial. J Arthroplasty 2018 Nov;33(11):3422-3428. [doi: 10.1016/j.arth.2018.06.024] [Medline: 30017217]
11. van der Meij E, Anema JR, Leclercq WK, Bongers MY, Consten EC, Schraffordt Koops SE, et al. Personalised perioperative care by e-health after intermediate-grade abdominal surgery: a multicentre, single-blind, randomised, placebo-controlled trial. Lancet 2018 Jul 07;392(10141):51-59. [doi: 10.1016/S0140-6736(18)31113-9] [Medline: 29937195]
12. Granger CL, Connolly B, Denehy L, Hart N, Antippa P, Lin KY, et al. Understanding factors influencing physical activity and exercise in lung cancer: a systematic review. Support Care Cancer 2017 Mar;25(3):983-999. [doi: 10.1007/s00520-016-3484-8] [Medline: 27900549]
13. Purswani JM, Ohri N, Champ C. Tracking steps in oncology: the time is now. Cancer Manag Res 2018;10:2439-2447 [FREE Full text] [doi: 10.2147/CMAR.S148710] [Medline: 30122993]
14. Mathie MJ, Coster AC, Lovell NH, Celler BG. Accelerometry: providing an integrated, practical method for long-term, ambulatory monitoring of human movement. Physiol Meas 2004 Apr;25(2):R1-20. [doi: 10.1088/0967-3334/25/2/r01] [Medline: 15132305]
15. Wu JM, Ho TW, Chang YT, Hsu C, Tsai CJ, Lai F, et al. Wearable-based mobile health app in gastric cancer patients for postoperative physical activity monitoring: focus group study. JMIR Mhealth Uhealth 2019 Apr 23;7(4):e11989 [FREE Full text] [doi: 10.2196/11989] [Medline: 31012858]
16. Barkley R, Khalil M, Shen P, Levine EA, Votanopoulos K, Clark CJ. Feasibility of low-cost accelerometers in measuring functional recovery after major oncologic surgery. J Surg Oncol (forthcoming) 2019 Nov 28. [doi: 10.1002/jso.25789] [Medline: 31782174]
17. Low CA, Danko M, Durica KC, Kunta AR, Mulukutla R, Ren Y, et al. A real-time mobile intervention to reduce sedentary behavior before and after cancer surgery: usability and feasibility study. JMIR Perioper Med 2020 Mar 23;3(1):e17292 [FREE Full text] [doi: 10.2196/17292] [Medline: 33393915]
18. Low CA. Harnessing consumer smartphone and wearable sensors for clinical cancer research. NPJ Digit Med 2020 Oct 27;3:140 [FREE Full text] [doi: 10.1038/s41746-020-00351-x] [Medline: 33134557]
19. Valkenet K, Bor P, Reijneveld E, Veenhof C, Dronkers J. Physical activity monitoring during hospital stay: a validation study. Disabil Rehabil 2022 Feb 17:1-6. [doi: 10.1080/09638288.2022.2034995] [Medline: 35175168]
20. van der Leeden M, Huijsmans R, Geleijn E, de Lange-de Klerk ES, Dekker J, Bonjer HJ, et al. Early enforced mobilisation following surgery for gastrointestinal cancer: feasibility and outcomes. Physiotherapy 2016 Mar;102(1):103-110. [doi: 10.1016/j.physio.2015.03.3722] [Medline: 26059985]
21. Brooke J. SUS: a 'quick and dirty' usability scale. In: Jordan PW, Thomas B, McClelland IL, Weerdmeester B, editors. Usability Evaluation in Industry. Boca Raton, FL, USA: CRC Press; 1996.
22. Douma JA, Verheul HM, Buffart LM. Feasibility, validity and reliability of objective smartphone measurements of physical activity and fitness in patients with cancer. BMC Cancer 2018 Oct 29;18(1):1052 [FREE Full text] [doi: 10.1186/s12885-018-4983-4] [Medline: 30373549]

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23. Wolk S, Linke S, Bogner A, Sturm D, Meißner T, Müssle B, et al. Use of activity tracking in major visceral surgery-the enhanced perioperative mobilization trial: a randomized controlled trial. J Gastrointest Surg 2019 Jun;23(6):1218-1226. [doi: 10.1007/s11605-018-3998-0] [Medline: 30298422]
24. Morgan GS, Haase AM, Campbell RM, Ben-Shlomo Y. A pilot randomised controlled trial of physical activity facilitation for older adults: feasibility study findings. Pilot Feasibility Stud 2019 Mar 8;5:40 [FREE Full text] [doi: 10.1186/s40814-019-0414-9] [Medline: 30891309]
25. Jonker LT, Plas M, de Bock GH, Buskens E, van Leeuwen BL, Lahr MM. Remote home monitoring of older surgical cancer patients: perspective on study implementation and feasibility. Ann Surg Oncol 2021 Jan;28(1):67-78 [FREE Full text] [doi: 10.1245/s10434-020-08705-1] [Medline: 32602060]
26. Creswell JC, Poth CN. Qualitative Inquiry and Research Design - Choosing Among Five Approaches. 4th edition. Thousand Oaks, CA, USA: Sage Publications; Jan 2017.
27. Essery R, Geraghty AW, Kirby S, Yardley L. Predictors of adherence to home-based physical therapies: a systematic review. Disabil Rehabil 2017 Mar;39(6):519-534. [doi: 10.3109/09638288.2016.1153160] [Medline: 27097761]
28. Jonker LT, Hendriks S, Lahr MM, van Munster BC, de Bock GH, van Leeuwen BL. Postoperative recovery of accelerometer-based physical activity in older cancer patients. Eur J Surg Oncol 2020 Nov;46(11):2083-2090 [FREE Full text] [doi: 10.1016/j.ejso.2020.06.012] [Medline: 32682650]
29. Timmerman JG, Dekker-van Weering MG, Wouters MW, Stuiver MM, de Kanter WW, Vollenbroek-Hutten MM. Physical behavior and associations with health outcomes in operable NSCLC patients: a prospective study. Lung Cancer 2018 May;119:91-98 [FREE Full text] [doi: 10.1016/j.lungcan.2018.03.006] [Medline: 29656759]
30. Adherence to long-term therapies: evidence for action. World Health Organization. Geneva, Switzerland: World Health Organization; 2003. URL: http://apps.who.int/iris/bitstream/handle/10665/42682/9241545992.pdf?sequence=1 [accessed 2022-05-25]
31. Beauchamp UL, Pappot H, Holländer-Mieritz C. The use of wearables in clinical trials during cancer treatment: systematic review. JMIR Mhealth Uhealth 2020 Nov 11;8(11):e22006 [FREE Full text] [doi: 10.2196/22006] [Medline: 33174852]

Abbreviations

ERAS: Enhanced Recovery After Surgery
HIPEC: hyperthermic intraperitoneal chemotherapy
PA: physical activity
PAM: Physical Activity Monitor
SUS: System Usability Scale

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Original Paper

Exploring Resource-Sharing Behaviors for Finding Relevant Health Resources: Analysis of an Online Ovarian Cancer Community

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Abstract

Background: Online health communities (OHCs) provide patients and survivors of ovarian cancer (OvCa) and their caregivers with help beyond traditional support channels, such as health care providers and clinicians. OvCa OHCs promote connections and exchanges of information among users with similar experiences. Users often exchange information, which leads to the sharing of resources in the form of web links. Although OHCs are important platforms for health management, concerns exist regarding the quality and relevance of shared resources. Previous studies have examined different aspects of resource-sharing behaviors, such as the purpose of sharing, the type of shared resources, and peer user reactions to shared resources in OHCs to evaluate resource exchange scenarios. However, there is a paucity of research examining whether resource-sharing behaviors can ultimately determine the relevance of shared resources.

Objective: This study aimed to examine the association between OHC resource-sharing behaviors and the relevance of shared resources. We analyzed three aspects of resource-sharing behaviors: types of shared resources, purposes of sharing resources, and OHC users' reactions to shared resources.

Methods: Using a retrospective design, data were extracted from the National Ovarian Cancer Coalition discussion forum. The relevance of a resource was classified into three levels: relevant, partially relevant, and not relevant. Resource-sharing behaviors were identified through manual content analysis. A significance test was performed to determine the association between resource relevance and resource-sharing behaviors.

Results: Approximately 48.3% (85/176) of the shared resources were identified as relevant, 29.5% (52/176) as partially relevant, and 22.2% (39/176) as irrelevant. The study established a significant association between the types of shared resources (χ^2_{18}=33.2; P<.001) and resource relevance (through chi-square tests of independence). Among the types of shared resources, health consumer materials such as health news (P<.001) and health organizations (P=.02) exhibited significantly more relevant resources. Patient educational materials (P<.001) and patient-generated resources (P=.01) were more significantly associated with partially relevant and irrelevant resources, respectively. Expert health materials, including academic literature, were only shared a few times but had significantly (P<.001) more relevant resources. A significant association (χ^2_{10}=22.9; P<.001) was also established between the purpose of resource sharing and overall resource relevance. Resources shared with the purpose of providing additional readings (P=.01) and pointing to resources (P=.03) had significantly more relevant resources, whereas subjects for discussion and staying connected did not include any relevant shared resources.

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Conclusions: The associations found between resource-sharing behaviors and the relevance of these resources can help in collecting relevant resources, along with the corresponding information needs from OvCa OHCs, on a large scale through automation. The results from this study can be leveraged to prioritize the resources required by survivors of OvCa and their caregivers, as well as to automate the search for relevant shared resources in OvCa OHCs.

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KEYWORDS

online health community; resource sharing; link sharing; topical relevance; information seeking; ovarian cancer; user behavior modeling

Introduction

Background and Motivation

Ovarian cancer (OvCa) affects approximately 22,000 women per year in the United States [1-3] with a 70% recurrence rate [4]. Survivors of OvCa are individuals diagnosed with cancer irrespective of their state of disease [5]. They typically receive intensive oncological treatment, which has adverse effects on their quality of life [6-10]. Both survivors of OvCa and their caregivers require support and have various information needs throughout the course of OvCa [11,12]. Health care providers try to address their common information needs through standardized patient and caregiver educational materials; however, these materials may lack information to address both survivors' and their caregivers' unique and dynamic information needs [13,14].

To meet their unique information needs, a growing number of survivors of OvCa and their caregivers generally seek support from online health communities (OHCs) on a regular basis. OHCs enable these individuals to connect and exchange information with other individuals with similar experiences [15-18]. OHCs specific to gynecological cancer also provide a platform where women with OvCa can freely share their experiences and feel a strong sense of belonging [19]. Owing to their powerful communal nature, OHCs could offer survivors of OvCa and their caregivers an opportunity to exchange information individualized to their needs. This exchange of information often leads to resource sharing among users in the form of web links [17,18]. The resources shared among OHC users can serve as educational materials that address their unique information needs. These shared resources can potentially benefit survivors and caregivers by helping them acquire knowledge about different aspects of the disease, including but not limited to treatment, diagnosis, and disease management.

Despite the benefits of shared resources, some important questions arise, given that OHC users are health consumers and might not be health experts: which resources shared by the OHC peers are relevant to the information needs of survivors of OvCa and their caregivers, and what aspects of resource sharing can help us determine resource relevance? Previous research examined health literacy in OHCs and revealed that most of the content is generated by users with underdeveloped skills in validating information sources and navigating the internet [20]. Therefore, users need help in finding the relevant resources generated or shared in OHCs [21]. Motivated by this, the objective of this study is to examine the connections between users' resource-sharing behaviors and the relevance of shared resources. The outcomes can help future research locate relevant resources that are helpful in educating survivors and caregivers on OvCa OHCs. This study is part of an ongoing project, Health e-Librarian with Personalized Recommender (HELPeR), which aims to recommend personalized, relevant information resources to survivors of OvCa and their caregivers (HELPeR study 1R01LM013038-01A1). The ultimate goal of HELPeR is to improve the quality of user-focused recommendations in all aspects of OvCa care.

Most previous studies examined resource sharing in OHCs [22,23], although little attention has been paid to understanding if these resources are relevant to user information needs. Few studies have examined the quality and relevance of user-generated data on OHCs [24-27]; however, these studies are based on the content of the user post and do not address the quality of shared resources. This study fills this gap by exploring the relevance of the shared resources. This study extends previous studies by determining the relevance of shared resources and post content. Examining the relevance of resources will reveal what resources can help fulfill the information needs of survivors of OvCa and caregivers. Resource relevance has multiple dimensions, including topical relevance, readability, trustworthiness, timeliness, and clinical validity [28,29]. This paper considers topical relevance, which defines whether the content addresses the information needed [28]. A resource is relevant if its content addresses the information needed by the user; otherwise, the resource is irrelevant. In the rest of the paper, the words *relevance* and *topical relevance* are used interchangeably.

User behavior has been substantially explored in the context of search engines and recommender systems [30-33]. For example, users' seeking behaviors are examined to improve search quality by determining the relevance of a search result against users' information needs [30,31,34]. User behavior can help provide 2 types of user feedback. *Explicit* feedback is where users themselves provide feedback about the relevance of an item (eg, liking a search result). On the other hand, implicit feedback is obtained without user intervention (eg, by tracking the dwell time on a search result page). Recently, user behavior has also been used in web-based community research [24,35]. Wanas et al [24] used web-based community–specific user behaviors, including the presence of quotations in a post (implicit) and the number of replies to a post (implicit), along with other features to train a post quality scoring algorithm. Explicit feedback, including post likes [35], and implicit feedback, including participant reputation [36], were also used to determine the relevant posts in a thread in a social media forum. Differing

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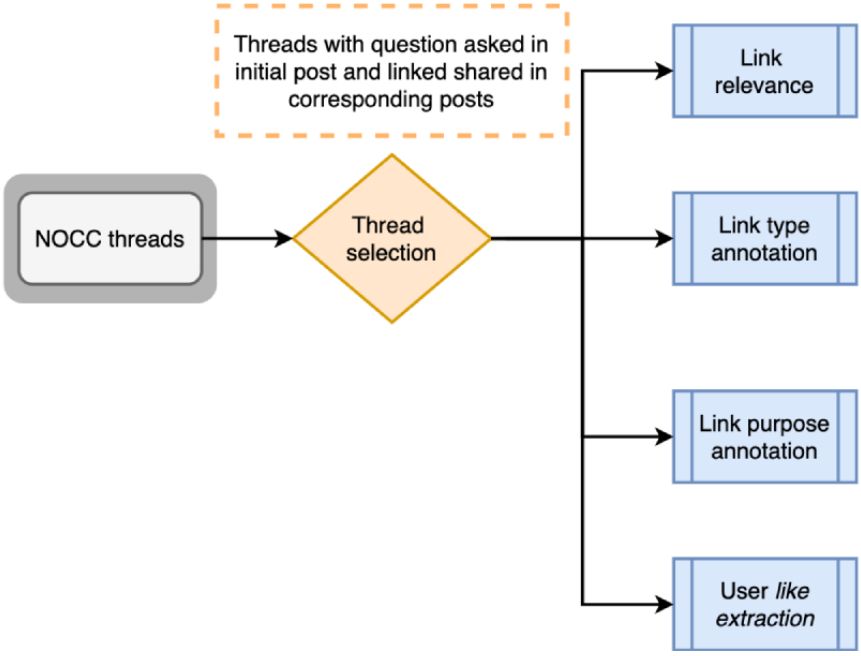
from previous studies, this study explores resource-sharing behaviors pertaining to OHC users to determine shared resource relevance. In OHCs, resource-sharing behaviors are examined to determine how OHC members engage with shared resources [22,23]. Zhang and Sun [22] examined the purpose of resource sharing in a web-based diabetes forum to reveal the support that shared resources provide. Nathan et al [23] studied the types of resources shared in an OHC and OHC users' *like* reaction on WebMD threads [37] to reveal the types of resources trusted by OHC users. Although resource-sharing behaviors have been studied in OHCs, there is no study on whether these resource-sharing behaviors can determine the relevance of shared resources. Given the dearth of research in this area, the purpose of this study is to examine (1) the relevance of resource sharing on an OvCa OHC and (2) users' resource-sharing behaviors associated with shared resource relevance in an OvCa OHC. Examining both resource relevance and resource-sharing behaviors provides insights into which user behaviors are associated with relevant and irrelevant resources.

Objectives

Figure 1 provides the overall description of our study design. This study was a descriptive analysis of the OvCa OHC threads. Three aspects of resource-sharing behaviors were considered: type of resource shared, purposes of sharing a resource, and OHC users' *like* reactions to the resource shared. Types of shared resources and the purpose of sharing resources provide implicit user feedback, as they do not explicitly reveal users' interests or likes on a resource. An OHC user's *like* reaction on the shared resource provides explicit user feedback, where the user explicitly reveals their interest in the shared resource. This study investigates the following three research questions (RQs) to explore resource relevance along with resource-sharing behaviors:

- RQ1: what is the relationship between the type of resources shared and the relevance of these resources in an OvCa OHC?
- RQ2: what is the relationship between the purpose of sharing resources and the relevance of these resources in an OvCa OHC?
- RQ3: what is the relationship between OHC users' reactions to comments on the shared link and the relevance of these resources in an OvCa OHC?

Figure 1. Workflow of the study. NOCC: National Ovarian Cancer Coalition.



Methods

The study was performed on the National Ovarian Cancer Coalition (NOCC) forum. To address the RQs, we first determined the relevance of the shared resources and later used different resource-sharing behaviors to calculate their association with relevance using a chi-square test.

Data Source and Collection

For OvCa OHC data, we relied on NOCC [38]. NOCC is a subcommunity of the Cancer Connect Community [39], which brings together survivors of OvCa and caregivers. NOCC users start threads in seeking information, receiving a second opinion, sharing experience, and receiving emotional support, whereas other participants provide support by replying to these threads in the form of comments. Forum users also express gratitude toward posts and comments using the like button. The NOCC is a patient-oriented community in which moderators are also survivors of OvCa or caregivers. We selected the NOCC because of its two unique properties:

1. It is an OvCa-specific community, which is a rare cancer with less exposure or awareness among general survivors of cancer and caregivers.
2. OvCa is a women-only cancer; therefore, the platform allows for the free exchange of information and resources with other individuals with similar experiences, where OHC

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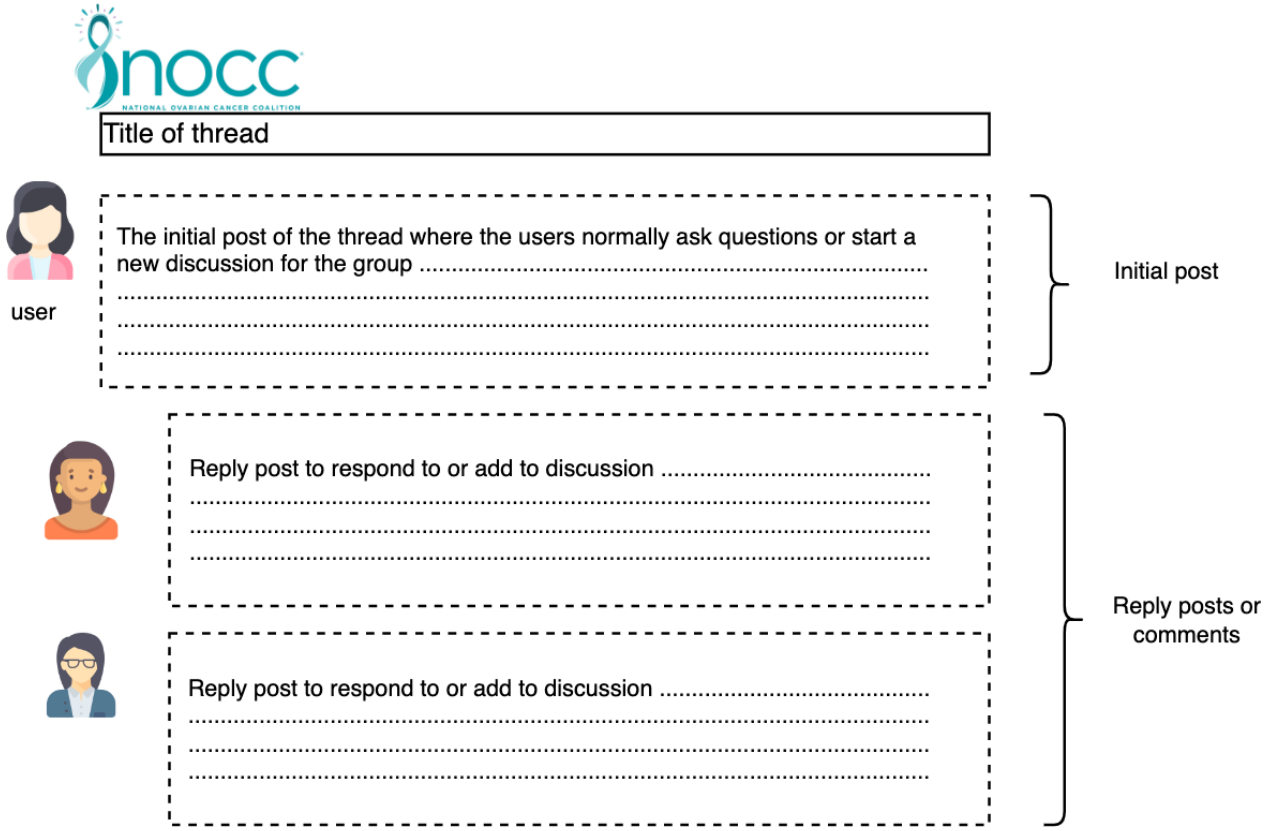
users have developed a sense of community and connection [19].

NOCC is not a public community; therefore, we obtained permission from the institutional review board to collect and analyze the forum content. We collected data available from June 2010 to December 2020. Each thread comprises an initial post and replies to comments. For each thread, the following information was recorded: the title of the thread, initial post content, poster's name, all comments on the post, comment users' names, number of likes on comments, number of likes on posts, users who liked, time of posts, and time of comments. Figure 2 shows an example of a NOCC thread and its different components. The actual content of the post was removed to better show the basic structure of the thread and ensure patient privacy. Each thread is initiated by a NOCC user, which includes the title of the thread and an initial post. The initial post is followed by comments and replies from the forum users. Comments or reply posts are where the resources are shared in response to the information needed in the initial post.

Figure 2. A typical National Ovarian Cancer Coalition thread component, which includes the thread poster, title of thread, initial post, reply posts, and *like* button. The actual content of the thread was removed for privacy of National Ovarian Cancer Coalition users. The purpose of this figure is to provide readers with a basic understanding of communication patterns on this forum.



The data for analysis were deidentified to remove participant information from the initial posts and all comments. From the 909 threads, we selected 105 (11.6%) threads for this study, as explained below:

1. First, we filtered posts containing advertisements from health organizations. These threads included advertisements such as survey enrollment, product advertisements, and monthly updates from the NOCC moderator.
2. Then, of the 909 threads, 495 (54.5%) threads were selected in which the initial post contained a question. For simplicity, in the following sections, we would refer to this data set of 105 threads as NOCC question threads.
3. From the 495 selected threads, we further examined 105 (21.2%) threads where users shared resources (URLs) in their reply comments.
4. Links were extracted from 105 threads using regular expressions [23]. We found 176 links shared among these 105 threads.
5. For our final data set, we assembled 176 post–comment pairs, where each post had a question, and each comment contained a shared link. Thereafter, we will call this data set with 176 post–comment pairs the NOCC shared resource (NOCC-RS) data set.

Manual content analysis was performed on NOCC-RS to annotate relevance, types of resources, and purpose of sharing resources (Figure 1). Each annotation procedure was performed separately to ensure that one annotation did not influence the other. To report the quality of each annotation, we calculated the interrater reliability score using Cohen κ [40]. Cohen κ (equation 1) is a widely accepted measure for ensuring the quality of annotator agreement and is more robust than calculating percentage agreement [40]. A percentage agreement of ≥0.85 [41] and a Cohen κ coefficient of ≥0.5 [42] are acceptable quality for annotations. As a result, an acceptable κ measure was obtained:

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Here, α_o is the probability of an item receiving the same code from both annotators, and α_c is the probability of agreement occurring by chance. N is the total number of items for annotation, and n_{li} is the number of times an annotator i predicted label l.

All annotators met every week to decide the coding schema for each annotation, discuss disagreements on overlapping samples, and calculate the κ score. In the following sections, each annotation process is discussed in detail, along with the coding schema.

Resource Relevance Annotation

To assess the relevance of each resource shared for the corresponding information needed (ie, the question in the initial post), we developed a coding scheme that classified the resources into three categories: relevant, partially relevant, and irrelevant. For each resource, annotators, VH and YC, first checked the initial post that contained the question and then read the comment post that contained the link. Relevance was judged based on the topical relevance between the link and the question asked in the corresponding thread. The study engaged two domain experts to accomplish this task: VH was a nurse, and YC was a researcher focused on the needs of survivors of OvCa and caregivers. Initially, the annotators started with a binary coding scheme: relevant and irrelevant. Later, after discussion among annotators, they found that there were many resources that did not provide the original information needed by the user but were still helpful to the user. Thus, although partially relevant resources did not answer the question, they were either usable for users, given their information needs, or helpful to the user to reach the relevant resource. This resulted in the 3 categories described in Textbox 1. Textbox 2 provides examples of all 3 categories from the NOCC forum post. The interrater agreement between the 2 annotators is Cohen κ=0.65, calculated on 39.8% (70/176) data overlap, with a substantial agreement of 81%.

Textbox 1. The classification scheme for resource relevancy with description and corresponding example.

Code and description (all relevance annotations were based on topical relevance)

- Irrelevant
  - The information provided through the resource does not address the corresponding question asked.
- Partially relevant
  - The information provided through the resource does not provide a direct answer to the corresponding question but can either provide some related information to find relevant information or is useful to the user.
- Relevant
  - The information provided through the resource directly addresses the corresponding question and provides an answer to the corresponding question.

Textbox 2. Example posts (some information is removed for anonymization).

Initial post with a question

- "I was diagnosed with ovarian stage 3c—background information—My doctor wants to add Avastin to my next 3 rounds of chemo. I am worried about adding it because of all the side effects I already had a reaction to the carbo once and that was very bad. Do you know anything about the side effects of Avastin?"

Relevance and comments with a shared resource

- Relevant resource: "Avastin definitely plays a major role in both treatment and maintenance therapy for a number of cancers. About Avastin; news.cancerconnect.com/treatment-care/answers-to-faq-s-about-avastin/"
- Partially relevant resource: "Hi XXX, treatment decision-making can be so difficult. Good for you for looking at all your options. Have you had a second opinion at another large cancer center? Asking your doctors about the risks and benefits of each treatment option is important. The NCCN patient guidelines for ovarian cancer might also be a helpful resource for you (www.nccn.org/patients/guidelines/ovarian/index.html). Hope this helps and keep us posted!"
- Irrelevant: "If you want to discuss this more and want to connect, please connect to my blog: http://xxx.blogspot.com"

Resource Type Annotation

To answer RQ1, the shared resources were categorized. Each resource was categorized based on the *domain* and *content* of the links. For domain name–based categorization, we relied on the top-level domain (TLD) of the URL, as in the study by Nathan et al [23]. Domain names are designed to represent websites distributed among various hosts and network systems,

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with a string of characters usually separated by dots as their structure. The TLD is the last part of the domain name of US websites. If a domain name is outside the United States, its TLD is the second to last part of the URL. From the TLD, one can determine the entity, administrator, and intended use of a website [43]. For example, the TLD of *ncbi.nlm.nih.gov* is *.gov*, indicating that the website belongs to a governmental entity, and that of *ovarian.org* is *.org*, indicating that it is an organization website. This study adopted 6 TLDs, including *.com*, *.edu*, *.org*, *.net*, *.io*, and *.gov*.

To move beyond simple domain name–based analysis, we manually examined each link and classified the shared resources into content-focused categories. Initially, two coders (KT and YC) separately coded the links using the coding scheme mentioned in [44], which is specifically used for the classification of health domain webpages during the consumer search process. During the subsequent debriefing, the discussion among coders about disagreements led to the refinement of the original categories. Two new categories were introduced—nonhealth articles and patient educational resources—which were missing from the previous study. Table 1 provides the final 10 types used to classify resources. It is assumed that the links belonging to each category have similar types of content and are for similar consumers. The interannotator agreement between 2 annotators was Cohen κ=0.8, calculated on 19.3% (34/176) data overlap.

Table 1. Coding scheme for resource types with description and corresponding example.

Code	Description	Example domains
Health articles	A link containing focused information about one specific health topic with content written for health consumers in mind; this could include health articles, health expert blogs, and health topic information websites	• Cancer.net [45] • Med-Health.com [46]
Health news	A webpage presenting health news; this could include news about findings in research, treatment results, and updates on medications and clinical trials	• CancerConnectNews [39] • Medicalexpress [47]
Patient educational resource	Resources provided by government and cancer organizations, including patient guidelines, factsheets, and patient booklets	• Cancer.gov [48] • NCCN.org [49]
Academic literature	Research articles and clinical trial articles	• NCBI.gov [50] • Eurekalert.org [51]
Web-based social groups	A link containing user discussions and posts on web-based communities, question answering forums, and social networking sites	• NOCC.ovarian.org [52] • CSN.Cancer.org [53] • Facebook [54]
Health organizations	A link referring to the home page of a health organization, medical school, nonprofit institute, or government website	• Ovarian.org [38] • Dana-Farber.org [55]
Patient blogs	Patient- or caregiver-generated personal websites and blogs	• xxx.blogspot.com
e-Commerce	Online shopping sites and product promotion/advertisement web pages	• Omiana [56] • 100percentpure [57]
Videos	Links to video content	• YouTube [58]
Nonhealth articles	Shared content outside of the health domain	• Lawfirm [59] • Wikipedia [60]

Resource Purpose Annotation

The purpose of a link refers to the role the link serves in a post [22]. Zhang et al [22] unveiled the relationship between the type of forum user (frequent vs occasional contributors) and the purpose of their link-sharing behavior. The coders started with the coding schema of Zhang et al [22], which defined six roles of links shared in the initial posts: *providing additional reading*, *supporting arguments*, *subjects for discussion*, *recommendations for peers*, *the source of a post*, and *asking for help*. As coding proceeded, we removed two categories that we considered inapplicable to the link-sharing purpose in the comments (*recommendation for peers* and *asking for help*), and we added two new categories: *pointing to resources* and *staying connected*.

The coding scheme includes *providing additional readings*, *supporting arguments*, *subjects for discussion*, *pointing to resources*, and *staying connected*. Table 2 presents the final definition of each purpose and an example comment with a URL link.

Resource purpose annotation was performed independently of resource relevance annotation and only by reading the comment and ignoring the initial post. Two coders independently annotated the role of the shared link with a 34.1% (60/176) overlap of comments between them. The final agreement after the second round of annotation was 93%, with Cohen κ=0.88, which indicates a substantial agreement. After addressing all the disagreements between the 2 coders, KT proceeded to code all the remaining comments.

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Table 2. Coding scheme for link-sharing purposes with description and corresponding example.

Code	Description	Example (anonymized or rephrased)
Providing additional readings	The information provided through the link provides reading materials to answer the corresponding questions.	"Olaparib is a PARP inhibitor. Are you platinum-sensitive and do you have a BRCA mutation? If you do olaparib works well. Here is a great article www.targetedonc.com/publications/targeted-therapies-cancer/2017/2017-august/the-current-status-of-parp-inhibitors-in-ovarian-cancer"
Pointing to resources	The information provided through the link does not provide a direct answer to the corresponding question but can provide some related information to search for relevant information or is useful to the user; for example, link to generic OvCa information, OvCa resource listing, and clinical trial search engine.	"SOOOOOOOOOOOOOO much interesting data in here—stuff we will benefit from! Yeehaw! news.mit.edu/search?keyword=Koch+Cancer+Center"
Supporting argument	The information provided in the comment directly addresses the users' information needs, whereas the link acts as evidence to support the facts mentioned in the comment.	"Yes, the PARP drugs seem to show promise with platinum resistance as well. news.cancerconnect.com/zejula-in-combination-with-keytruda-appears-promising-in-patients-with-platinum-resistant-refractory-ovarian-cancer/ Best XXX"
Staying connected	The link is provided for the advertisement of a personal blog, providing an email address, or connecting to an existing ovarian group.	"It is good to hear about another MMMT survivor. There seem to be so few of us because it is such an aggressive cancer cell. If you would like to connect with me more, I am at XXX@gmail.com (personal email), or XXXblogspot.com (personal blog). XXX, thank you for your kind wishes."
Subject for discussion	"The link content is the topic that the replier wants to discuss."	"What do you know about CART- T Immunotherapy? cancerresearch.org/immunotherapy/cancer-types/ovarian-cancer"

User Reaction to Shared Resources

OHC websites usually provide ways for users to provide feedback (liking, disliking, and helpfulness) on posts and comments. NOCC offers its users a *like* button that can be used to display gratitude and other positive feelings about a post or comment. In modern recommender systems, signs of user appreciation such as thumbs-up and likes are signs of item relevance for the user and form the main source of knowledge for recommendations [32]. The motivation for RQ3 was to reassess this assumption in the context of an OHC and determine whether *like* reactions of OHC users on comments that contained shared resources could be used as a sign of relevance to cross-recommend *liked* resources and to serve as a *gold standard* for resource relevance studies. The *like* reactions were explored in two ways: first, *like* reaction from the user who asked the question in the initial post and second, *like* reactions from all peers on NOCC. Our hypothesis is that as the resource is shared for the information needed from the thread initiator, the *like* from this user might be a good indicator of the relevance of a resource.

Ethical Approval

NOCC is not a public community; therefore, we obtained permission from the institutional review board to collect and analyze the forum content. Ethical approval for the study was granted in June 2021 by the Institutional Review Board of University of Pittsburgh (STUDY21050190). The institutional review board determined that the proposed activity is not research involving human subjects as defined by Department of Health and Human Services and Food and Drug Administration regulations.

Results

Overview

We obtained all threads from a period of 10 years from the NOCC, which is a well-known site for patients with OvCa. OvCa is a rare cancer; therefore, the NOCC had 909 threads from a period of 10 years of data collection. Furthermore, from the 909 threads, we obtained 105 (11.6%) threads with an information need (NOCC question threads), where 176 links were shared in the comments. These 176 shared links, along with the initial posts and comments with links, formed our NOCC-RS data set.

In the following sections, first, the statistics on resource relevance are presented, followed by a discussion of the association between resource relevance and resource-sharing behaviors.

Resource Relevance

There were 85 relevant, 52 partially relevant, and 39 irrelevant resources. The relevance distribution indicates that 48.3% (85/176) of all shared links lead to resources that are relevant to the needs expressed in the original post. Furthermore, we observed that out of 105 threads, only 53 (50.5%) were answered by sharing at least one relevant resource. Of the remaining 52 posts, 48 (92%) obtained no relevant resources but ≥1 partially relevant resource. Finally, 3.8% (4/105) of posts did not receive any relevant or partially relevant resources in response.

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Resource Type

Resource Type Based on TLD

The most frequent TLD was *.com*, which covers 56.3% (51/176) of all shared resources (eg, *cancerconnect.com*, *youtube.com*, and *xxx.blogspot.com*), followed by *.org* (eg, *nccn.org*, *ovarian.org*, and *dana-farber.org*), *.gov* (eg, *cancer.gov*, *ncbi.nlm.nih.gov*, and *nccih.nih.gov*), *.edu* (eg, *harvard.edu*, *mit.edu*, and *vcu.edu*), *.io* (eg, *mavendoctors.io*), and *.net* (eg, *med-health.net* and *cancer.net*). We merged the remaining 2 TLDs together, which were *.me* and *.nz*, and were shared only once. Table 3 provides details on the number of links shared in each TLD and percentage of relevant resources.

To answer RQ1, we examined the association between TLDs and the relevance of a resource. The chi-square test of independence was performed on two categorical variables: TLDs (*.com*, *.gov*, *.org*, *.edu*, *.io*, and *.net*) and relevance (relevant, partially relevant, and irrelevant). The results indicated no association between TLD and relevance (χ^2_{12}=19.2; *P*=.10).

Table 3. Top-level domain (TLD)-based distribution of shared resources and percentage of relevant resources (N=176 links).

TLD	Links, n (%)	Relevant resources (n=85), n (%)	Partially relevant resources (n=52), n (%)	Irrelevant resources (n=39), n (%)
.com	99 (56.3)	50 (58.8)	27 (51.9)	22 (56.4)
.org	45 (25.6)	20 (23.5)	16 (30.8)	9 (23.1)
.gov	16 (9.1)	9 (10.6)	5 (9.6)	2 (5.1)
.edu	8 (4.5)	2 (2.4)	2 (3.8)	4 (10.3)
.io	3 (1.7)	2 (2.4)	1 (1.9)	0 (0)
.net	3 (1.7)	2 (2.4)	0 (0)	1 (2.6)
Other	2 (1.1)	0 (0)	1 (1.9)	1 (2.6)

Resource Type Based on Content

Table 4 provides the distribution of resources based on content type, whereas Table 1 shows an example of each resource type. Health news and health articles were the topmost shared types of resources and together accounted for 42% (74/176) of the links shared. These types were closely followed by health organizations and patient educational resources. The videos were shared in approximately 4.5% (8/176) of cases and included discussions by health experts (OncLive TV [61]), patient experiences, and other emotional support videos (relaxing music). NOCC peers also shared health organizations' websites to fulfill information needs related to physician listings, funding institutes, and nearby nonprofit organizations. Web-based social groups were shared most of the time to point to similar previous discussions in the same OHC or another OHC. NOCC users shared their own blogs and their life journeys with their peers. Patient blogs were shared so that other OHC users could contact them, whereas commerce websites were used to share organic cosmetic products or clothing for patients with cancer.

Table 4. Resource type-based distribution of shared resources and percentage of relevant resources (N=176 links).

Resource type	Links, n (%)	Relevant resources (n=85), n (%)	Partially relevant resources (n=52), n (%)	Irrelevant resources (n=39), n (%)
Health news	38 (21.6)	23 (27.1)	12 (23.1)	3 (7.7)
Health articles	36 (20.5)	20 (23.5)	11 (21.2)	5 (12.8)
Health organizations	21 (11.9)	12 (14.1)	6 (11.5)	3 (7.7)
Web-based social groups	20 (11.4)	8 (9.4)	6 (11.5)	6 (15.4)
Patient resources	18 (10.2)	5 (5.9)	11 (21.2)	2 (5.1)
E-commerce	12 (6.8)	6 (7.1)	1 (1.9)	5 (12.8)
Academic literature	11 (6.3)	8 (9.4)	2 (3.8)	1 (2.6)
Patient blogs	9 (5.1)	2 (2.4)	3 (5.8)	4 (10.3)
Video	8 (4.5)	0 (0)	0 (0)	8 (20.5)
Nonhealth articles	3 (1.7)	1 (1.2)	0 (0)	2 (5.1)

To answer RQ1, the distribution of resource relevance was checked for each resource type. Table 4 provides details of the distribution of these resources. Table 4 shows that most of the relevant resources came from health news and articles, followed by health organizations. It was also interesting that the fraction of relevant resources within the category was the highest for shared academic articles. To answer RQ1, we performed a chi-square test of independence between resource relevance and resource types. We found a significant association between resource relevance and resource type (χ^2_{18}=33.2; *P*<.001). Furthermore, we applied the chi-square test of goodness of fit for each resource type. The results indicated that health news

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(χ^2_2=22.4; *P*<.001), health organizations (χ^2_2=6.0; *P*=.02), patient educational materials (χ^2_2=7.0; *P*<.001), and academic articles (χ^2_2=7.8; *P*=.01) were not equally distributed among relevant, nonrelevant, and partially relevant resources.

Resource Purpose

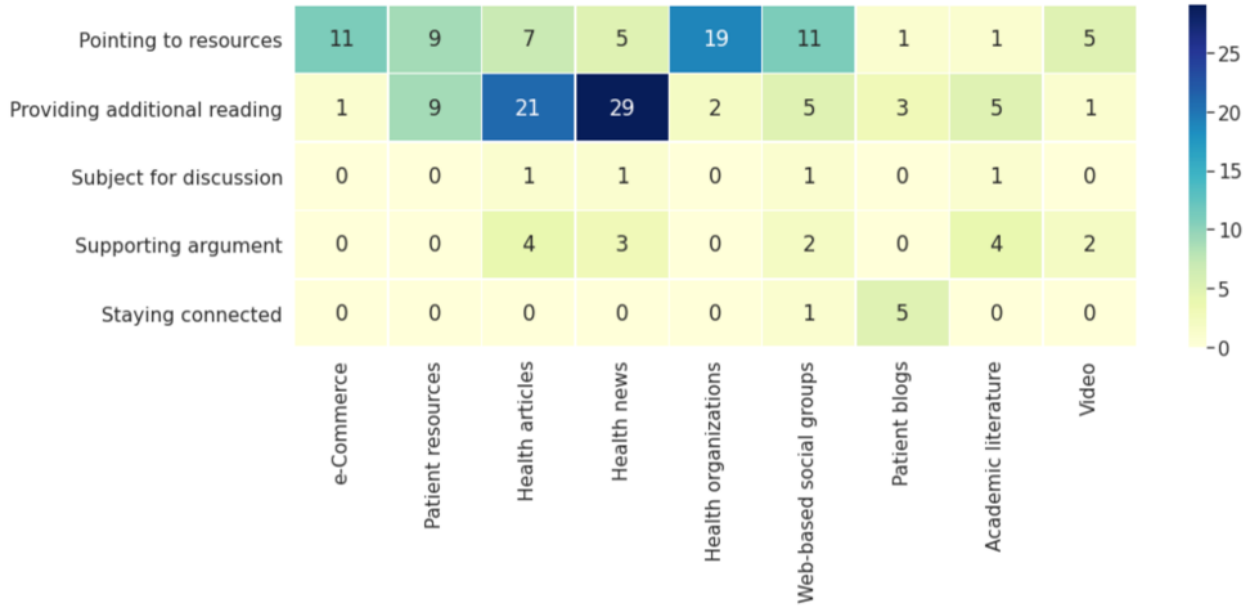
Table 5 shows the distribution of the purposes of resource sharing. Most of the resources were shared to provide additional readings and point to resources. A much smaller proportion of the resources was shared to provide supporting arguments and subjects for discussion and to stay connected. Figure 3 shows the distribution of resource types in each of the purposes of sharing resources. It can be observed that providing additional readings can be achieved by sharing every resource type except videos. NOCC users found most of the additional readings from health articles and health news. Pointing to resources came mostly from health organizations. Academic literature was mostly shared to provide additional reading and supporting arguments.

Table 5 shows the percentage distribution of relevance for each sharing purpose. It was observed that supporting arguments resulted in the highest percentage of relevant documents, followed by providing additional readings and pointing to resources. No relevant documents were found in the roles of staying connected and subjects for discussion. The category of staying connected had some partially relevant documents; these were the cases when the initial post users' information needs indicated an interest in connecting with patients and caregivers with similar experiences. The chi-square test of independence between resource relevance and resource-sharing purposes showed a significant association between both variables (χ^2_8=21.1; *P*<.001). Furthermore, we applied the chi-square test of goodness of fit for each resource type. Providing additional readings (χ^2_2=22.9; *P*=.01) and pointing to resources (χ^2_2=7.7; *P*=.03) were not equally distributed among relevant, nonrelevant, and partially relevant resources. This indicates that these behaviors can be used to differentiate relevant and irrelevant documents.

Table 5. Purpose-based distribution of shared resources and percentage of relevant resources (N=176 links).

Purpose of shared resource	Links, n (%)	Relevant resources (n=85), n (%)	Partially relevant resources (n=52), n (%)	Irrelevant resources (n=39), n (%)
Providing additional readings	84 (47.7)	43 (50.6)	26 (50)	15 (38.5)
Pointing to resources	67 (37.6)	32 (36.8)	21 (40.4)	14 (35.9)
Supporting argument	13 (7.3)	10 (11.5)	2 (3.8)	1 (2.6)
Subject for discussion	6 (3.4)	0 (0)	0 (0)	6 (15.4)
Staying connected	6 (3.4)	0 (0)	3 (5.8)	3 (7.7)

Figure 3. Number of different types of shared resources within each purpose.



User Reaction to Shared Resources

Overview

In this section, we examine the *like* reactions of the forum users to a post in the thread and its connection to the information *value* of the post. This analysis is important to assess whether the number of *likes* from the community could be considered as a sign of a post's *value* so that posts with many *likes* could be promoted and recommended as valuable. Table 6 arranges the *like* statistics for different groups of posts in order of general increase of their value. We considered comments with links and

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comments to a post started by a question as potentially more valuable than average comments, as a link could provide valuable information, and a comment to a question is likely to contain a valuable answer. Comments with both properties (posted in response to a question and has a link) should be more valuable than comments with only one of these properties. To examine these *most valuable* comments in more detail, we selected 105 threads where a question was asked in initial posts and links were shared in comment posts. In Table 6, these threads are referred to as *filtered* threads. Arguably, the peak value is reached in comments within the threads that have links that are judged to be relevant to the question by the annotators. It should be noted that just the fact that a post has a link and is posted in response to a question does not assure that the link is relevant: only approximately 48.3% (85/176) of these links are relevant.

Table 6. Details of OHC[a] user reactions on comments with shared resources[b].

Comments	Relevance	Number of threads	Number of comments	Likes on comments		
				All NOCC[c] users		Users who started the thread, n/N (%)
				Values, n (%)	Likes, mean (SD)	
All comments (909 threads)	—[d]	909	14,814	11,853 (80.01)	2.95 (2.41)	283/14,814 (1.9)
Comments with links	—	187	487	374 (76.83)	2.34 (2.01)	8/487 (1.6)
Comments in NOCC-QT[e]	—	435	6063	4382 (72.27)	2.55 (2.47)	119/6063 (2)
Comments in NOCC-RS[f]	—	105	176	110 (63.21)	1.47 (1.69)	7/176 (2.8)
Comments in NOCC-RS	Irrelevant	21	39	23 (58.82)	0.98 (1.31)	2/39 (2.9)
Comments in NOCC-RS	Partially relevant	37	52	27 (52.83)	1.41 (1.86)	1/52 (1.8)
Comments in NOCC-RS	Relevant	57	85	60 (70.93)	1.74 (1.71)	3/85 (3.5)

[a]OHC: online health community.

[b]Filtered threads are 105 threads considered in this study where a question is asked in initial posts and links are shared in comments posts.

[c]NOCC: National Ovarian Cancer Coalition.

[d]Not available.

[e]NOCC-QT: National Ovarian Cancer Coalition question threads.

[f]NOCC-RS: National Ovarian Cancer Coalition shared resource.

Reaction From Thread Initiator

We started by examining the *like* reactions from the user who started the thread with a question, as shown in the last column of Table 6. As the data show, the assumption that the *likes* of the target user (who wants an answer) reflect the value of the post is correct: the fraction of *liked* posts increases as we go down the table. The assumption that the target user will have a stronger *like* reaction to relevant documents shared in response to the original post is generally correct. The proportion of target user likes for *any* response to a question (119/6063, 2.04%) is higher than the number of their *likes* of an arbitrary post (283/14,814, 1.91%). The proportion of likes for a response to a question with links is even higher (7/176, 2.8%), and the proportion of likes on responses with *relevant* links (3/85, 4%) is the highest overall, approximately twice as high as an average post with a resource link (8/487, 1.6%). Unfortunately, even for relevant links, the proportion of cases in which the post initiator likes a comment to their post is very low. Although these likes follow the expected trend, their low proportion makes it impractical to use the *like* behavior of the target user as a source of data to distinguish and recommend relevant documents. To examine whether the *like* behavior is associated with the relevance of a shared resource, we performed a nonparametric Kruskal-Wallis test (H test). The H test was selected as the data were not normally distributed, and the H test was performed to compare likes by thread initiators on filtered threads. Although the percentage of likes was higher for comments with relevant resources, there was no significant difference (H=0.073; P=.70) between likes on comments with shared links and comments with shared relevant links.

Reaction From the Community

If we consider the whole community (ie, the *like* reaction of all forum users), the *coverage* of comments with likes remarkably increases. Although only 1.91% (283/14,814) of all comments were *liked* by the originating user, 80.01% (909/14,814) of comments received at least one like from the whole community, with 2.95 likes per comment on average. However, the connection between the *likes* and the information *value* of the post surprisingly goes in the opposite direction. Although the proportion of likes from the target user *increases* as we go down the table to more *valuable* posts, the proportion of community likes *decreases*. Instead of increasing the *likeability* of a post, adding a link decreases the community *likeability* of a post to 76.8% (187/487; mean 2.34, SD 2.01 *likes*). This trend is even more pronounced in filtered threads that start with a question, where *likeability* falls from 72.27% (435/6063; mean 2.55, SD 2.47) to 63.2% (105/176; mean 1.47, SD 1.69) for replies with a link. This trend breaks only at the very end of the table: answers with relevant links (57/85, 71%; mean 1.94 *likes*) were still slightly more likable than average answers with links but

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were still less likable than an average reply to a post with a question (436/6063, 72.27%; mean 2.55). This interesting data indicate that the *liking* behavior of the originating user is different from the *liking* behavior of the whole community. We hypothesized that the likes of the target user were driven mostly by appreciation of the information and its relevance, whereas the *likes* of the community are driven more by compassion and acknowledgment of the effort to answer. In this situation, posts with links, which require more cognitive effort to consume before acknowledging, receive a lower share of *likes*, even if these posts look relevant. Unfortunately, this observation also means that community liking behavior cannot be considered a reliable indicator of a post's value. An *H* test on *likes* from the community on comments with filtered threads further revealed that there was no significant difference (H=2.1; P=.10) between likes on comments with shared links and likes on comments with relevant shared links.

Discussion

Principal Findings

Survivors of OvCa and caregivers increasingly rely on OHCs for informational support [15,16]. Survivors of OvCa and caregivers can exchange information individualized to their needs on OvCa OHCs [15-18]. As a result of this information exchange, users often share resources through web links [17,18]. Survivors of OvCa and caregivers might not be health experts [62]; thus, it is vital to know if the resources shared on OvCa OHCs are relevant to their information needs. Research has examined resource sharing in OHCs in the past; however, there is a paucity of studies that look at the relevance of such resources. This study fills this gap by examining the relevance of shared resources on an OvCa OHC forum and extends prior research [22,23] by examining the association of resource relevance with different aspects of resource-sharing behavior. An in-depth understanding of resource-sharing behaviors associated with resource relevance can help find informative resources shared in OHCs. As expected, this study found that only half of all the shared resources were relevant to information needs. An analysis of different aspects of resource-sharing behavior suggests that resource behavior, including the purpose of sharing a resource and the type of resource, can be a reliable indicator of relevant shared resources, whereas explicit feedback of OHC users on a shared resource was not a reliable indicator of resource relevance.

Resource Relevance

The results show that OvCa OHC peers can provide relevant resources related to the information needs of OvCa OHC users only half the time. This result does not indicate that users' information needs from the initial post were not met. Rather, the results indicate that OvCa OHC users, who are survivors of OvCa and their caregivers (health care consumers who most of the time are not health care experts), might not be as efficient as we expected in finding relevant resources. For example, the user asks about the side effects of specific chemotherapy (altretamine), but the resource shared is pointing to the National Comprehensive Cancer Network guidelines [63], which contain general side effects from any chemotherapy but not specific to altretamine. In addition, from the shared resources, approximately 29.5% (52/176) of time the resources shared were partially relevant, which indicates that OvCa OHC users' information needs are sometimes individualized and not addressed by generalized OvCa resources, such as patient education materials. This insight provides motivation for building a health resource recommender system that would individualize resources based on patients' information needs and current disease trajectories.

This study found two important indicators for the topical relevance of shared resources: the types of shared resources and the purpose of shared resources. The findings related to the relationship between topical relevance and different resource-sharing behaviors complement and extend the study conducted by Zhang and Sun [22]. They studied the shared resources in the initial posts of a thread, whereas we investigated the shared resources in the comment posts to address the information needed in the initial post from the same thread. The fact that we studied the topical relevance of these resources and unveiled the association between resource-sharing behaviors and topical relevance may have the following benefits: (1) recognize the sources from which OvCa OHC users find relevant resources, (2) use resource-sharing behaviors to aggregate reliable shared resources in an OHC, and (3) recommend resources to OHC users with similar information needs so that they do not have to always rely on peer users.

Resource Type and Resource Relevance

Exploration of resource type sharing revealed that NOCC users rely more on health consumer materials, including health news, health articles, and patient education resources, and less on health professional materials, such as academic literature (only 11/176, 6.3%). This could be as survivors of OvCa and caregivers often do not have adequate health literacy to understand health professional articles. On the other hand, patient materials targeted toward health consumers are probably more suitable [64]. However, when shared, academic literature was relevant to the information needed 73% (8/11) of the time. We assume that the high relevance of academic literature is because it can fulfill the complex information needs of OvCa OHC users.

NOCC peers also shared patient-generated materials, including patient blogs. Most of the time, patient blogs were meant to share their life journey and survival experiences with fellow users going through the OvCa journey. "...Is there anyone who has something similar?..." and "...Anyone out there survived against all odds for longer than 3 years before recurrence?" are some examples of information needed for which patient blogs were shared. A few times, patient blogs were also shared with the purpose *of staying connected* to the user who asked the question, as shown in the two following comments: "If XXX or you would like to connect with me more, I am at www.xxxblog.com" and "I recommend you go to my blog www.xxx.blogspot.com if you would like to stay in touch." Thus, patient blogs are important resources that contain real patient experiences and provide a platform for connecting with fellow OHC users. Previous studies have found that forum users prefer narrative articles and user blogs over nonnarrative articles

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[65,66]. However, our study observed that patient blogs were shared only 4.5% (8/176) of the time. In addition, patient blogs shared with the purpose of *staying connected* were mostly partially relevant or irrelevant, as they were not targeted to answer OHC users' specific information needs. We assume that the reason could be the complex and unique information needs of OvCa forum users. Hence, finding similar experiences is not always feasible. Therefore, only a few patient-generated articles were shared.

Prior research [22] observed that news articles were shared only 13% of the time, whereas we observed that news articles were shared many times (38/176, 21.6%). One of the reasons for this could be the rarity of OvCa. Survivors of OvCa and caregivers are looking for new treatments and information on clinical trials, and symptom management and health news are good resources for identifying these new findings. There were many shared resources pertaining to the news that included news on new clinical trials, the studied effect of OvCa medication, and recent studies about new treatments, which further clarified that survivors of OvCa and caregivers are eager to learn about new findings and treatments available for a cure.

Resource Purpose and Resource Relevance

Zhang and Sun [22] studied the different purposes of resource sharing in a diabetes OHC. They studied resource sharing in initial posts, which were posted to share experiences, start discussions, and ask questions. However, we studied resource sharing in reply comments, which were intended to answer questions asked in the initial post of the thread. This is important as this study aimed to understand the relevance of shared resources, and questions asked in the initial post act as information needed against which the resource is shared.

Similar to Zhang et al [22], OvCa OHC users' purposes for sharing resources include staying connected, providing further reading, subjects for discussion, and supporting arguments. However, a new category of *pointing to resources* was introduced in this study after the first round of annotator discussion. The *pointing to resources* category was added to handle cases where the purpose of the link was to provide available health resources (health institutions, search engines, or physicians) rather than providing direct reading material. We believe the reason for this category in our post is that Zhang et al [22] studied link sharing in initial posts, whereas this study focused on comment posts, where resources were shared to answer questions in the initial post. The *pointing to resources* purpose was used to answer questions regarding funding resources, clinical trials, and physicians' listings. This category had the second-highest purpose of sharing resources. This finding also provides an important insight that patients on OvCa OHC require much advice on searching for treatment and funding resources. A chi-square test revealed that *pointing of resources* is associated with relevant articles and is an important indicator of relevant resources.

User Reaction to Shared Resource and Resource Relevance

Previous studies have shown that the perceived credibility of a post increases if more people like the post or show gratitude toward it [67]. NOCC followed a similar pattern, with more *likes* on relevant links and fewer *likes* on nonrelevant and partially relevant links. However, these likes are different from average *like* behavior on links; thus, they are difficult to rely on as they are not significantly associated with shared resource relevance (Table 6). This can be inferred from users' average *like* behavior, which changed from 1.41 to 1.74; therefore, is hardly noticeable and is not significant, as shown in Table 6. Sarma et al [36] observed that user *like* reactions were not useful in ranking informative comments on the Twitter platform [68]. In line with previous studies, despite higher coverage, the *like* reaction of the whole community might not be a reliable indicator of the overall usefulness of a resource in NOCC [69-71]. Furthermore, a *like* reaction from the original user with the question could serve as an indicator of resource relevance; however, the low coverage of these likes (at maximum 3/85, 4% for relevant resources) makes it difficult to use this source of feedback in practice for finding relevant resources.

Future Work and Practical Implications

Health Care Educators

Our study observed that patient education materials were shared only 10.2% (18/176) of the time and were partially relevant or irrelevant 72% (13/18) of the time. This result informs health educators that patients often seek other materials to fulfill their information needs. One of the well-known education materials for patients with OvCa is the OvCa guidelines from the National Comprehensive Cancer Network. The guidelines were identified as partially relevant to the needs 86% (6/7) of the times shared. A possible reason could be that patient education materials have to be more personalized to satisfy an individual patient's needs. This finding highlights a research gap for further improvement of patient education materials. For example, educational materials could include relevant patient case studies to be more personalized.

Another insight on patient educational materials is that patients with OvCa found more relevant documents from the news. This suggests that patient education materials can be updated with new facts and findings so that patients do not have to rely on external resources, which can potentially be misleading or untrustworthy.

OHC Administrators and Users

This study found that it is not informative on the relevance of shared resources to examine OHC users' behaviors on the *like* button as feedback. This informs OHC forum administrators that a better and more informative feedback mechanism should be considered for OHCs. Our finding is also consistent with that of a recent study by Sarma et al [36], who found that forum user feedback in the form of *likes* is not enough to obtain informative feedback. A few examples of more informative feedback are the *helpful* button for shared resources, *best answer* button for initial post user feedback, and *best answer* button for forum moderator feedback. A more comprehensive study is required to understand better ways of obtaining user feedback on OHCs.

The study also reveals that there is an association between relevance and different aspects of resource-sharing behaviors.

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An important implication of this study could be the accumulation of a library of patients with OvCa and their caregivers. OHC administrators can collect the resources shared by users and provide a library of resources to users so that they can bookmark and use these resources for future use. Survivors of OvCa have different information needs at different stages of the disease and treatment trajectory [72]. A health article library with predefined information needs and topics could work as a frequently asked questions list, which patients can browse through to meet their specific needs.

Recommender Engine

It is a challenge to make informative content discoverable for patients with cancer. In addition, OvCa is a rare disease for which the internet has relatively fewer resources and experiences low quality [73]. Search engines help patients find information; however, their precision on the internet is low [16]. This study was conducted as part of our HELPeR project [74]. The goal of the HELPeR is to provide survivors of OvCa and caregivers with personalized health resources and reading materials. The study finding that relevant resources are shared only half of the time for a corresponding information need provides a motivation for the requirement of a recommender engine. It also provides insights that inform the types of resources to include and what roles these sources can fulfill; for instance, recommending more health news, health articles, and resources from health organizations that are frequently shared on NOCC. The finding of an association between relevance and resource-sharing behaviors reveals which user behaviors are reliable in determining the relevance of a resource. This can be used to automate data collection for training a machine learning–based recommender engine.

Limitations

First, the relevance of a resource is based on topical relevance, which measures whether the provided resource addresses the corresponding question asked by the user. While checking for relevance, users' knowledge level is not considered, which could play a major role in the relevance of a resource to an individual's information need. For example, if a person with no medical background is provided with academic literature to fulfill their information needs, it may be difficult for them to understand the literature [20,75,76]. Similarly, other aspects of relevance, including the trustworthiness and clinical validity of the document, were not considered in this study [23,77]. Future work should combine the three aspects together to understand the relevance of a document, including topical relevance, users' knowledge level, and resource trustworthiness.

Second, the study assumed OHC users' information needs based on the questions asked by the user and the background information provided by the user within this post. The relevance of the shared resources is based on the user's expressed information needs. This might not affect relevance if the actual information needed is different. For example, the user may not know how to express their information needs, or the user may not provide a proper context to fully understand their information needs.

Third, the study only analyzed 1 OvCa OHC; therefore, the results cannot be generalized to all OvCa OHCs. NOCC is a private and closely connected community; therefore, these results cannot be generalized to open OHCs such as WebMD [37] and question answering forums such as Yahoo Answers [78]. The study included data generated by the NOCC from 2010 to 2020 (10 years). However, NOCC contained only 909 threads during this period. This could be as OvCa is a rare cancer and is diagnosed in later stages. Hence, the study was performed on a very small data set. Future studies can include data from other OvCa OHCs to further improve the generalization and study scale.

Fourth, the study did not differentiate forum users based on their cancer stage and disease trajectory. We acknowledge that users in the later stages of the disease trajectory might have more expertise in handling the disease and treatment [76] and would thus have different views of relevant resources. However, as presented before, this is an inherent limitation of using a web-based forum, as users' information about the disease trajectory, medications, and ongoing treatment might not be available.

In future work, we would also like to study how different types of information needs influence the relevance of resources. The type of information needed can range from early diagnosis to treatment decisions, disease management, and palliative care. This investigation can reveal specific cases or topics for which peers are unable to find relevant information. This will help in determining the simple and complex needs of OvCa OHC users and help us investigate which needs are still not fulfilled by OvCa OHC peers.

Conclusions

Health professionals and clinicians are unable to support each need of survivors of OvCa and their caregivers. Health professionals provide survivors of OvCa with generic patient educational materials that are not sufficiently individualized to meet the needs specific to each patient. OHCs provide clinicians and researchers with a platform to observe the needs of survivors of OvCa and the resources that they rely on. In this study, we leveraged OHCs to investigate the resources that survivors of OvCa and their caregivers entrust to accomplish their and their peers' information needs. Our study revealed that OHC users found more relevant resources from health news and health articles. Further investigation of OHC resource-sharing behavior revealed that direct evidence such as user reactions and TLDs were not enough to reveal the relevance of a resource, whereas implicit behavior, including types of resources shared and the purpose of resource sharing, had a direct association with resource relevance. The findings present implications and motivations for designing web-based recommender systems to support health information–seeking survivors of OvCa and caregivers. Subsequently, this resource collection will become part of our recommender system. Subsequent studies should further investigate how a resource's relevance is influenced by the different types of information needs.

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Conflicts of Interest

None declared.

References

1. Key statistics for ovarian cancer. American Cancer Society. 2022. URL: https://www.cancer.org/cancer/ovarian-cancer/about/key-statistics.html [accessed 2022-01-16]
2. Torre LA, Trabert B, DeSantis CE, Miller KD, Samimi G, Runowicz CD, et al. Ovarian cancer statistics, 2018. CA Cancer J Clin 2018 Jul;68(4):284-296 [FREE Full text] [doi: 10.3322/caac.21456] [Medline: 29809280]
3. Survival rates for ovarian cancer. American Cancer Society. 2022. URL: https://www.cancer.org/cancer/ovarian-cancer/detection-diagnosis-staging/survival-rates.html [accessed 2021-06-17]
4. Miyoshi A, Kanao S, Naoi H, Otsuka H, Yokoi T. Ovarian cancer: post-relapse survival and prognostic factors. J Clin Gynecol Obstet 2018 Jun;7(2):31-36 [FREE Full text] [doi: 10.14740/jcgo488w]
5. Definition of survivor - NCI Dictionary of Cancer Terms. National Cancer Institute. URL: https://www.cancer.gov/publications/dictionaries/cancer-terms/def/survivor [accessed 2021-07-29]
6. van Eenbergen MC, van de Poll-Franse LV, Krahmer E, Verberne S, Mols F. Analysis of content shared in online cancer communities: systematic review. JMIR Cancer 2018 Apr 03;4(1):e6 [FREE Full text] [doi: 10.2196/cancer.7926] [Medline: 29615384]
7. von Gruenigen VE, Huang HQ, Gil KM, Gibbons HE, Monk BJ, Rose PG, et al. A comparison of quality-of-life domains and clinical factors in ovarian cancer patients: a Gynecologic Oncology Group study. J Pain Symptom Manage 2010 May;39(5):839-846 [FREE Full text] [doi: 10.1016/j.jpainsymman.2009.09.022] [Medline: 20471545]
8. Sun CC, Bodurka DC, Weaver CB, Rasu R, Wolf JK, Bevers MW, et al. Rankings and symptom assessments of side effects from chemotherapy: insights from experienced patients with ovarian cancer. Support Care Cancer 2005 Apr;13(4):219-227. [doi: 10.1007/s00520-004-0710-6] [Medline: 15538640]
9. Degner LF, Kristjanson LJ, Bowman D, Sloan JA, Carriere KC, O'Neil J, et al. Information needs and decisional preferences in women with breast cancer. JAMA 1997 May 14;277(18):1485-1492. [Medline: 9145723]
10. von Gruenigen VE, Huang HQ, Gil KM, Gibbons HE, Monk BJ, Rose PG, et al. Assessment of factors that contribute to decreased quality of life in gynecologic oncology group ovarian cancer trials. Cancer 2009 Oct 15;115(20):4857-4864 [FREE Full text] [doi: 10.1002/cncr.24520] [Medline: 19691091]
11. Petricone-Westwood D, Hales S, Galica J, Stragapede E, Lebel S. What do partners of patients with ovarian cancer need from the healthcare system? An examination of caregiving experiences in the healthcare setting and reported distress. Support Care Cancer 2021 Mar;29(3):1213-1223. [doi: 10.1007/s00520-020-05599-3] [Medline: 32613371]
12. Berry LL, Dalwadi SM, Jacobson JO. Supporting the supporters: what family caregivers need to care for a loved one with cancer. J Oncol Pract 2017 Jan;13(1):35-41. [doi: 10.1200/JOP.2016.017913] [Medline: 27997304]
13. Stewart DE, Wong F, Cheung AM, Dancey J, Meana M, Cameron JI, et al. Information needs and decisional preferences among women with ovarian cancer. Gynecol Oncol 2000 Jun;77(3):357-361. [doi: 10.1006/gyno.2000.5799] [Medline: 10831342]
14. Stead ML, Brown JM, Fallowfield L, Selby P. Lack of communication between healthcare professionals and women with ovarian cancer about sexual issues. Br J Cancer 2003 Mar 10;88(5):666-671 [FREE Full text] [doi: 10.1038/sj.bjc.6600799] [Medline: 12618871]
15. Willis E, Royne MB. Online health communities and chronic disease self-management. Health Commun 2017 Mar;32(3):269-278. [doi: 10.1080/10410236.2016.1138278] [Medline: 27218836]
16. Kanthawala S, Vermeesch A, Given B, Huh J. Answers to health questions: internet search results versus online health community responses. J Med Internet Res 2016 Apr 28;18(4):e95 [FREE Full text] [doi: 10.2196/jmir.5369] [Medline: 27125622]
17. Carron-Arthur B, Ali K, Cunningham JA, Griffiths KM. From help-seekers to influential users: a systematic review of participation styles in online health communities. J Med Internet Res 2015 Dec 01;17(12):e271 [FREE Full text] [doi: 10.2196/jmir.4705] [Medline: 26627369]
18. Rubenstein EL. Crowdsourcing health literacy: the case of an online community. Proc Am Soc Info Sci Tech 2014 May 08;50(1):1-5. [doi: 10.1002/meet.14505001119]
19. Ahn MY, Davis HH. Sense of belonging as an indicator of social capital. IJSSP 2020 Apr 30;40(7/8):627-642. [doi: 10.1108/ijssp-12-2019-0258]
20. Goeuriot L, Suominen H, Kelly L, Miranda-Escalada A, Krallinger M, Liu Z, et al. Overview of the CLEF eHealth evaluation lab 2020. In: Experimental IR Meets Multilinguality, Multimodality, and Interaction: 11th International Conference of the

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CLEF Association. 2020 Sep 15 Presented at: CLEF '20; September 22-25, 2020; Thessaloniki, Greece p. 255-271. [doi: 10.1007/978-3-030-58219-7_19]
21. Rothrock SG, Rothrock AN, Swetland SB, Pagane M, Isaak SA, Romney J, et al. Quality, trustworthiness, readability, and accuracy of medical information regarding common pediatric emergency medicine-related complaints on the web. J Emerg Med 2019 Oct;57(4):469-477 [FREE Full text] [doi: 10.1016/j.jemermed.2019.06.043] [Medline: 31561928]
22. Zhang Y, Sun Y. Users' link sharing behaviour in an online health community. Inf Res 2015 Mar;20(1):195-204.
23. Nath C, Huh J, Adupa AK, Jonnalagadda SR. Website sharing in online health communities: a descriptive analysis. J Med Internet Res 2016 Jan 13;18(1):e11 [FREE Full text] [doi: 10.2196/jmir.5237] [Medline: 26764193]
24. Wanas N, El-Saban M, Ashour H, Ammar W. Automatic scoring of online discussion posts. In: Proceedings of the 2nd ACM workshop on Information credibility on the web. 2008 Presented at: WICOW '08; October 30, 2008; Napa Valley, CA, USA p. 19-26. [doi: 10.1145/1458527.1458534]
25. Dobbins M, Watson S, Read K, Graham K, Yousefi Nooraie R, Levinson AJ. A tool that assesses the evidence, transparency, and usability of online health information: development and reliability assessment. JMIR Aging 2018 May 07;1(1):e3 [FREE Full text] [doi: 10.2196/aging.9216] [Medline: 31518240]
26. Knoepke CE, Slack DH, Ingle MP, Matlock DD, Marzec LN. Quality of medical advice provided between members of a web-based message board for patients with implantable defibrillators: mixed-methods study. JMIR Cardio 2018 Dec 04;2(2):e11358 [FREE Full text] [doi: 10.2196/11358] [Medline: 31758775]
27. Lui M, Baldwin T. Classifying user forum participants: separating the gurus from the hacks, and other tales of the internet. In: Proceedings of the Australasian Language Technology Association Workshop. 2010 Presented at: ALTA '10; December 9-10, 2010; Melbourne, Australia p. 49-57 URL: https://aclanthology.org/U10-1009
28. Cosijn E, Ingwersen P. Dimensions of relevance. Inf Process Manag 2000 Jul 01;36(4):533-550. [doi: 10.1016/s0306-4573(99)00072-2]
29. Sun J, Gao H, Yang X. Towards a quality-oriented real-time web crawler. In: Proceedings of the 2010 international conference on Web information systems and mining. 2010 Oct Presented at: WISM'10; October 23-24, 2010; Sanya, China p. 67-76. [doi: 10.1007/978-3-642-16515-3_10]
30. Kelly D. Implicit feedback: using behavior to infer relevance. In: Spink A, Cole C, editors. New directions in cognitive information retrieval. Dordrecht, The Netherlands: Springer; 2005:169-186.
31. Agichtein E, Brill E, Dumais S. Improving web search ranking by incorporating user behavior information. In: Proceedings of the 29th annual international ACM SIGIR conference on Research and development in information retrieval. 2006 Presented at: SIGIR '06; August 6-11, 2006; Seattle, WA, USA p. 19-26. [doi: 10.1145/1148170.1148177]
32. Adomavicius G, Tuzhilin A. Toward the next generation of recommender systems: a survey of the state-of-the-art and possible extensions. IEEE Trans Knowl Data Eng 2005 Jun;17(6):734-749. [doi: 10.1109/tkde.2005.99]
33. Halder K, Kan MY, Sugiyama K. Health forum thread recommendation using an interest aware topic model. In: Proceedings of the 2017 ACM on Conference on Information and Knowledge Management. 2017 Nov Presented at: CIKM '17; November 6-10, 2017; Singapore, Singapore p. 1589-1598. [doi: 10.1145/3132847.3132946]
34. Granka LA, Joachims T, Gay G. Eye-tracking analysis of user behavior in WWW search. In: Proceedings of the 27th annual international ACM SIGIR conference on Research and development in information retrieval. 2004 Jul Presented at: SIGIR '04; July 25-29, 2004; Sheffield, UK p. 478-479. [doi: 10.1145/1008992.1009079]
35. Osman A, Salim N, Saeed F. Quality dimensions features for identifying high-quality user replies in text forum threads using classification methods. PLoS One 2019;14(5):e0215516 [FREE Full text] [doi: 10.1371/journal.pone.0215516] [Medline: 31091242]
36. Das Sarma A, Das Sarma A, Gollapudi S, Panigrahy R. Ranking mechanisms in twitter-like forums. In: Proceedings of the third ACM international conference on Web search and data mining. 2010 Feb Presented at: WSDM '10; February 4-6, 2010; New York, NY, USA p. 21-30. [doi: 10.1145/1718487.1718491]
37. Better information. Better health. WebMD. URL: https://www.webmd.com/default.htm [accessed 2021-05-29]
38. National Ovarian Cancer Coalition. URL: http://ovarian.org/ [accessed 2021-05-29]
39. CancerConnect. URL: https://news.cancerconnect.com/ [accessed 2021-05-29]
40. Cohen J. A coefficient of agreement for nominal scales. Educ Psychol Meas 1960 Apr 01;20(1):37-46 [FREE Full text] [doi: 10.1177/001316446002000104]
41. Lombard M, Snyder-Duch J, Bracken CC. Practical resources for assessing and reporting intercoder reliability in content analysis research projects. Intercoder Reliability in Content Analysis 2005 Jan 01;19(2002):1-18.
42. Sierra F, Cárdenas A. Evidence-based medicine (EBM) in practice: agreement between observers rating esophageal varices: how to cope with chance? Am J Gastroenterol 2007 Nov;102(11):2363-2366. [doi: 10.1111/j.1572-0241.2007.01225.x] [Medline: 17958753]
43. Mewes HN. Memorandum Of understanding on the generic top-level domain name space of the internet domain name system. Berkeley Technol Law J 1998;13(1):235-247 [FREE Full text]
44. Chi Y, He D, Jeng W. Laypeople's source selection in online health information‐seeking process. J Assoc Inf Sci Technol 2020 Feb 24;71(12):1484-1499 [FREE Full text] [doi: 10.1002/asi.24343]

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45. Cancer.Net | Oncologist-approved cancer information from the American Society of Clinical Oncology. American Society of Clinical Oncology. 2016. URL: https://www.cancer.net/ [accessed 2022-03-21]
46. Med-Health.net. URL: http://www.med-health.net/ [accessed 2021-05-29]
47. Medical express has joined forces with onward healthcare. URL: https://www.onwardhealthcare.com/medical-express-redirect/ [accessed 2021-05-29]
48. National Cancer Institute. Comprehensive cancer information. URL: http://www.cancer.gov/ [accessed 2021-05-29]
49. National Comprehensive Cancer Network. URL: https://www.nccn.org/ [accessed 2021-05-29]
50. National Center for Biotechnology Information. URL: https://www.ncbi.nlm.nih.gov [accessed 2021-05-29]
51. EurekAlert! Trending news releases. URL: https://www.eurekalert.org/ [accessed 2021-05-29]
52. CancerConnect Community. National Ovarian Cancer Coalition. URL: http://nocccommunity.ovarian.org/ [accessed 2021-05-29]
53. Cancer Survivors Network. URL: https://csn.cancer.org/ [accessed 2021-05-29]
54. Facebook. URL: https://www.facebook.com/ [accessed 2021-05-29]
55. Cancer treatment and research in Boston, MA. Dana-Farber Cancer Institute. URL: https://www.dana-farber.org/ [accessed 2021-05-29]
56. Omiana. URL: https://www.omiana.com/ [accessed 2021-05-29]
57. 100% Pure: Organic and Natural Beauty Products. URL: https://www.100percentpure.com/ [accessed 2021-05-29]
58. YouTube. URL: https://www.youtube.com/ [accessed 2021-05-29]
59. Personal Injury Attorneys. TheLawFirm. URL: https://thelawfirm.com/ [accessed 2021-05-30]
60. Wikipedia - The Free Encyclopedia. URL: https://en.wikipedia.org/wiki/Main_Page [accessed 2021-05-30]
61. OncLive TV. URL: https://www.onclive.com/onclive-tv [accessed 2021-05-30]
62. Petrič G, Atanasova S, Kamin T. Ill literates or illiterates? Investigating the ehealth literacy of users of online health communities. J Med Internet Res 2017 Oct 04;19(10):e331 [FREE Full text] [doi: 10.2196/jmir.7372] [Medline: 28978496]
63. Bristow RE, Chang J, Ziogas A, Anton-Culver H. NCCN treatment guidelines for ovarian cancer: a population-based validation study of structural and process quality measures. Gynecologic Oncology 2013 Jul;130(1):e18. [doi: 10.1016/j.ygyno.2013.04.104]
64. Kim H, Goryachev S, Rosemblat G, Browne A, Keselman A, Zeng-Treitler Q. Beyond surface characteristics: a new health text-specific readability measurement. AMIA Annu Symp Proc 2007 Oct 11:418-422 [FREE Full text] [Medline: 18693870]
65. Stavrositu CD, Kim J. All blogs are not created equal: the role of narrative formats and user-generated comments in health prevention. Health Commun 2015;30(5):485-495. [doi: 10.1080/10410236.2013.867296] [Medline: 24978046]
66. Gesser-Edelsburg A. Using narrative evidence to convey health information on social media: the case of COVID-19. J Med Internet Res 2021 Mar 15;23(3):e24948 [FREE Full text] [doi: 10.2196/24948] [Medline: 33674257]
67. Seo Y, Kim J, Choi YK, Li X. In “likes” we trust: likes, disclosures and firm-serving motives on social media. EJM 2019 Oct 07;53(10):2173-2192. [doi: 10.1108/ejm-11-2017-0883]
68. Twitter. URL: https://twitter.com/home [accessed 2021-05-30]
69. Borah P, Xiao X. The importance of 'likes': the interplay of message framing, source, and social endorsement on credibility perceptions of health information on Facebook. J Health Commun 2018;23(4):399-411. [doi: 10.1080/10810730.2018.1455770] [Medline: 29601271]
70. Hartzler A, Huh J. Level 3: Patient power on the web: the multifaceted role of personal health wisdom. In: Wetter T, editor. Comsumer health informatics. Cham, Switzerland: Springer; 2016:135-146.
71. Liu J, Kong J. Why do users of online mental health communities get likes and reposts: a combination of text mining and empirical analysis. Healthcare (Basel) 2021 Aug 31;9(9):1133 [FREE Full text] [doi: 10.3390/healthcare9091133] [Medline: 34574907]
72. Madathil KC, Greenstein JS, Juang KA, Neyens DM, Gramopadhye AK. An investigation of the informational needs of ovarian cancer patients and their supporters. Proc Hum Factors Ergon Soc Annu Meet 2013 Sep 30;57(1):748-752. [doi: 10.1177/1541931213571163]
73. Pauer F, Litzkendorf S, Göbel J, Storf H, Zeidler J, Graf von der Schulenburg JM. Rare diseases on the internet: an assessment of the quality of online information. J Med Internet Res 2017 Jan 18;19(1):e23 [FREE Full text] [doi: 10.2196/jmir.7056] [Medline: 28100442]
74. HELPeR. URL: https://sites.pitt.edu/~dah44/helper/ [accessed 2021-05-30]
75. Palotti J, Goeuriot L, Zuccon G, Hanbury A. Ranking health web pages with relevance and understandability. In: Proceedings of the 39th International ACM SIGIR conference on Research and Development in Information Retrieval. 2016 Jul 07 Presented at: SIGIR '16; July 17-21, 2016; Pisa, Italy p. 965-968. [doi: 10.1145/2911451.2914741]
76. Hartzler A, Pratt W. Managing the personal side of health: how patient expertise differs from the expertise of clinicians. J Med Internet Res 2011 Aug 16;13(3):e62 [FREE Full text] [doi: 10.2196/jmir.1728] [Medline: 21846635]
77. Battineni G, Baldoni S, Chintalapudi N, Sagaro GG, Pallotta G, Nittari G, et al. Factors affecting the quality and reliability of online health information. Digit Health 2020;6:2055207620948996 [FREE Full text] [doi: 10.1177/2055207620948996] [Medline: 32944269]
78. Yahoo Answers. URL: http://answers.yahoo.com [accessed 2021-05-30]

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Abbreviations

HELPeR: Health e-Librarian with Personalized Recommender
NOCC: National Ovarian Cancer Coalition
NOCC-RS: National Ovarian Cancer Coalition shared resource
OHC: online health community
OvCa: ovarian cancer
RQ: research question
TLD: top-level domain

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Original Paper

Development of a Web-Based Decision Aid and Planning Tool for Family Building After Cancer (Roadmap to Parenthood): Usability Testing

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Abstract

Background: Owing to gonadotoxic cancer treatments, young adult female survivors often report uncertainty about their fertility, reproductive potential, and family-building options after treatment. *Roadmap to Parenthood* is a web-based decision aid and planning tool for family building after cancer.

Objective: As part of a patient-centered development process, this study evaluated the usability of the decision aid website to inform design modifications and improve user experience.

Methods: In total, 2 rounds of usability testing were conducted with the target population of young adult female cancer survivors. During the testing sessions, participants viewed the website twice; first, as a *think-aloud* exercise, and second, while a researcher interrupted at key points to obtain user feedback. Quantitative and qualitative data were collected to assess website usability. Quantitative measures included the System Usability Scale, WebQual, and eHealth Impact Questionnaire. An exit interview with open-ended questions gathered feedback on likes and dislikes and suggestions for improvement.

Results: Participants (N=10) were young adult women, with average age of 30.9 (SD 4.51) years, and average time since treatment was 4.44 (SD 3.56) years. Website usability scores improved on the System Usability Scale from "acceptable" in round 1 to "excellent" in round 2 after making design changes based on user feedback (scores of 68 and 89.4, respectively). WebQual scores showed similar improvement from round 1 to round 2 of testing (mean 5.6 to 6.25; range 1-7). On the eHealth Impact Questionnaire, the information and presentation of the website was perceived as comprehensive, easy to understand, and trustworthy. Participants also reported improved confidence to discuss and manage fertility and family-building issues and felt encouraged to play a more active role in managing their fertility. In all, 3 usability themes were identified from the qualitative feedback: ease of use, visibility and navigation, and informational content and usefulness. Overall feedback was positive, and participants reported intentions to use the decision aid website in the future. In total, 10% (1/10) of the participants reported negative emotions when learning about infertility risks and potential family-building challenges.

Conclusions: Website usability improved after design changes were made in response to user feedback. Young adult female survivors reported positive views about the website and indicated that the decision aid would be useful in decision-making about family building after cancer. Future studies will include further design modifications to consider the emotional experiences of users and any additional navigational features or content to optimize the ease of use and support provided by the tool.

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KEYWORDS

young adult cancer; cancer survivorship; decision-making; decision aids; fertility; reproductive health; mobile phone

Introduction

Background

In young adult cancer survivors, gonadotoxic treatments may negatively affect fertility and reproductive health [1,2]. In the aftermath of cancer, questions surrounding fertility status and implications for family-building options are often distressing, particularly for young women who may wonder about their chances of achieving pregnancy, reproductive time line, or health risks [3,4]. On the basis of the principles of patient-centered care, women should be supported in making informed, values-based decisions that align with their long-term goals for family building [5]. Resources are needed to educate and support women in seeking reproductive health care after treatment and making decisions about family-building options.

Fertility and Family Building After Cancer

It is well established that young adult female cancer survivors are often uninformed and worried about potential fertility issues following cancer treatment and endorse high rates of unmet support needs [6-8]. Most are unable to preserve fertility before treatment owing to many factors (eg, time constraints, emotional distress, and cost), and there is great uncertainty about fertility and family-building options after treatment is completed [9-11]. Among women who wanted children after cancer, 64% worried about fertility problems; however, only 10% had undergone fertility evaluation since their treatment ended [6]. Fertility is recognized as an important survivorship issue [12]; however, patients are often not counseled about options to evaluate and monitor fertility over time or about alternative family-building options if natural conception is not possible. These options include using reproductive medicine (eg, in vitro fertilization or surrogacy with fresh, frozen, or donated gametes) or adoption or fostering, but have medical, psychosocial, financial, legal, and logistical challenges [13-15].

Decision-making About Family Building After Cancer

Making decisions about reproductive health care and family building after cancer can be overwhelming and distressing. Previously, we found high rates of decisional conflict about family building among young adult female survivors who reported feeling uninformed about their options (86%) and unclear about personal values (74%) and lacked guidance (70%) and adequate emotional support (35%) [6]. Even when informed, women still face uncertainties surrounding inexact estimates of fertility potential, likelihood of success with assisted reproductive technology, health risks, direct and indirect costs, and unknown bureaucratic difficulties. Decision aids have proven effective in helping young women diagnosed with cancer to make decisions about fertility preservation before treatment [16]. We are aware of 10 decision aids designed for women with cancer who are considering fertility preservation before treatment (only 4 aids are in English and 6 aids are for breast cancer only); efficacy data are available for 4 of these decision aids as of September 2021. Studies report good acceptability and satisfaction among women and positive effects on decision-making outcomes (eg, improved knowledge and decisional conflict) [17-19]. Consistent with the broader decision science literature [20], these studies provide initial support for the utility of decision aids for young adult female cancer survivors facing fertility decisions. However, none of them include comprehensive information about decisions that must be made *after* treatment is completed to address follow-up questions about fertility outcomes and decisions about reproductive health care and family building and to help plan for the future for those not yet ready to start their family building. Other oncofertility resources exist (eg, educational materials), but these are of varying quality with limited data about their development and efficacy; very few describe user-centered design processes [21].

On the basis of extensive pilot study and following user-centered design practices [6,11,13,22], we developed a web-based decision aid and planning tool for family building after cancer, *Roadmap to Parenthood*. Briefly, the interactive tool provides information about cancer treatment's effects on fertility and family-building options if natural conception is not possible and includes a values-clarification tool, family-building stories from other survivors, and guidance for *next steps* action planning. Additional resources include in-depth information about specific topics, financial loans and grants, and psychological support including connecting with cancer-related and fertility-related organizations. It was designed to be used by single and partnered women, inclusive of sexual orientations, and it is appropriate for all stages of decision-making readiness and expected family-building time lines. In other words, women can use the tool to make intermediary decisions about preparatory actions (eg, seek a fertility evaluation, undergo fertility preservation after treatment if possible, or plan financially) and plan for the future if they are at risk for experiencing fertility problems (eg, premature menopause), but their desired time frame for parenthood is not many years. Ultimately, the overarching goal of the *Roadmap to Parenthood* decision aid tool is to encourage survivors to be informed about family-building options, set realistic expectations about potential difficulties, and plan ahead if desired, while also inspiring hope and confidence that parenthood may be achieved, despite their cancer histories.

Objectives

Previously, we described the development of the *Roadmap to Parenthood* decision aid website prototype [23]. Previous studies have shown that usability testing can help developers optimize decision support tools for future end users [24,25]. The usability of such a tool refers to the extent to which it may be used effectively and efficiently to achieve specified goals in a specified context of use and includes user satisfaction (eg, the tool is easy to learn, tasks can be performed quickly with minimal errors, and the design is pleasant) [26,27]. Usability is an aspect of the overall user experience, which is a broad concept that includes all components of a user's motivations and needs and their interaction with and perceptions of the tool, such as whether it is useful, usable, desirable, accessible,

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credible, and valuable [28,29]. Here, we have reported the results of usability testing of the tool and responsive design changes as part of an iterative user-centered development process. Our goal was to evaluate and improve the usability of the website, thus contributing to a positive user experience, and to optimize the website as a support resource for young adult female cancer survivors.

Methods

The study was conducted at Northwell Health and the affiliated Feinstein Institutes for Medical Research, a large academic hospital and research institute in New York.

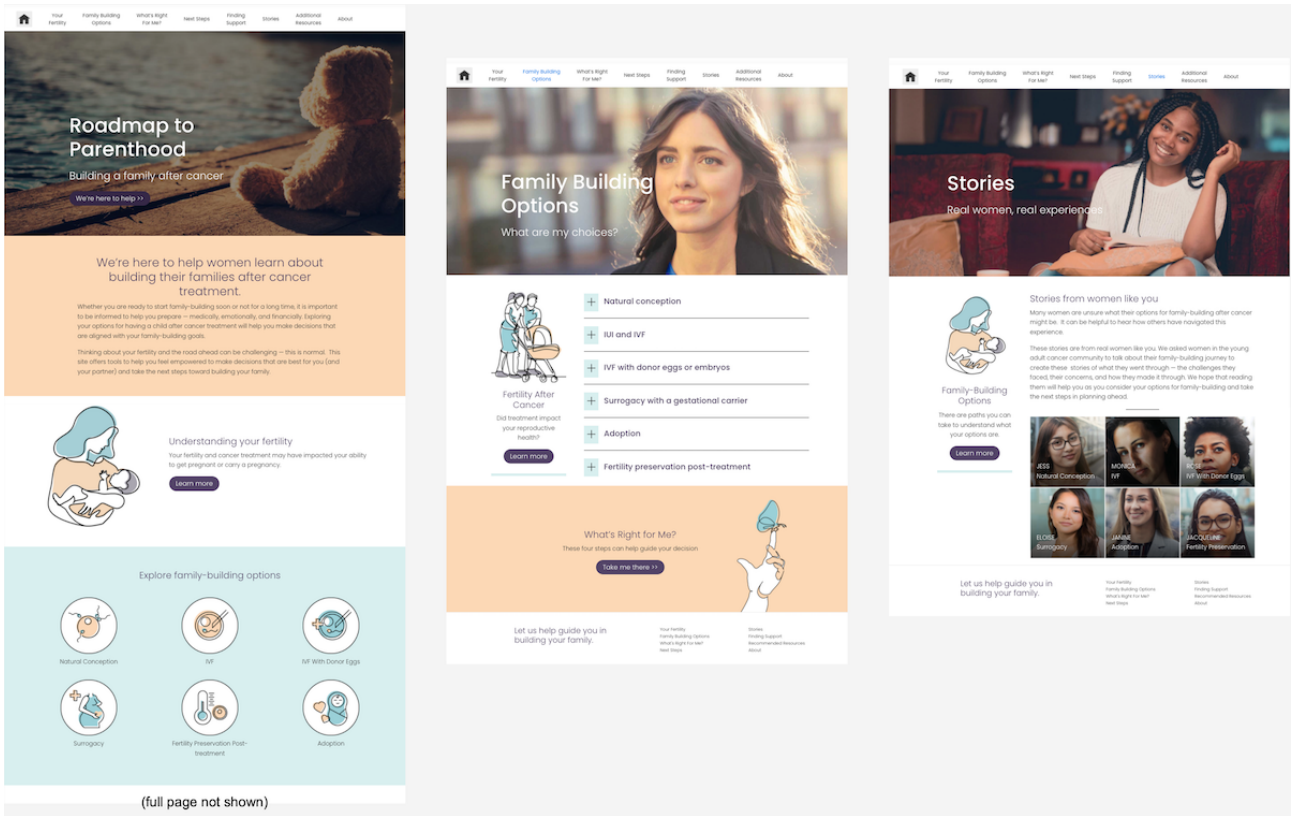
Ethics Approval

All the study procedures were approved by the Northwell Health Institutional Review Board (18-0516).

Decision Aid Prototype

As described in the previous section, the *Roadmap to Parenthood* is a web-based decision aid and planning tool for family building after cancer, designed to be used by young adult female cancer survivors who may be at risk for fertility and family-building problems owing to gonadotoxic treatments. It is based on the experiences of young adult female survivors in the United States and is written in English. Personalized information about infertility risk and likelihood of success with family-building options is not provided. The design of the decision aid followed guidelines from the International Patient Decision Aid Society and Ottawa Decision Support Framework for developing patient decision aids [30-32]. Guidelines from the Office of Disease Prevention and Health Promotion [33], National Institutes of Health [34], Centers for Medicare and Medicaid Services [35], and Stanford University Office of Digital Accessibility [36] also were followed to ensure that the design and content were accessible to most users, including users with varying levels of health literacy, users with disabilities, and culturally diverse populations (previously described by Benedict et al [23]). Selected pages from the website are shown in Figure 1.

Figure 1. Selected pages from the Roadmap to Parenthood decision aid website. Some of the design aspects illustrated by these pages include the top and bottom navigation bars; using color, white space, and drawer design to chunk and divide sections; using icons to indicate information about family-building options; and call-to-action buttons (side and bottom) to guide the user journey.



Participants

Eligible participants were English-speaking women, aged 18 to 39 years, who completed potentially gonadotoxic cancer treatment (eg, systemic chemotherapy, radiation to the pelvic area or brain, or surgery affecting the reproductive organs) and reported a desire for future children or uncertainty about family-building plans. Participants needed to have internet access and use a computer, tablet, or smartphone.

Procedures

Participants (N=10) were recruited through the Northwell Health system and social media. It has been established that testing a product with 5 participants is sufficient to reveal approximately 80% of the product's usability issues [37]. For hospital-based recruitment, a list of eligible patients was generated using electronic health record data, and letters were mailed to invite participation. Young adult cancer organizations (eg, Stupid Cancer and Lacuna Loft) also posted institutional review

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board–approved advertisements on their social media pages, with links to submit contact information via a secure platform. A research coordinator followed up with those who submitted their contact information via a telephone call to describe the study and answer questions. Participants were provided with information about the study objectives and participation requirements. Written informed consent was obtained remotely (via REDCap [Research Electronic Data Capture; Vanderbilt University]), and then, the participants were scheduled for a usability testing session. Compensation (US $10) was provided after completion of the testing session.

Usability testing was conducted by the principal investigator (PI) and Northwell Usability Lab, which has extensive experience and expertise in developing patient decision aids following user-centered design approaches, including usability testing and data analysis [38]. Totally, 2 rounds of usability testing were conducted, allowing the study team to make design changes that were responsive to initial usability problems and, then, to test an updated prototype. Each participant completed only 1 usability testing session (ie, different participants were included in round 1 and round 2 of testing). The first round of testing included 6 testing sessions, at which point saturation was reached in identifying usability issues [39], and a decision to halt testing to address critical design flaws was made. Following changes to the website in response to the initial user feedback, the second round of testing included 4 additional sessions with new participants to evaluate the updated website.

For each round of usability testing, participants completed a brief baseline survey and then participated in a usability testing session (30-45 minutes). A member of the Northwell Usability Lab led the testing sessions with at least one other study team member and the PI (CB) present, allowing for observer triangulation to identify problems in user experience and design. To evaluate website usability, certain key issues were assessed, including evaluation of users' ability to find desired information, evaluation of the clarity of and comfort with the website content, and identification of barriers to full use and ease of navigating through the website. Participants were asked to view the website prototype twice. First, they explored the website in a *think-aloud* exercise in which they provided a verbal talk-track describing their experiences with the content and navigation through the site, while the researchers also observed how they interacted with the site. Then, they reviewed the website a second time, and a researcher interrupted at key points to obtain feedback on specific visual and written content, transitions between webpages, information flow, and design. These interruptions were responsive to the actions of the users as they explored the website and enabled the research team to clarify various aspects of the user experience, points of confusion, and users' preferred modifications. The sessions were recorded via audio and screen capture (ie, recording participants' verbal feedback and visual representations of website navigation), and members of the research team took notes during each testing session. Upon completion, participants completed a survey and an exit interview.

Measures

The baseline survey included standard sociodemographic and medical history questions and the *eHealth Impact Questionnaire (eHIQ)-part 1* (10 items), a validated measure of general attitudes toward using the internet to access health information and perceived value of web-based health-related resources [40].

Following the testing session, several measures quantified the usability and impact of the website, including aspects of user experience (eg, perceptions of credibility and value). The *System Usability Scale* (SUS; 10 items) is a reliable, industry-standard tool to measure perceived ease of use of a website across usability factors [41]. Scores are converted to a 0 to 100 scale, with a score of 68 considered as cutoff point for "above average" and a score of 85 considered as "excellent" usability [42,43]. *WebQual* (7 items) is a multidimensional measure of consumer evaluation of websites (eg, perceived usefulness, ease of use, and intent to reuse the website) [44]. Scores range from 1 to 7, with higher scores indicating more positive evaluation of the website. The eHIQ-part 2 assesses the impact of using a specific website for health purposes. Subscales of the eHIQ-part 2 include the following: *Confidence and Identification*, measuring confidence to discuss health with others and ability to identify with the website (9 items); *Information and Presentation*, measuring perceived trust and suitability of the website content (8 items); and *Understanding and Motivation*, assessing understanding and learning about relevant information and motivation to take action (9 items) [40]. Scores range from 0 to 100, with higher scores indicating more positive evaluation and impact of using the website. Finally, open-ended questions during the exit interview explored the participants' overall impressions, likes and dislikes, emotional reflections, recommendations, and expectations for future use.

Data Analysis

Descriptive statistics were used to analyze the sociodemographic and medical characteristics of the sample and the eHIQ-part 1 data, providing a baseline understanding of participants' general attitudes toward web-based health resources (ie, not specifically related to the decision aid tool).

Qualitative and quantitative data from the usability testing sessions were analyzed. Think-aloud feedback and answers to the open-ended questions of the exit interview were analyzed qualitatively to capture perceptions of usability, aspects of user experience, and user recommendations for design changes. Coding team members performed content analyses of testing session notes, grouping the feedback points from each participant into overarching categories based on *a priori* codes derived from previous studies on developing patient decision aids and the literature [25,45]. An iterative process of coding and group discussion was conducted to verify initial codes, definitions, and overarching themes. At least 2 team members coded all the data. Team members revisited the audio and Hypercam (Hyperionics) recordings for content and wording clarifications when necessary. Northwell Usability Lab members ensured that coding was consistent across coders by creating a code book with definitions, discussing how they would code sample sections of the session notes and confirming team member agreement of coded data. The PI (CB) reviewed the

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coding and thematic categories and discussed with the team how the results should be used to make website design changes. Data from open-ended questions during the exit interview were summarized to identify patterns in likes and dislikes, emotional reflections, and recommendations and for additional context to understand participant feedback and the overall user experience. In addition, quantitative survey data (ie, SUS, WebQual, and eHIQ-part 2) collected after participants completed the usability testing session were summarized descriptively. Data were divided between the 2 rounds of testing (round 1: 6/10, 60% of the total sample and round 2: 4/10, 40% of the total sample) and compared. Design modifications were made after the first round of testing, when content analysis of the testing data indicated that no new usability issues were identified. Thus, comparing the results across these subgroups allowed us to evaluate whether improvements in usability were successful with design changes and assess whether optimal usability had been reached. Given the small sample size, tests of statistical significance were not performed.

Results

Participant Characteristics

Participants (N=10) were young adult female cancer survivors with average age of 30.78 (SD 4.51) years, with previous diagnoses of breast cancer, cervical cancer, uterine or endometrial cancer, Hodgkin lymphoma, or leukemia. On average, time since treatment was 4.44 years (SD 3.56 years; Table 1).

At baseline, before viewing the website, participants reported strong agreement that the internet can be useful to deal with health problems, and 60% (6/10) of the participants *agreed* or *strongly agreed* that they would use the internet to help make decisions about health (eHIQ-part 1 items). The internet was also seen as a good resource to learn about others' health-related experiences and decision-making, and health-related websites could provide reassurance that participants were not alone with their health concerns.

Table 1. Sociodemographic and medical characteristics of the sample (N=10).

Sample characteristics	Values
Age (years), mean (SD; range)	30.90 (4.51; 25-39)
Age at diagnosis (years), mean (SD; range)	26.13 (6.59; 15-35)
Time since treatment (years), mean (SD; range)	4.44 (3.56; 0.6-10.92)
Race, n (%)	
White	9 (90)
>1 race	1 (10)
Ethnicity, n (%)	
Hispanic	1 (10)
Education (highest attained to date), n (%)	
High school degree	1 (10)
College degree	4 (40)
Postgraduate degree	5 (50)
Cancer diagnosis, n (%)	
Breast	2 (20)
Cervical	1 (10)
Uterine or endometrial	1 (10)
Hodgkin lymphoma	5 (50)
Leukemia	1 (10)
Cancer treatment (not mutually exclusive), n (%)	
Chemotherapy	10 (100)
Surgery that involved removal of the uterus or both ovaries	2 (20)
Radiation that included the abdominal or pelvic region or brain	3 (30)
Bone marrow or stem cell transplant	2 (20)
Hormone therapy or immunotherapy	1 (10)
Other	1 (10)

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Usability Survey Data

Scores on usability measures demonstrated improvement in website usability from round 1 to round 2 of testing (before and after making design changes). SUS scores in round 1 averaged 68 (possible range 0-100), indicating "acceptable" usability. After design modifications, SUS scores in round 2 averaged 89.4, representing "excellent" usability and reaching the threshold for optimal usability for a website. Average WebQual scores (possible range 1-7) also improved from round 1 (mean 5.6) to round 2 of testing (mean 6.25; Figure 2). On a scale from 1 (not at all likely) to 10 (extremely likely), all participants in round 2 responded that they would recommend the website to a friend or other cancer survivor, with scores ranging from 9 to 10.

Perceptions of the website were also evaluated using the eHIQ-part 2. Previous studies have used a cutoff score of ≥65 for eHIQ subscales to indicate that the website was rated positively by users [46], and all subscale scores in round 2 of testing were higher than this cutoff (Figure 3). The information in and presentation of the website were perceived as being comprehensive and easy to understand, and pictures or images were viewed as being used appropriately. In addition, the website was perceived as trustworthy. Participants reported that the website improved their confidence to discuss fertility and family-building topics with others and to manage difficulties that may arise, while also indicating that they identified with other people who use the website. Participants reported that the website felt reassuring, helped them gain a better understanding of their fertility and family-building options, and encouraged them to play a more active role in managing their fertility to align with their family-building goals. All participants indicated that they agree or strongly agree with the statements, "the website encourages me to take actions that could be beneficial to my health" and "I feel more inclined to look after myself after visiting the website."

Figure 2. WebQual: Measures of website usability. Improvements in website usability were observed from round 1 to round 2 of testing (pre-post design changes). Average scores across WebQual items are depicted for both rounds of testing. The possible range of scores is 1 (strongly disagree) to 7 (strongly agree).

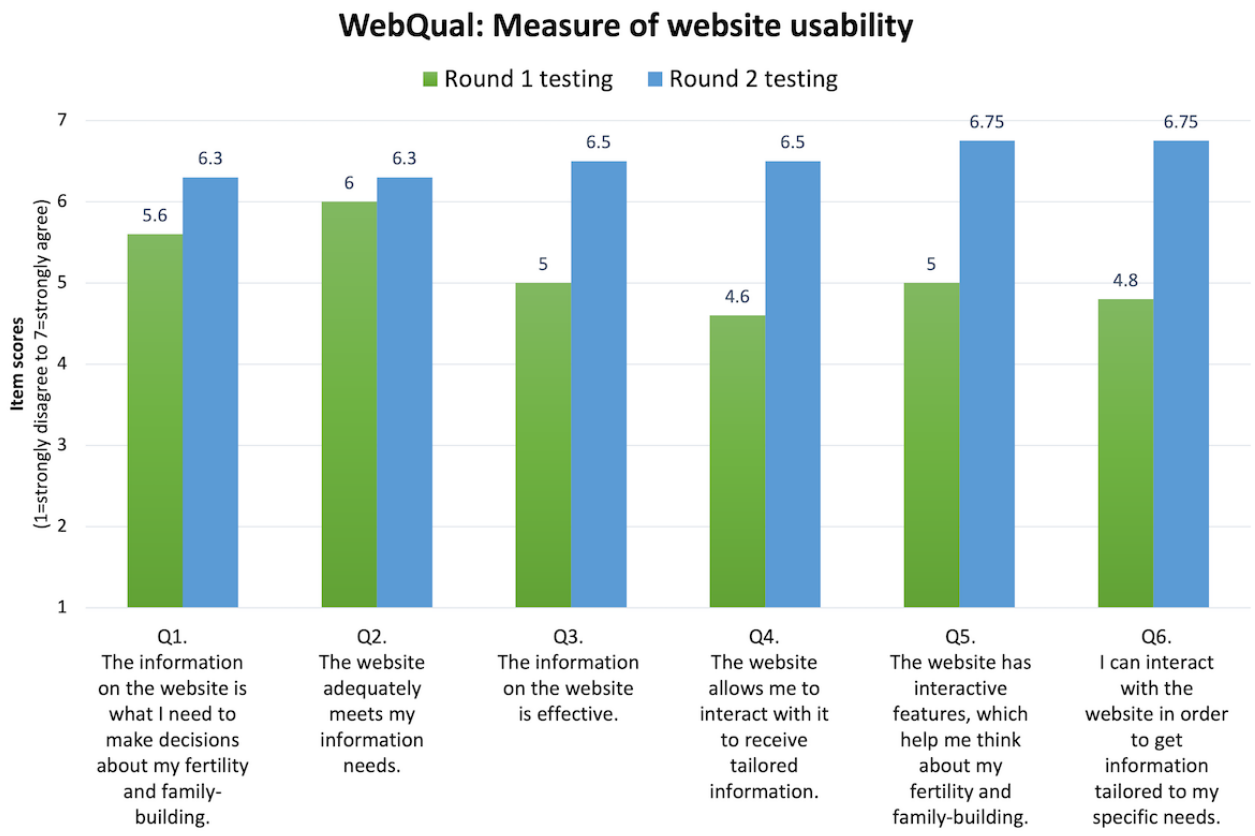

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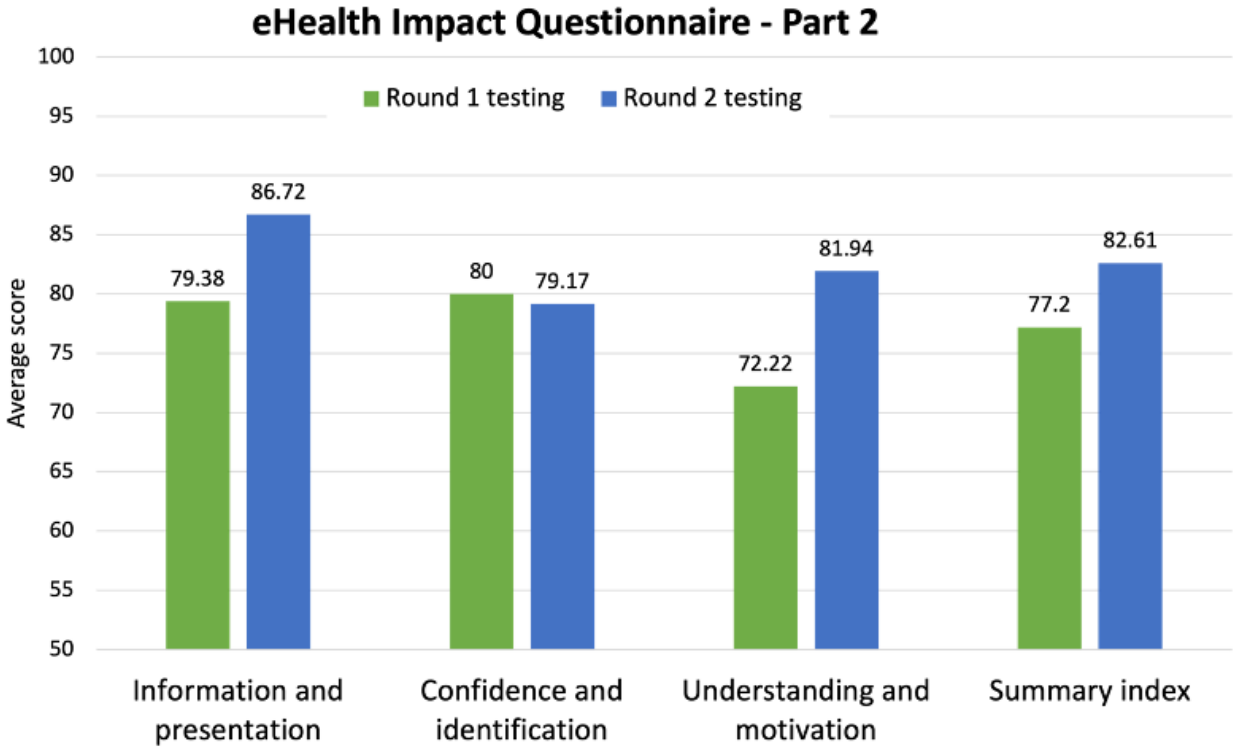
Figure 3. eHealth Impact Questionnaire - Part 2. Improvements were observed across 2 of the 3 domains of the eHIQ-part 2, assessing the impact of using the *Roadmap to Parenthood* website.



Qualitative Feedback

Overview

Data from the think-aloud portion of the usability testing sessions were analyzed to further characterize the usability issues. Totally, 3 main themes that represent different aspects of website usability were identified: ease of use, visibility and navigation, and informational content and usefulness. Table 2 describes the main themes identified across the 2 rounds of testing and the content modifications and design solutions that were implemented after round 1 or are planned to be implemented in response to round 2 feedback. Consistent with survey data, we observed differences in qualitative feedback, suggesting that the initial design problems identified in round 1 were largely resolved with the modifications that were made. In contrast, round 2 of testing identified more specific and nuanced usability problems and patient-driven suggestions for design changes.

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Table 2. Qualitative themes identified from usability testing.

Theme	Definition	Sample quotes	Design changes
Ease of use	Describes how easily users could use and understand the website	• "I like the family building options section a lot – a nice menu showing all the options and then you can click on the one you want to learn more about – sticks out as being very user-friendly" • "...just the presentation of the data. Once I knew what my options were, I would want a lot of information. But I would only want to see that about what I was feeling right then and get the information about that one thing. Bullet points."	• Attention to health literacy and reading levels, for example, use of medical terminology with definitions • Improved presentation of information, for example, better use of headers and subheaders, font and color changes, short paragraphs, white space, and use of drawer design • Language or word changes to improve relatability
Visibility and navigation	Website workflow: whether the website's components were readily and easily discoverable (visible) and whether users found it easy to transition between different parts of the website in a logical and intuitive manner (navigate)	• "I feel like when I go from page to page, it flows really well, but I feel like I'm so deep into it that when I want to go to a different page or the beginning, I don't know where to go. The restart is very helpful. But I do feel like there's a logical flow otherwise."	• Top navigation bar and drop-down menus depicting website pages • Call-to-action buttons • In-page guidance (signposts) suggesting next steps in the user journey • Navigation footer (particularly helpful for mobile phone users)
Informational content and usefulness	Presentation of information and the utility of informational content	• "I like [the personal worksheet page] because it's interactive in a way that what you're reading from the website, you can use on this and it'll help you take the next step." • "This is really interesting to me – very applicable to my stage of family building. I had no idea how expensive it was going to be to build a family afterwards. I felt like everybody said, 'oh freeze your eggs!' but they never said how expensive it would be after, and now I feel pressure having the eggs and having to take that path." • "Maybe it's just [because] that's something that's a really big fear for a lot of women, but [the graph of declining ovarian reserve] is terrifying. I don't know that that would be the first thing I wanted to see if I went here because that's where everybody's mind is going to go immediately is like, 'Oh no, what if this happens?'...It might be scary."	• Reordering of content with careful consideration of text and images • Changes to highlight important pieces of information in conjunction with images or pictures • Improved user journey and navigation guide to connect information to appropriate follow-up pages and resources for support (eg, in-page links and signposts to connect user to resources)

Ease of Use

The *ease of use* theme describes the degree of ease with which users can use and understand the website. Round 1 of testing identified several significant problems that affected the website's ease of use and the overall user experience. Participants felt that the presentation of information was overwhelming in sections that had long paragraphs of text and on pages that required excessive scrolling to view the content. Accordingly, for pages containing large amounts of content, a *drawer design* was implemented such that the content was hidden from view and only made visible if the user clicked on the header (Figure 1), or the content was divided into separate pages. In addition, font sizes and colors were changed to make the section headers more noticeable, divide the text more clearly, and use white space effectively. Text was divided into short, more digestible paragraph lengths to aid both readability and comprehension.

Compared with round 1, comments obtained in round 2 were more specific. Some participants pointed out preferences around syntax that interfered with optimal use of the website, mentioning specific words or phrases they disliked or found unclear or suggesting optimizations with the content.

Visibility and Navigation

The *visibility and navigation* theme focuses on feedback on the website's workflow, including whether the website's components are readily and easily discoverable (visible) and whether users find it easy to transition between different parts of the website in a logical and intuitive manner (navigate). In

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round 1, participants had difficulty in navigating through the website pages (eg, difficulty in finding pages, got lost between pages, and dead-end pages). The website was designed to personalize their user journey, allowing them to access relevant content based on their needs and where they were in their family-building time line. This involved an omnichannel user journey design, similar to *choose your own adventure*, in which users could follow any number of user pathways specific to their needs. Initial testing in round 1 revealed errors in the user journey flow and a lack of structure in guiding the user experience, which appeared to be confusing to the user. To address these issues, navigation bars and call-to-action buttons were added to help signpost content across website pages and guide the user journey. Drop-down menus were also added to the navigation bar to depict multiple pages within the same section, allowing users to jump to the section they were most interested in, while maintaining visual cues to easily move to the other sections as desired. For example, the *Next Steps* tab of the top navigation bar had a drop-down menu including each page within that section (eg, *Ask Your Oncologist*, *Ask a Fertility Specialist*, *Financial Planning*, and *Talk to Your Partner*). In addition, callout links were added to help with navigation by suggesting next pages to visit, thereby providing guidance for the user journey, while simultaneously providing users the freedom to bypass the callouts and follow their preferred path if desired.

The visibility and navigation issues identified in round 1 appeared to be largely resolved in round 2 of testing with the design changes that were implemented. However, additional minor problems were identified, which will be addressed in the next iteration of the decision aid website.

Informational Content and Usefulness

The *informational content and usefulness* theme emphasizes how information is presented on the website and the utility of informational content to future end users. In round 1 of testing, some of the most poignant feedback was given in response to the *Understanding Your Fertility* page, which provided information in the form of text and graphs about female reproductive health and potential effects of cancer treatment on fertility. A user found the graphs of declining ovarian reserve with advancing age and impact of cancer treatment “terrifying” and suggested changing the order of the graph and text to reduce the emotional impact. We made the suggested changes and modified the text to more clearly highlight that the data presented are based on population-level statistics and may not apply to all women and that users must speak with a health care provider to obtain individualized information about their reproductive health. The graph was also edited to soften the depiction of risks surrounding infertility and appear less threatening (eg, bold cutoff points were changed to gradations). A few participants also suggested ways to improve the relatability of the site. For example, a user noted that some survivors want children but do not identify as “young”; therefore, the use of this terminology could make the website feel less relatable. An additional area where users felt content and usefulness could be improved was the *Personal Worksheet* page. A participant suggested that we add more detailed information on next steps based on the users’ worksheet data. Other suggestions indicated a need for more information on early menopause, specific questions to ask a fertility specialist, and more direct links to external resources and organizations that users could access in the future. Content was edited in response to each comment that was received.

After we made modifications based on round 1 feedback, participants of round 2 had suggestions for additional helpful content focused on financial information, insurance coverage limitations, finding adoption agencies that work with cancer survivors, working with surrogate agencies or attorneys, contacting human resource departments for assistance, and information about genetic risks.

General Feedback

Finally, the exit interviews provided additional data about usability and user experiences and included general feedback about users’ likes and dislikes, emotional reflections, and recommendations. Overall, we received positive feedback from participants about the website. Young adult women reported that they identified with the website and felt the information was relevant to their needs:

> *You understand me as a woman really well. You understand what kind of information I’d be looking for.*

When asked what they liked best about the website, the most common answer was the inclusion of stories representing family-building options, with participants stating that it felt good to hear peer stories with which they could identify. Other sections noted as favorites were those providing information about talking to one’s partner, questions to ask one’s oncologist, the values-clarification exercise, and the resources page. Participants reported that they liked the breadth of information and felt it was relevant and accessible. When asked what they liked the least about the website, consistent with qualitative themes, participants indicated navigation problems (primarily in round 1) and other minor design and content issues (eg, small font size). When asked if anything was missing from the website, participants indicated a preference for more photographs and videos and again suggested additional information topics and resources (eg, app recommendations for period tracking). Participants described the website as a “unique resource” and “one-stop-shop tool to learn about fertility options and to help you make informed decisions.” They indicated that the information was comprehensive and understandable:

> *For normal people...not too scientific, but for people like us.*

They also discussed the emotional impact of having access to the decision aid tool:

> *A really great resource depending on your own individual situation to make you less overwhelmed and guide you through the process.*

When prompted for final thoughts and impressions, a participant said the following:

> *Let me know when I can share it with the world [because] I know a lot of people that would find this helpful.*

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Overall, this positive feedback was encouraging and suggested that the decision aid tool would be useful, appealing, and well received by future end users.

Discussion

Principal Findings

The aim of this study was to evaluate the usability of a web-based decision aid and planning tool for family building after cancer, *Roadmap to Parenthood*, to inform design modifications and better understand user experience as part of an iterative, user-centered development process. Website usability was evaluated quantitatively and qualitatively across 2 rounds of testing, along with some aspects of user experience, to understand the context and impact of using the decision aid tool. Average usability scores improved from "acceptable" in round 1 to "excellent" in round 2 after making design changes based on user feedback. We identified 3 usability themes that represented issues related to ease of use, visibility and navigation, and informational content and usefulness. This study is among the limited number of usability studies that evaluated digital health tools for young adults affected by cancer and, to the best of our knowledge, the only evidence-based decision support resource for family building after cancer [21,47].

Website usability improved with modifications based on initial user feedback, including user perceptions of how easy it was to use the website, find information, and navigate through the website and their perceptions of its content and usefulness. However, as just a part of the user experience, the broader context must also be understood. User experience includes the motivations, emotions, and expectations that users have before interacting with the technology; end-to-end interaction with the technology; and reflective emotions and behaviors after use. At baseline, this sample of young adult cancer survivors had positive views about using the internet for health-related problems, including to access information and support for health-related decision-making. General feedback about the website was positive, and users reported an intention to use the decision aid in the future. All participants, across both rounds of testing, *agreed* or *strongly agreed* that they felt more informed after viewing the website and would consult the website to make decisions about fertility and family building. They trusted the information on the website and felt understood by the people who developed it. In open-ended feedback, participants consistently expressed appreciation that a trusted resource existed, as they were otherwise unsure about where to access this information and decision support. In a systematic review of web-based oncofertility decision aids and health education materials, the quality of websites was found to be variable and, among the decision aids, the content focused primarily on fertility preservation before cancer treatment initiation [21]. More generally, public websites providing cancer-related information have been shown to be largely incomplete in the information they provide, with questions about decision-making being discussed the least [48]. Furthermore, web-based patient information about cancer survivorship and fertility preservation has been shown to be written, on average, at high school senior and junior college levels [49], thus failing to meet health literacy standards [50]. Results suggest that finding reliable, understandable, and trustworthy information about family building after cancer may be a difficult task for young adult female cancer survivors and this decision aid tool fills this critical unmet need.

Unlike most decision aids that are developed for one-time treatment decisions involving discrete time [20], in this case, decision making may include an ongoing process of considering numerous intermediary decisions along the path to family building, such as considering a reproductive endocrinologist consultation, seeking legal advice, and looking for financial planning information. Women may also need to reconsider decisions if their preferred option to achieve parenthood is unsuccessful, such as considering donated gametes, surrogacy, or adoption after failed in vitro fertilization attempts or based on changing priorities or partner preferences. This has important implications for the use of the website and whether users will return to the tool as new decision points arise. Future studies will need to explore longitudinal website engagement and evaluate whether it meets the needs of young adult female cancer survivors who face more complicated paths to family building. The website was designed for survivors to use individually, inclusive of both single and partnered women, but exploration of the involvement of partners in decision-making processes and the need for resources is also critical [51].

Findings also indicated that the *Roadmap to Parenthood* website improved self-efficacy in managing health issues related to fertility. Participants reported that the website encouraged them to take action to manage their health and made them feel more prepared to do so. However, this may not hold true for all users, as a few participants reported neutral scores (*neither agree nor disagree*) when asked whether they felt confident and prepared to manage their concerns about family building after cancer treatment. This is consistent with qualitative feedback, in which a participant felt overwhelmed and distressed by the delivery of risk information and implications for potential challenges in family building. We have gathered strong evidence that the website made users feel more informed about their fertility and family-building options. However, a lingering question is whether women feel equipped to manage emotions that arise when facing decision-making tasks and whether they are prepared to pursue family-building goals. It may be that dissemination and implementation strategies should include health care providers, integration with survivorship care visits, and counseling for immediate added support if needed.

One of the main objectives of the decision aid tool was to make users aware of family-building options, including realistic expectations about potential difficulties, while also inspiring hope that parenthood may be achieved and that early planning may help to avoid or mitigate challenges. The delivery of information about risks and challenges may naturally be upsetting. A participant stated that the graphs depicting the effects of cancer treatment on ovarian reserve was "terrifying." However, when asked whether images on the website were generally distressing, only 10% (1/10) of the participants agreed. Lim et al [52] noted that website development and evaluation typically focus on traditional usability aspects (eg, screen layout and navigation features), whereas the emotional experiences of

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users and, in turn, the ways in which a website supports users' emotions are more likely to be neglected. For websites that deliver health information that may include distressing news, even those without personalized data, such as ours, considering the emotional impact of design features is important. Choe et al [53] put forth *hypotheses* for implementing empathic communication within digital health systems, including normalization of users' emotional experiences (eg, "Many people feel worried or upset when learning this news...") and helping the user to identify clear, actionable steps that can be taken (eg, "There are things you can do to help reduce your risk..."). Consistent with these recommendations, we made design changes to reduce the impact of the perceived distressing information. Experiencing negative emotions can also be useful when interacting with technology, but the line between helpful and harmful emotions may be tenuous [54]. It may be necessary to draw from digital mental health interventions (eg, stress management, affect regulation, or mindfulness-based strategies) to include in our website to provide additional support [55-58], while balancing the scope of the intervention. Our findings indicate that only a subset of users may need additional support to manage distress, suggesting that a stepped care model may be appropriate [59].

We have partnered with a website design firm, digital health researchers, and intervention developers to explore optimal digital solutions for addressing the lingering usability issues including users' emotional experiences. Future studies will also further explore user feedback in a single-arm pilot study [60] and assess the need for additional content, website design changes, and intervention components to meet the needs of young adult female cancer survivors who are concerned about fertility and family building in posttreatment survivorship.

Limitations

This study evaluated the usability of a web-based decision aid and planning tool for young adult female cancer survivors considering future family building. Although it has been shown that testing a product with 5 participants can uncover approximately 80% of a product's usability issues [37], the study included a relatively small sample size, and the results may not be generalizable. Participants were also primarily White and highly educated, and further testing with women from diverse racial, ethnic, and socioeconomic backgrounds is needed. Disparities in oncofertility care have been reported based on age, socioeconomic status, access to insurance, religious factors, and gender or sexual minority identification [61]. Greater effort to engage diverse subgroups and use methodologies that lead to representative samples is needed.

Conclusions

The *Roadmap to Parenthood* decision aid tool fills an important resource need for young adult female cancer survivors hoping to pursue parenthood in the future. The development process involved a patient-centered approach and an iterative framework for design modifications based on user experience and feedback. General feedback about the website was positive. Future studies will include additional content and design changes to optimize usability, with a particular focus on the emotional experiences of users. We will also pilot-test a decision aid intervention using the website in a longitudinal study design [60]. This will extend the focus of oncofertility research to include survivors' fertility and family-building experiences after treatment and survivorship care needs.

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Conflicts of Interest

CB is on the board of directors of Stupid Cancer and is a research advisor to GRYT Health (unpaid positions).

References

1. van Dorp W, Haupt R, Anderson RA, Mulder RL, van den Heuvel-Eibrink MM, van Dulmen-den Broeder E, et al. Reproductive function and outcomes in female survivors of childhood, adolescent, and young adult cancer: a review. J Clin Oncol 2018 Jul 20;36(21):2169-2180 [FREE Full text] [doi: 10.1200/JCO.2017.76.3441] [Medline: 29874135]
2. Su HI, Kwan B, Whitcomb BW, Shliakhsitsava K, Dietz AC, Stark SS, et al. Modeling variation in the reproductive lifespan of female adolescent and young adult cancer survivors using AMH. J Clin Endocrinol Metab 2020 Aug 01;105(8):2740 [FREE Full text] [doi: 10.1210/clinem/dgaa172] [Medline: 32270202]
3. Gorman JR, Bailey S, Pierce JP, Su HI. How do you feel about fertility and parenthood? The voices of young female cancer survivors. J Cancer Surviv 2012 Jun;6(2):200-209 [FREE Full text] [doi: 10.1007/s11764-011-0211-9] [Medline: 22179785]
4. Armuand GM, Wettergren L, Rodriguez-Wallberg KA, Lampic C. Women more vulnerable than men when facing risk for treatment-induced infertility: a qualitative study of young adults newly diagnosed with cancer. Acta Oncol 2015 Feb;54(2):243-252. [doi: 10.3109/0284186X.2014.948573] [Medline: 25140859]
5. Institute of Medicine (US) Committee on Quality of Health Care in America. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC, USA: National Academies Press (US); Aug 30, 2001.
6. Benedict C, Thom B, Friedman DN, Diotallevi D, Pottenger EM, Raghunathan NJ, et al. Young adult female cancer survivors' unmet information needs and reproductive concerns contribute to decisional conflict regarding posttreatment

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fertility preservation. Cancer 2016 Jul 01;122(13):2101-2109 [FREE Full text] [doi: 10.1002/cncr.29917] [Medline: 27213483]
7. Logan S, Perz J, Ussher JM, Peate M, Anazodo A. A systematic review of patient oncofertility support needs in reproductive cancer patients aged 14 to 45 years of age. Psychooncology 2018 Feb;27(2):401-409. [doi: 10.1002/pon.4502] [Medline: 28734119]
8. Logan S, Perz J, Ussher JM, Peate M, Anazodo A. Systematic review of fertility-related psychological distress in cancer patients: informing on an improved model of care. Psychooncology 2019 Jan;28(1):22-30. [doi: 10.1002/pon.4927] [Medline: 30460732]
9. Halliday LE, Boughton MA. Exploring the concept of uncertain fertility, reproduction and motherhood after cancer in young adult women. Nurs Inq 2011 Jun;18(2):135-142. [doi: 10.1111/j.1440-1800.2011.00532.x] [Medline: 21564394]
10. Benedict C, Shuk E, Ford JS. Fertility issues in adolescent and young adult cancer survivors. J Adolesc Young Adult Oncol 2016 Mar;5(1):48-57 [FREE Full text] [doi: 10.1089/jayao.2015.0024] [Medline: 26812452]
11. Benedict C, Hahn AL, McCready A, Kelvin JF, Diefenbach M, Ford JS. Toward a theoretical understanding of young female cancer survivors' decision-making about family-building post-treatment. Support Care Cancer 2020 Oct;28(10):4857-4867 [FREE Full text] [doi: 10.1007/s00520-020-05307-1] [Medline: 31993754]
12. Coccia PF. Overview of adolescent and young adult oncology. J Oncol Pract 2019 May;15(5):235-237. [doi: 10.1200/JOP.19.00075] [Medline: 31009282]
13. Benedict C, McLeggon JA, Thom B, Kelvin JF, Landwehr M, Watson S, et al. "Creating a family after battling cancer is exhausting and maddening": exploring real-world experiences of young adult cancer survivors seeking financial assistance for family building after treatment. Psychooncology 2018 Dec;27(12):2829-2839 [FREE Full text] [doi: 10.1002/pon.4898] [Medline: 30238545]
14. Gorman JR, Whitcomb BW, Standridge D, Malcarne VL, Romero SA, Roberts SA, et al. Adoption consideration and concerns among young adult female cancer survivors. J Cancer Surviv 2017 Feb;11(1):149-157 [FREE Full text] [doi: 10.1007/s11764-016-0572-1] [Medline: 27696249]
15. Quinn GP, Vadaparampil ST, McGowan Lowrey K, Eidson S, Knapp C, Bukulmez O. State laws and regulations addressing third-party reimbursement for infertility treatment: implications for cancer survivors. Fertil Steril 2011 Jan;95(1):72-78. [doi: 10.1016/j.fertnstert.2010.05.017] [Medline: 20576264]
16. Wang Y, Anazodo A, Logan S. Systematic review of fertility preservation patient decision aids for cancer patients. Psychooncology 2019 Mar;28(3):459-467. [doi: 10.1002/pon.4961] [Medline: 30523651]
17. Ehrbar V, Urech C, Rochlitz C, Zanetti Dällenbach R, Moffat R, Stiller R, et al. Randomized controlled trial on the effect of an online decision aid for young female cancer patients regarding fertility preservation. Hum Reprod 2019 Sep 29;34(9):1726-1734. [doi: 10.1093/humrep/dez136] [Medline: 31398258]
18. Garvelink MM, Ter Kuile MM, Louwé LA, Hilders CG, Stiggelbout AM. Feasibility and effects of a decision aid about fertility preservation. Hum Fertil (Camb) 2017 Jun;20(2):104-112. [doi: 10.1080/14647273.2016.1254821] [Medline: 27848252]
19. Peate M, Meiser B, Cheah BC, Saunders C, Butow P, Thewes B, et al. Making hard choices easier: a prospective, multicentre study to assess the efficacy of a fertility-related decision aid in young women with early-stage breast cancer. Br J Cancer 2012 Mar 13;106(6):1053-1061 [FREE Full text] [doi: 10.1038/bjc.2012.61] [Medline: 22415294]
20. Stacey D, Légaré F, Lewis K, Barry MJ, Bennett CL, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev 2017 Apr 12;4:CD001431 [FREE Full text] [doi: 10.1002/14651858.CD001431.pub5] [Medline: 28402085]
21. Speller B, Micic S, Daly C, Pi L, Little T, Baxter NN. Oncofertility decision support resources for women of reproductive age: systematic review. JMIR Cancer 2019 Jun 06;5(1):e12593 [FREE Full text] [doi: 10.2196/12593] [Medline: 31199289]
22. Benedict C, Nieh J, Hahn AL, McCready A, Diefenbach M, Ford JS. "Looking at future cancer survivors, give them a roadmap": addressing fertility and family-building topics in post-treatment cancer survivorship care. Support Care Cancer 2021 Apr;29(4):2203-2213 [FREE Full text] [doi: 10.1007/s00520-020-05731-3] [Medline: 32889581]
23. Benedict C, Dauber-Decker KL, King D, Hahn A, Ford JS, Diefenbach M. A decision aid intervention for family building after cancer: developmental study on the initial steps to consider when designing a web-based prototype. JMIR Form Res 2021 Jan 22;5(1):e20841 [FREE Full text] [doi: 10.2196/20841] [Medline: 33480848]
24. Bates DW, Kuperman GJ, Wang S, Gandhi T, Kittler A, Volk L, et al. Ten commandments for effective clinical decision support: making the practice of evidence-based medicine a reality. J Am Med Inform Assoc 2003;10(6):523-530 [FREE Full text] [doi: 10.1197/jamia.M1370] [Medline: 12925543]
25. Li AC, Kannry JL, Kushniruk A, Chrimes D, McGinn TG, Edonyabo D, et al. Integrating usability testing and think-aloud protocol analysis with "near-live" clinical simulations in evaluating clinical decision support. Int J Med Inform 2012 Nov;81(11):761-772. [doi: 10.1016/j.ijmedinf.2012.02.009] [Medline: 22456088]
26. Ergonomics of human-system interaction — Part 11: usability: definitions and concepts (ISO 9241-11:2018 - en). International Organization for Standardization. 2018. URL: https://www.iso.org/obp/ui/#iso:std:iso:9241:-11:ed-2:v1:en [accessed 2022-04-06]

XSL•FO
RenderX

27. Nielsen J. Usability 101: Introduction to Usability. Nielsen Norman Group, World Leaders in Research-Based User Experience. 2012 Jan 3. URL: https://www.nngroup.com/articles/usability-101-introduction-to-usability/ [accessed 2022-04-06]
28. Norman D, Nielsen J. The Definition of User Experience (UX). Nielsen Norman Group, World Leaders in Research-Based User Experience. URL: https://www.nngroup.com/articles/definition-user-experience/ [accessed 2022-04-06]
29. Usability. 2014. URL: https://www.usability.gov/what-and-why/user-experience.html [accessed 2019-09-19]
30. Coulter A, Stilwell D, Kryworuchko J, Mullen PD, Ng CJ, van der Weijden T. A systematic development process for patient decision aids. BMC Med Inform Decis Mak 2013;13 Suppl 2:S2 [FREE Full text] [doi: 10.1186/1472-6947-13-S2-S2] [Medline: 24625093]
31. Patient Decision Tools: Development Toolkit. The Ottawa Hospital Research Institute. 2018 Aug 14. URL: https://decisionaid.ohri.ca/resources.html [accessed 2019-06-04]
32. Sepucha KR, Abhyankar P, Hoffman AS, Bekker HL, LeBlanc A, Levin CA, et al. Standards for UNiversal reporting of patient Decision Aid Evaluation studies: the development of SUNDAE Checklist. BMJ Qual Saf 2018 May;27(5):380-388 [FREE Full text] [doi: 10.1136/bmjqs-2017-006986] [Medline: 29269567]
33. Hou S. Health literacy online: a guide to writing and designing easy-to-use health web sites. Health Promot Pract 2012 Sep;13(5):577-580. [doi: 10.1177/1524839912446480] [Medline: 22763891]
34. Clear Communication - Health Literacy. National Institutes of Health. 2015. URL: https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication/health-literacy [accessed 2019-05-24]
35. Toolkit for Making Written Material Clear and Effective. Centers for Medicare & Medicaid Services. 2012. URL: https://www.cms.gov/Outreach-and-Education/Outreach/WrittenMaterialsToolkit/index.html [accessed 2019-05-24]
36. Office of Digital Accessibility. Stanford University IT. URL: https://uit.stanford.edu/accessibility/ [accessed 2021-06-30]
37. Informa Healthcare, Karwowski W. Determining usability test sample size. In: International Encyclopedia of Ergonomics and Human Factors - 3 Volume Set. 2nd ed. Boca Raton, FL, USA: CRC Press; 2006.
38. Learn about Northwell's Institute of Health System Science Usability Lab Core. Northwell Health. URL: https://predictivemedicine.northwell.edu/ [accessed 2022-04-27]
39. Fusch PI, Ness LR. Are we there yet? Data saturation in qualitative research. Qual Rep 2015 Sep 8;20(9):1408-1416. [doi: 10.46743/2160-3715/2015.2281]
40. Kelly L, Ziebland S, Jenkinson C. Measuring the effects of online health information: scale validation for the e-Health Impact Questionnaire. Patient Educ Couns 2015 Nov;98(11):1418-1424 [FREE Full text] [doi: 10.1016/j.pec.2015.06.008] [Medline: 26162953]
41. Usability. 2013. URL: https://www.usability.gov/how-to-and-tools/index.html [accessed 2020-05-14]
42. Sauro J. Measuring Usability with the System Usability Scale (SUS). Measuring U. 2011 Feb 3. URL: https://measuringu.com/sus/ [accessed 2021-07-02]
43. Bangor A, Kortum P, Miller J. Determining what individual SUS scores mean: adding an adjective rating scale. J Usability Stud 2009;4(3):114-123 [FREE Full text]
44. Loiacono ET, Watson RT, Goodhue DL. WebQual: an instrument for consumer evaluation of web sites. Int J Electron Commer 2007;11(3):51-87. [doi: 10.2753/jec1086-4415110302]
45. Dauber-Decker KL, Basile M, King D, Polo J, Calise K, Khan S, et al. Developing a decision aid to facilitate informed decision making about invasive mechanical ventilation and lung transplantation among adults with cystic fibrosis: usability testing. JMIR Hum Factors 2021 Apr 14;8(2):e21270 [FREE Full text] [doi: 10.2196/21270] [Medline: 33851921]
46. Talboom-Kamp E, Tossaint-Schoenmakers R, Goedhart A, Versluis A, Kasteleyn M. Patients' attitudes toward an online patient portal for communicating laboratory test results: real-world study using the eHealth Impact questionnaire. JMIR Form Res 2020 Mar 04;4(3):e17060 [FREE Full text] [doi: 10.2196/17060] [Medline: 32024632]
47. Hanghøj S, Boisen KA, Hjerming M, Elsbernd A, Pappot H. Usability of a mobile phone app aimed at adolescents and young adults during and after cancer treatment: qualitative study. JMIR Cancer 2020 Jan 02;6(1):e15008 [FREE Full text] [doi: 10.2196/15008] [Medline: 31895046]
48. Warren E, Footman K, Tinelli M, McKee M, Knai C. Do cancer-specific websites meet patient's information needs? Patient Educ Couns 2014 Apr;95(1):126-136. [doi: 10.1016/j.pec.2013.12.013] [Medline: 24447523]
49. Alejos D, Tregubenko P, Jayarangaiah A, Steinberg L, Kumar A. We need to do better: readability analysis of online patient information on cancer survivorship and fertility preservation. J Cancer Policy 2021 Jun;28:100276. [doi: 10.1016/j.jcpo.2021.100276]
50. Rosenberg SA, Francis D, Hullett CR, Morris ZS, Fisher MM, Brower JV, et al. Readability of online patient educational resources found on NCI-designated cancer center web sites. J Natl Compr Canc Netw 2016 Jun;14(6):735-740 [FREE Full text] [doi: 10.6004/jnccn.2016.0075] [Medline: 27283166]
51. Mathur A, Hoffman AS, Weston J, Crocker LC, Holman DA, Bradford A, et al. How do couples and spouses/partners consider fertility preservation decisions during cancer treatment planning? A qualitative analysis of dyadic decision making. J Psychosoc Oncol 2021;39(2):268-284. [doi: 10.1080/07347332.2020.1836546] [Medline: 33306007]

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52. Lim YK, Donaldson J, Jung H, Kunz B, Royer D, Ramalingam S, et al. Emotional experience and interaction design. In: Peter C, Beale R, editors. Affect and Emotion in Human-Computer Interaction: From Theory to Applications. Berlin, Germany: Springer; 2008:116-129.
53. Choe EK, Duarte ME, Suh H, Pratt W, Kientz JA. Communicating bad news: insights for the design of consumer health technologies. JMIR Hum Factors 2019 May 17;6(2):e8885 [FREE Full text] [doi: 10.2196/humanfactors.8885] [Medline: 31102374]
54. Luria M, Zoran A, Forlizzi J. Challenges of designing HCI for negative emotions. arXiv (forthcoming) 2019 Aug 20 [FREE Full text] [doi: 10.48550/arXiv.1908.07577]
55. Børøsund E, Varsi C, Clark MM, Ehlers SL, Andrykowski MA, Sleveland HR, et al. Pilot testing an app-based stress management intervention for cancer survivors. Transl Behav Med 2020 Aug 07;10(3):770-780 [FREE Full text] [doi: 10.1093/tbm/ibz062] [Medline: 31330023]
56. Victorson D, Murphy K, Benedict C, Horowitz B, Maletich C, Cordero E, et al. A randomized pilot study of mindfulness-based stress reduction in a young adult cancer sample: feasibility, acceptability, and changes in patient reported outcomes. Psychooncology 2020 May;29(5):841-850 [FREE Full text] [doi: 10.1002/pon.5355] [Medline: 32040222]
57. Campo RA, Bluth K, Santacroce SJ, Knapik S, Tan J, Gold S, et al. A mindful self-compassion videoconference intervention for nationally recruited posttreatment young adult cancer survivors: feasibility, acceptability, and psychosocial outcomes. Support Care Cancer 2017 Jun;25(6):1759-1768. [doi: 10.1007/s00520-017-3586-y] [Medline: 28105523]
58. Cuthbert CA, Farragher JF, Hemmelgarn BR, Ding Q, McKinnon GP, Cheung WY. Self-management interventions for cancer survivors: a systematic review and evaluation of intervention content and theories. Psychooncology 2019 Nov;28(11):2119-2140. [doi: 10.1002/pon.5215] [Medline: 31475766]
59. Igelström H, Hauffman A, Alfonsson S, Sjöström J, Cajander A, Johansson B. User experiences of an Internet-based stepped-care intervention for individuals with cancer and concurrent symptoms of anxiety or depression (the U-CARE AdultCan Trial): qualitative study. J Med Internet Res 2020 May 19;22(5):e16604 [FREE Full text] [doi: 10.2196/16604] [Medline: 32427108]
60. Benedict C, Ford JS, Schapira L, Simon P, Spiegel D, Diefenbach M. Family-building decision aid and planning tool for young adult women after cancer treatment: protocol for preliminary testing of a web-based decision support intervention in a single-arm pilot study. BMJ Open 2019 Dec 29;9(12):e033630 [FREE Full text] [doi: 10.1136/bmjopen-2019-033630] [Medline: 31888941]
61. Appiah L, Anazodo A, Salama M, Reinecke J, Rios JS, Sender L, et al. Inclusion and diversity in oncofertility care. J Adolesc Young Adult Oncol 2021 Apr;10(2):120-126. [doi: 10.1089/jayao.2021.29006.rdt] [Medline: 33848436]

Abbreviations

eHIQ: eHealth Impact Questionnaire
PI: principal investigator
REDCap: Research Electronic Data Capture
SUS: System Usability Scale

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Original Paper

An Examination of Patients and Caregivers on Reddit Navigating Brain Cancer: Content Analysis of the Brain Tumor Subreddit

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Abstract

Background: Occurring in up to 40% of all patients with cancer, the incidence of brain tumors has caused limited survival, a high psychosocial burden, and an increase in the loss of decision-making capability for the unique population. Although specific symptoms depend on the type of brain tumor, a clinical team of physicians, nurses, and other individuals commonly assist patients and their caregivers with how to tackle the upcoming challenges of their diagnosis. Despite the support from clinical team members, many patients and caregivers may still seek outside support through social media to process their emotions and seek comfort outside of the clinical setting. Specifically, online resources such as Reddit are used where users are provided with the anonymity they need to show their true behavior without fear of judgment. In this study, we aimed to examine trends from Reddit discussion threads on brain tumors to identify areas of need in patient care.

Objective: Our primary aims were to determine the type of Reddit user posting, classify the specific brain tumors that were the subject of the posts, and examine the content of the original posts.

Methods: We used a qualitative descriptive design to understand patients' and caregivers' unmet and met needs. We selected posts from the top-rated 100 posts from the r/braincancer subreddit from February 2017 to June 2020 to identify common themes using content analysis.

Results: The qualitative content analysis revealed how Reddit users primarily used the forum as a method to understand and process the emotions surrounding a brain tumor diagnosis. Three major topic areas from content analysis emerged as prominent themes, including (1) harnessing hope, (2) moving through the grief process, and (3) expressing gratitude toward other Reddit users. Most of the authors of the posts were patients with brain tumors (32/88, 36%) who used Reddit as a reflective journaling tool to process the associated emotions of a challenging diagnosis.

Conclusions: This study shows the potential of Reddit to serve as a unique group therapy platform for patients affected by brain tumors. Our results highlight the support provided by the Reddit community members as a unique mechanism to assist cancer survivors and caregivers with the emotional processing of living with brain tumors. Additionally, the results highlight the importance of recommending Reddit as a therapeutic virtual community and the need for implementing online resources as a part of a health care professional's repertoire to understand the level of support they can give their patients.

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KEYWORDS

brain tumor; internet; social media; Reddit; cancer; emotional support; self-management

Introduction

Brain metastases remain the most common intracranial tumors in adults and can occur in up to 40% of all patients with cancer [1]. With more than 100 histopathologic types of primary central nervous system tumors [2], glioblastoma remains the most common malignant brain tumor in adults and continues to have a grim prognosis [3]. In comparison to other cancers, the potential limited overall survival, the higher psychosocial burden, and the increased likelihood of eventual loss of decision-making capability make patients with brain tumors a unique population. The emotional and physical sequalae following a brain tumor diagnosis can be devastating for patients, caregivers, family members, and friends. This may include dealing with difficult emotions such as sadness or anger and coping with the costs of cancer care with treatments and visits with the medical team. Patient advocacy groups such as the National Coalition for Cancer Survivorship have advocated for the incorporation of more patient-centered communication throughout the cancer care continuum [4].

The clinical team of neurosurgeons, medical and surgical oncologists, radiation oncologists, oncology nurses, and other patient care members guides patients and caregivers throughout the process. Team members assist patients and caregivers with what to expect with treatment and how to prepare for upcoming mental, emotional, and physical challenges. Although specific symptoms depend on the type of brain tumor, common challenges include weakness and balance difficulties along with changes in memory and even personality. Executive functioning can often be significantly impaired, and perception of this decline is often concordant between the patient and caregiver [5,6]. Even though the team members guide patients and caregivers through the process of diagnosis through end-of-life care, patients and caregivers may look for other avenues to express and ultimately process their emotions to make sense of the brain tumor diagnosis. However, these other avenues such as online resources for self-management of living with primary brain cancer have significant gaps in addressing patient and caregiver needs in the areas of rehabilitation, behavioral changes, recurrence, and the transition to palliative care [7].

Patients and caregivers may seek out and use social media to make sense of their illness. These social media platforms can also capture key attitudes and behaviors that are not always reflected in traditional medical surveys [8-11]. The social media sites including Reddit, Instagram, Twitter, and Facebook allow users to share stories, solicit advice, make recommendations, and establish a sense of virtual community. One of these social media sites (Reddit) provides anonymity that can give users a sense of comfort where they are allowed to act in accordance with their natural disposition without fear of judgement [12]. The anonymity combined with virtual storytelling can foster a real therapeutic relationship for patients and caregivers, especially for those affected by life-changing disease processes such as brain tumors [13,14]. In addition to patients and caregivers, key stakeholders such as physicians, patient advocates, patient organizations, and medical researchers use social media sites for the dissemination of information [15-17].

Though these therapeutic virtual relationships can be beneficial for patients and caregivers, health care professionals (HPs) may also be interested in examining the content of these posts to determine if any additional clinical support may be needed. Identifying the category of Reddit user (eg, patient, caregiver, or friend), type of brain tumor, and type of content within the posts may provide HPs with additional knowledge on how their patients are using social media sites like Reddit to potentially cope with their diagnoses. This may help HPs better understand the potential positive role that social media plays in their patients' lives during their cancer treatment experiences and into palliative care.

Although previous research has drawn information from Reddit to examine various other diseases [18-20], no studies have examined Reddit discussion threads on brain tumors. A thorough content analysis of users' posts may contribute to a greater understanding of how patients and caregivers use Reddit as a social media platform to discuss and cope with brain tumors. Additionally, determining the category of Reddit users and types of brain tumors identified in the posts may add a greater understanding to specific populations' needs. Our primary goals were to determine the type of Reddit user posting, classify the specific brain tumors that were the subject of the posts, and examine the content of the original posts.

Methods

Overview

The data were obtained from the top-rated 100 posts of the subreddit "r/braincancer" from February 2017 to June 2020. We were able to identify the top-rated posts using the "Top" and "All-time" selection features that sort the subreddit posts from the most upvoted post to the least upvoted post. A post can be upvoted or downvoted by subreddit users as being relevant or recommended to other users, if other users resonate with the content made by the original user who made the post, or to increase visibility of the post to the broader subreddit community. An upvote means the post contributes to the conversation in the subreddit, and a downvote means the post does not contribute [21]. Each user is only granted one vote per post. Subreddit users can then self-select to see only the top-rated posts. All posts that were obtained after applying the filters discussed brain tumors in a variety of contexts.

We extracted data in the posts including title, text, images, usernames, and content. All data was deidentified by removing usernames and then imported into Word (Microsoft Corporation), followed by MAXQDA (VERBI GmbH) for analysis [22]. This software was chosen based on the endorsement of the home institution where the data analysis was conducted. Any posts that were not available at the time of data extraction were not included in the analysis.

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Four authors (SDT, PDP, AVP, and AR) agreed upon and set codes to categorize users and types of brain tumors a priori to determine who was posting and which type of brain tumor was being discussed. Two authors (SDT and PDP) then used open coding to reveal the themes of the post content. After identifying the initial list of themes, the two team members met to agree upon the categories to be used for coding. All team members met to discuss the naming of the themes, which were interpretations directly supported by the data. As a final step in the data analysis, we then sorted the themes into categories following Yalom's [23] group psychotherapeutic factors. This sorting of data was a last step to present the findings in a cohesive manner that resembled the key therapeutic factors in a group setting, and we then applied these factors to a virtual group community. Any discordant coding was resolved and reviewed by an expert in qualitative research.

Ethical Considerations

This study did not meet the criteria for human participant research review through the University of Arkansas for Medical Sciences Institutional Review Board for protocol #27446. The data were obtained from a publicly available anonymous online forum. Each post included an author's self-chosen username, and even though these usernames were anonymous, we maintained confidentiality by removing usernames prior to importing the data into the software used for data analysis.

Results

Overview

The subreddit "r/braincancer" included a high number of members (n=1900), and the posts covered topics about numerous aspects of brain cancer from treatment to emotional support. The content of the original posts ranged from journal-style storytelling to the sharing of images and uplifting graphics.

Of the top 100 posts, all posts were written by individual users as unique cases. Most of the 88 Reddit users (n=58, 66%) who posted in the "r/braincancer" subreddit were writing about their experience with a patient with a brain tumor. Many of the posts came from users writing about their parent's (n=32, 36%), spouse's (n=9, 10%), or children's (n=9, 10%) experiences with brain tumors. A smaller percentage of Reddit users wrote about their own experiences with brain tumors (n=30, 34%). Only 12 users did not disclose their relationship about who they were writing about in the subreddit thread (see Table 1).

Almost half (n=47, 47%) of the 100 Reddit users directly mentioned glioblastoma in their posts. A smaller amount of Reddit users (n=16, 16%) identified another primary brain tumor that included anaplastic astrocytoma, ganglioglioma, and others. However, more than one-third of Reddit users (n=37, 37%) did not disclose the type of brain tumor classification or gave an unclear description that could not be categorized (see Table 2).

Table 1. Categories of users among the top 100 Reddit posts under r/braintumor.

Classification of user	Users (n=88)[a], n (%)
Writing about others with brain tumors	58 (66)
Parents	32 (36)
Spouse	9 (10)
Child	9 (10)
Extended family	1 (1)
Writing about self with a brain tumor	30 (34)

[a]Reddit users did not disclose their category in 12 posts and were omitted from the final percentage count.

Table 2. Brain tumor classification among the top 100 Reddit posts under r/braintumor.

Tumor type	Posts, n (%)
Glioblastoma	47 (47)
Unknown	37 (37)
Other primary brain tumor	16 (16)

Qualitative Content Results

Lastly, the content analysis of these posts revealed how Reddit users primarily used the forum as a method to understand and process the emotions surrounding a brain tumor diagnosis. Three major themes within the content emerged: (1) harnessing hope, (2) appreciating the group, and (3) moving through the grief process.

Most of the posts of the subreddit "r/braincancer" were written by others who were witnessing the effects of brain tumors, specifically glioblastoma, on their loved ones. Our results are reasonable given that a majority of content that was posted was an in-depth storytelling experience in the treatment of the onset of a brain tumor with much less content focused on the end of life. Most of the Reddit users posted within a relatively short time, as the users were experiencing these events firsthand. One anonymous user wrote about their son, "At 4:44 this morning he took his last breath. He was at home with his wife and I by his side." Other users allowed for some time to process before posting on Reddit. One user posted on Reddit about a week after receiving the news of their mother's diagnosis and wrote:

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> *They said there is no treatment they can offer us and she probably only has weeks to live. I am absolutely devastated and don't even know how to begin processing this.*

The posting and real-life experiences occurred almost simultaneously, and the content topics revealed similar patterns of congruence following three major themes: (1) harnessing hope, (2) appreciating the group, and (3) moving through the grief process.

First, many of the Reddit users wrote encouraging words in the effort to *harness hope* for each other, and thereby, for themselves. The posts were generally written with an introductory description of their disease process, most notably by Reddit users who were also patients. Reddit users shared their own stories and acknowledged the severity of the disease. After this disclosure, many Reddit users then encouraged others in the forum. One user posted about their own diagnosis and then offered a suggestion to uplift others. They said:

> *Ever since being diagnosed with GBM Grade IV several months ago, I have gone through things I never imagined before the age of 24...But through all of it I have wanted to help other cancer patients by spreading what (little) I have learned about the whole process.*

The user then described how making "silly" videos was therapeutic and ended the post by writing:

> *I know I am not the first person to do this, but I love making videos and being silly! So hopefully me putting up content about my surgery or mental health can help someone or someone you care about...Stay strong!*

Other users went on to directly address the emotional sequalae of the brain tumor diagnosis and were direct in their encouragement to commend others to take hold of and harness their hope. A user who was diagnosed with anaplastic astrocytoma wrote:

> *So, if you're lost and feeling hopeless? Don't be. It's gonna be a long...journey filled with anxiety, scare or even depression. There will be tough days, but you gotta not let it bring you down every day you are alive after going through so much just to live.*

Lastly, a vast majority of users concluded their posts by offering to be someone's "listening ear" or to offer any support. One user who was 8 months from his diagnosis wrote "Keep fighting, everyone. If anyone has questions about my experience, I'm an open book." These messages of resiliency remind other users to *harness hope* and move forward with bravery. The messages are a real-world account of lived experiences that are interwoven with the Reddit user's own meanings of these experiences. This provides other users with applicable, comforting, and realistic messages tailored for a unique subgroup of a population dealing with brain tumor diagnoses.

Second, many of the Reddit users shared their *appreciation for the group*, which was most common among friends, caregivers, and siblings. Reddit users were thankful for the virtual support offered through the forum. After one user's husband received a diagnosis of medulloblastoma, she was crippled by the prognosis and used Reddit to share and process her emotions. She candidly expressed her *appreciation for the group* by writing:

> *This subreddit, silly as it sounds, has been a God send...Even if no one reads this I want to thank you all for sharing here. I was alone and stunned sitting in my garage and not knowing what to do and you all gave me such insight and hope.*

Another user wrote about their mother's glioblastoma diagnosis and found comfort in the group setting. They wrote:

> *thank you so much to those kind souls who commented on here. I was feeling so alone and so overwhelmed and it honestly helped reading these.*

In other cases, users were patients and expressed gratitude for the group while going through treatment. One man who was recently diagnosed with a brain tumor in his mid-20s described his clinical journey and concluded with:

> *So maybe I've been way off topic, but I really wanted to share my story. It's just really nice to talk about it. I rarely talk about this and have never shared my story on Reddit.*

The supportive, nurturing environment of Reddit was acknowledged among both friends, caregivers, and family members as well as patients. Most of the users expressed their appreciation of the group with deep sincerity.

Third, several Reddit users (friends, caregivers, family members, etc) described their overwhelming emotions and the associated grappling as they *moved through the grief process* around their loved ones as explained by Kübler-Ross [24]. The content of these posts showed almost an equal representation of anger, depression (written by a variety of users), and acceptance, which was written exclusively by friends, caregivers, and family members. Little was mentioned surrounding denial or bargaining. One user posted about his wife who recently was diagnosed with glioblastoma. His anger was palpable. He wrote, "I want to punch someone. I want to break the terrariums and burn the wedding presents." In the same post he went on to write:

> *I love her so much. How do you go on when your world crumbles? How do you eat? How do you focus on anything that even resembles the future? I hate the universe.*

One woman wrote about her husband's recent diagnosis and disclosed her painful realization about his prognosis and the associated depression. She said:

> *Knowing we'll never make that (anniversary)...It feels like all my hopes and dreams have shattered into a million pieces.*

A son wrote about his father's recent death and shared his depression:

> *I find myself extremely sad in waves. I'm ok for a little bit, but then think of something and I just cry. I'm not sure if that will go away.*

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Additionally, a patient with glioblastoma wrote about his depression as he moved through his own grief process and said:

> *...All I ever hear in my daily life is how good I look, or how inspiring I am. That couldn't be farther from the truth. I am a broken man just trying to do the right things.*

Lastly, the voices of the Reddit users shifted to exclusively friends, caregivers, and family members as they wrote about the acceptance after a loved ones' death. One user wrote about their father's death from glioblastoma resembling some acceptance and said, "I am sad, we are all sad, but I am happy too, because he won't suffer through pointless treatment. He is free." Another Reddit user posted about their father's death and said:

> *I miss my dad a ton already, but we know that at least he got to see both his kids grown and married and had a good several years of retirement and travel with my mom to enjoy before he got sick.*

Discussion

Principal Findings

In most of these posts, the users describe their emotional movement through the grief process with no expectation of a reply or comment from others. The posts, in turn, become a living therapeutic tool to help Reddit users process and heal from the emotional turmoil associated with brain tumors.

Overall, the three themes in the subreddit "r/braincancer" mirror the unique group psychotherapy process. Much of the content is aligned with Yalom's [23] 11 therapeutic factors used in group psychotherapy, namely, installation of hope, universality, imparting information, altruism, group cohesiveness, catharsis, and existential factors. In the Reddit forum, users *harnessed hope* for themselves and others (Yalom's [23] instillation of hope), and in this sharing, the users helped others to realize they are not alone in their journey (universality) with a brain tumor diagnosis. Additionally, users *harnessed hope* by offering advice and support to others (imparting information) thus creating therapeutic bonds within the forum members. Reddit users also were encouraging to one another (altruism) as they shared their *appreciation for the group*. This anonymous online forum created an overall feeling of acceptance and belonging (group cohesiveness) between members. Finally, Reddit users *moved through the grief process* where they shared their anger, depression, and acceptance (catharsis and existential factors; see Table 3).

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Table 3. Overview of therapeutic factors and quotes in the top 100 Reddit posts under r/braintumor.

Yalom's [23] therapeutic factors[a]	Definition	Quotes	Themes
Instillation of hope	Sharing good news, encouraging others, fostering hope	• "So hopefully me putting up content [humorous videos] about my surgery or mental health can help someone or someone you care about...Stay strong!" • "I've been struggling since the right side of my body went numb with my cognitive challenges but, we should stand strong. We are survivors until the day we die." • "Cancer is definitely a dark thing in our world and it's easy to drown in the misery that comes with it, but I would advise anyone going through this to 'find their light' in the situation and focus on that." • "There will be tough days, but you gotta not let it bring you down every day you are alive after going through so much just to live."	Harnessing hope
Universality	Validating others' experiences, helping members realize they are not alone	• "Thank you so much to those kind souls who commented on here. I was feeling so alone and so overwhelmed and it honestly helped reading these." • "There are lots of support resources out there...you are not alone!"	Harnessing hope
Imparting information	Formally sharing knowledge, resources, ideas, advice	• "But through all of it I have wanted to help other cancer patients by spreading what (little) I have learned about the whole process." • "If you have any questions or just want to talk, please PM me. Anything I can do to help. I love you all so much." • "...Get hospice involved early, you will need supplies, medicine, advice and help they can provide when you're lost."	Harnessing hope
Altruism	Members finding meaning and value in listening and sharing in group	• "Thank you so much to those kind souls who commented on here. I was feeling so alone and so overwhelmed and it honestly helped reading these." • "Hello everybody...Thank you to everyone who has offered their company, thoughts, and prayers with my SO [significant other] and I."	Appreciation of the group
Group cohesiveness	Members feel gratitude for group; have a sense of acceptance, belonging	• "I was alone and stunned sitting in my garage and not knowing what to do and you all gave me such insight and hope" • "I can't tell you how AMAZING each and every one of you are." • "This brain cancer stuff is really scary, and I just really appreciate the support of this group." • "I thank everyone for their support and comforting words over the past year."	Appreciation of the group
Catharsis	Emotional release and promotes healing by sharing information to group	• "I want to punch someone. I want to break the terrariums and burn the wedding presents." • "I hate that she has to go through this. I hate brain cancer. Just needed to rant for a second." • "I hate how glioblastoma takes away the person little by little."	Moving through the grief process
Existential factors	Finding meaning through loss; life will continue on with pain, death, sadness, regret, joy	• "I am sad, we are all sad, but I am happy too, because he won't suffer through pointless treatment. He is free." • "Taking the opportunity to reach out to those who have recently lost someone to this horrible disease and letting you know that day by day, things do get easier."	Moving through the grief process

[a]Only seven of Yalom's [23] therapeutic factors were applicable.

Clinical Application and Comparison With Prior Work

The utility of social media platforms in brain tumor treatment and the associated outcome of palliative care continue to expand [25]. Our study is the first of its kind to evaluate the content within the public forum of Reddit. While our data did not necessarily reflect the transition to palliative care, this is a frequent progression for many patients with brain tumors, especially glioblastoma (almost half of our participants; see Table 2). As a result, HPs may want to consider assessing and treating associated symptoms, as these patients have high levels of anxiety, depression, and cognitive symptoms especially in transitioning to palliative care [26]. Additionally, psychological stress can also be a significant factor in the quality of survivorship in patients with brain tumors [27]. Other stresses included financial burden and workforce morbidity. These stressors affect patients from various sociodemographic backgrounds [28-30]. Rising out-of-pocket spending and drug

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costs increase the financial burden on patients [31]. One study showed that 40% to 80% of patients undergoing cancer treatment stop working [32], while other studies document that patients miss up to 6 months before returning to the workforce [33]. Online public anonymous forums such as Reddit may not necessarily offset the financial burden but may provide a way for patients to share their experiences or offer resources of additional financial support. All these factors are considerations in survivorship planning, and the Society for Neuro-Oncology Guidelines Committee has a recommended survivorship care plan for adult patients with brain tumors [4]. HPs may want to integrate social media or online, public, anonymous forums such as Reddit as a therapeutic tool into personalized care plans for caregivers as their loved ones enter into palliative care. HPs should consider telling patients and caregivers that, while such online forums can be virtual therapeutic spaces, patients and caregivers should still take precautions to safeguard against any unwanted spam or harmful posts (as with all online interactions). The moderation policies of this particular subreddit follow the eight guidelines listed for all of the Reddit communities, and moderators have the ability to ban any users who harass, bully, or promote violence [34].

Limitations

While our analysis was unique in that we examined the content thread of the subreddit "r/braincancer," our study was not without limitations. Our analysis only included the content of the original post. We attempted to set limits for our data analysis by focusing only on the original post. As a result, we did not include comments in our data analysis, and we may have missed more content and dynamic interactions within this virtual group setting. Our sample only included the top 100 upvoted (or recommended) posts, and these posts may not have been a full representation of the subreddit user experiences. Additionally, our data collection represents a point in time. Other posts may appear after data collection, as the subreddit posts are constantly evolving due to participant interactions. Additionally, the demographics of Reddit users skew towards young males [35], which might not reflect most patients and caregivers affected by brain tumors.

Researchers may want to consider analyzing all of the comments in the subreddit threads to better understand the group therapy processes within anonymous online forums such as Reddit. Additional qualitative analysis using the "best" filter may be another way to determine the interaction between participants. The "best" filter is an algorithm that adds weight to the quality of the vote based on the length of time the comment was posted. Using this feature may reveal additional posts to add another layer of richness to the data.

Conclusions

The results of this study show the unique group therapy processes on a virtual platform for those affected by brain tumors. HPs may want to consider providing supportive online resources for their patients and caregivers. The various themes we identified in our sample are suggestions of topics that HPs may want to consider addressing to provide more tailored treatment planning.

Acknowledgments

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Conflicts of Interest

None declared.

References

1. Boire A, Brastianos PK, Garzia L, Valiente M. Brain metastasis. Nat Rev Cancer 2020 Jan;20(1):4-11. [doi: 10.1038/s41568-019-0220-y] [Medline: 31780784]
2. Ostrom Q, Gittleman H, Truitt G, Boscia A, Kruchko C, Barnholtz-Sloan JS. CBTRUS statistical report: primary brain and other central nervous system tumors diagnosed in the United States in 2011-2015. Neuro Oncol 2018 Oct 01;20(suppl_4):iv1-iv86. [doi: 10.1093/neuonc/noy131] [Medline: 30445539]
3. Lah TT, Novak M, Breznik B. Brain malignancies: glioblastoma and brain metastases. Semin Cancer Biol 2020 Feb;60:262-273 [FREE Full text] [doi: 10.1016/j.semcancer.2019.10.010] [Medline: 31654711]
4. Leeper H, Acquaye AA, Bell S, Clarke JL, Forst D, Laack NN, et al. Survivorship care planning in neuro-oncology. Neurooncol Pract 2018 Mar;5(1):3-9 [FREE Full text] [doi: 10.1093/nop/npx034] [Medline: 31386011]
5. Cantisano N, Menei P, Roualdes V, Seizeur R, Allain P, Le Gall D, et al. Patient-reported functional executive challenges and caregiver confirmation in adult brain tumor survivors. J Cancer Surviv 2021 Oct;15(5):696-705. [doi: 10.1007/s11764-020-00961-0] [Medline: 33106993]

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6. Loughan AR, Braun SE, Lanoye A. Executive dysfunction in neuro-oncology: Behavior Rating Inventory of Executive Function in adult primary brain tumor patients. Appl Neuropsychol Adult 2020;27(5):393-402. [doi: 10.1080/23279095.2018.1553175] [Medline: 30714410]
7. Schaefer I, Heneka N, Luckett T, Agar MR, Chambers SK, Currow DC, et al. Quality of online self-management resources for adults living with primary brain cancer, and their carers: a systematic environmental scan. BMC Palliat Care 2021 Jan 23;20(1):22 [FREE Full text] [doi: 10.1186/s12904-021-00715-4] [Medline: 33485331]
8. Jacobs R, Prabhu AV, Monaco EA, Tonetti D, Agarwal N. Patient perception of gamma knife stereotactic radiosurgery through twitter and instagram. Interdisciplinary Neurosurg 2018 Sep;13:138-140. [doi: 10.1016/j.inat.2018.05.005]
9. Buntinx-Krieg T, Caravaglio J, Domozych R, Dellavalle RP. Dermatology on Reddit: elucidating trends in dermatologic communications on the world wide web. Dermatol Online J 2017 Jul 15;23(7):13030/qt9dr1f7x6 [FREE Full text] [Medline: 29469693]
10. Himelboim I, Han JY. Cancer talk on Twitter: community structure and information sources in breast and prostate cancer social networks. J Health Commun 2014;19(2):210-225. [doi: 10.1080/10810730.2013.811321] [Medline: 24111482]
11. Derksen C, Serlachius A, Petrie KJ, Dalbeth N. "What say ye gout experts?" a content analysis of questions about gout posted on the social news website Reddit. BMC Musculoskelet Disord 2017 Nov 23;18(1):488 [FREE Full text] [doi: 10.1186/s12891-017-1856-y] [Medline: 29169350]
12. Hirsh JB, Galinsky AD, Zhong C. Drunk, powerful, and in the dark: how general processes of disinhibition produce both prosocial and antisocial behavior. Perspect Psychol Sci 2011 Sep;6(5):415-427. [doi: 10.1177/1745691611416992] [Medline: 26168194]
13. Smailhodzic E, Hooijsma W, Boonstra A, Langley DJ. Social media use in healthcare: a systematic review of effects on patients and on their relationship with healthcare professionals. BMC Health Serv Res 2016 Aug 26;16:442 [FREE Full text] [doi: 10.1186/s12913-016-1691-0] [Medline: 27562728]
14. Ventola CL. Social media and health care professionals: benefits, risks, and best practices. P T 2014 Jul;39(7):491-520. [Medline: 25083128]
15. Feliciano JT, Salmi L, Blotner C, Hayden A, Nduom EK, Kwan BM, et al. Brain tumor discussions on Twitter (#BTSM): social network analysis. J Med Internet Res 2020 Oct 08;22(10):e22005 [FREE Full text] [doi: 10.2196/22005] [Medline: 33030435]
16. Cutshall NR, Kwan BM, Salmi L, Lum HD. "It Makes People Uneasy, but It's Necessary. #BTSM": using Twitter to explore advance care planning among brain tumor stakeholders. J Palliat Med 2020 Jan;23(1):121-124. [doi: 10.1089/jpm.2019.0077] [Medline: 31170019]
17. Salmi L, Lum HD, Hayden A, Reblin M, Otis-Green S, Venechuk G, et al. Stakeholder engagement in research on quality of life and palliative care for brain tumors: a qualitative analysis of #BTSM and #HPM tweet chats. Neurooncol Pract 2020 Dec;7(6):676-684 [FREE Full text] [doi: 10.1093/nop/npaa043] [Medline: 33304602]
18. Park A, Conway M. Harnessing Reddit to understand the written-communication challenges experienced by individuals with mental health disorders: analysis of texts from mental health communities. J Med Internet Res 2018 Apr 10;20(4):e121 [FREE Full text] [doi: 10.2196/jmir.8219] [Medline: 29636316]
19. Thomas J, Prabhu AV, Heron DE, Beriwal S. Reddit and radiation therapy: a descriptive analysis of posts and comments over 7 years by patients and health care professionals. Adv Radiat Oncol 2019;4(2):345-353 [FREE Full text] [doi: 10.1016/j.adro.2019.01.007] [Medline: 31011680]
20. Liu Y, Yin Z. Understanding weight loss via online discussions: content analysis of Reddit posts using topic modeling and word clustering techniques. J Med Internet Res 2020 Jun 08;22(6):e13745 [FREE Full text] [doi: 10.2196/13745] [Medline: 32510460]
21. What does it really mean to upvote/downvote a post? Reddit. 2013. URL: https://www.reddit.com/r/TheoryOfReddit/comments/1lpws2/what_does_it_really_mean_to_upvotedownvote_a_post/ [accessed 2022-06-14]
22. MAXQDA Standard. MAXQDA. Berlin, Germany: VERBI Software; 2022. URL: https://www.maxqda.com/products/maxqda-standard [accessed 2021-03-01]
23. Yalom ID. Inpatient Group Psychotherapy. New York, NY: Basic Books; 1983:350.
24. Kübler-Ross E. On Death & Dying: What the Dying Have to Teach Doctors, Nurses, Clergy & Their Own Families. New York, NY: Scribner; 1969.
25. Bird C, Kozin ED, Connors S, LoBue C, Abdullah K. A quantitative analysis of social media to determine trends in brain tumor care and treatment. Cureus 2020 Nov 17;12(11):e11530. [doi: 10.7759/cureus.11530] [Medline: 33354474]
26. Rogers J, Vera E, Acquaye A, Briceno N, Jammula V, King AL, et al. Living with a central nervous system (CNS) tumor: findings on long-term survivorship from the NIH Natural History Study. Neurooncol Pract 2021 Aug;8(4):460-474 [FREE Full text] [doi: 10.1093/nop/npab022] [Medline: 34277024]
27. Nicol C, Ownsworth T, Cubis L, Nguyen W, Foote M, Pinkham MB. Subjective cognitive functioning and associations with psychological distress in adult brain tumour survivors. J Cancer Surviv 2019 Oct;13(5):653-662. [doi: 10.1007/s11764-019-00784-8] [Medline: 31313128]

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28. Haider SA, Asmaro K, Kalkanis SN, Lee IY, Bazydlo M, Nerenz DR, et al. The economic impact of glioma survivorship: the cost of care from a patient perspective. Neurology 2020 Sep 15;95(11):e1575-e1581. [doi: 10.1212/WNL.0000000000010263] [Medline: 32646959]
29. Forst D, Quain K, Landay SL, Anand M, Kaslow-Zieve E, Mesa MM, et al. Perceptions of prognosis and goal of treatment in patients with malignant gliomas and their caregivers. Neurooncol Pract 2020 Oct;7(5):490-497 [FREE Full text] [doi: 10.1093/nop/npaa021] [Medline: 33014389]
30. Lwin Z. From survivorship to end-of-life discussions for brain tumor patients. Neurooncol Pract 2021 Jun;8(3):231-232 [FREE Full text] [doi: 10.1093/nop/npab025] [Medline: 34055369]
31. Fitzner K, Oteng-Mensah F, Donley P, Heckinger EA. Safety of cancer therapies: at what cost? Popul Health Manag 2017 Aug;20(4):318-328. [doi: 10.1089/pop.2016.0097] [Medline: 28112578]
32. de Boer AGEM, Taskila T, Ojajärvi A, van Dijk FJH, Verbeek JHAM. Cancer survivors and unemployment: a meta-analysis and meta-regression. JAMA 2009 Feb 18;301(7):753-762. [doi: 10.1001/jama.2009.187] [Medline: 19224752]
33. Bradley CJ, Oberst K, Schenk M. Absenteeism from work: the experience of employed breast and prostate cancer patients in the months following diagnosis. Psychooncology 2006 Aug;15(8):739-747. [doi: 10.1002/pon.1016] [Medline: 16374893]
34. Reddit content policy. Reddit. 2022. URL: https://www.redditinc.com/policies/content-policy [accessed 2022-06-14]
35. Sattelberg W. The demographics of Reddit: who uses the site? Alphr. 2021. URL: https://www.alphr.com/demographics-reddit/ [accessed 2022-06-14]

Abbreviations

HP: health care professional
NIH: National Institutes of Health
TRI: Translational Research Institute

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Original Paper

Implementing a Health Care Professional–Supported Digital Intervention for Survivors of Cancer in Primary Care: Qualitative Process Evaluation of the Renewed Intervention

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Abstract

Background: Primary care plays an important role in supporting survivors of cancer; however, support is limited because of practitioners' perceived lack of expertise and time. A digital intervention for survivors of cancer could provide an efficient way for primary care staff to support survivors of cancer without the need to accumulate expertise and skills to help patients make behavior changes; providing very brief support alongside this could maximize adherence to digital interventions. *Renewed* is a digital intervention that combines web-based behavior change advice with brief health care practitioner support from a nurse or health care assistant. Knowledge about the views and experiences of primary care staff providing support alongside a digital intervention for survivors of cancer is sparse, limiting the understanding of the acceptability and feasibility of this type of intervention.

Objective: This study aims to explore supporters' experiences of providing support to survivors of cancer using *Renewed*, understand potential barriers to and facilitators of the implementation of *Renewed* in practice, and investigate the strengths and weaknesses of the intervention from the perspective of health care professionals.

Methods: This was a qualitative process evaluation nested within a large trial evaluating *Renewed*. A total of 28 semistructured telephone interviews were conducted with nurses and health care assistants. Data were analyzed using inductive thematic analysis.

Results: Four themes were developed during the analysis, which reflected the factors that supporters identified as hindering or enabling them to provide support alongside *Renewed Online*: *Renewed Online* as an acceptable digital tool with some improvements, confidence in enacting the supporter role, practicalities of delivering support alongside a digital intervention, and managing a patient-led approach. The analysis suggests that supporters perceived that a digital intervention such as *Renewed* would be beneficial in supporting survivors of cancer in primary care and fit within current practices. However, barriers to providing support alongside the intervention were also identified, including concerns about how to facilitate rapport building and, in a minority, concerns about using a nondirective approach, in which most advice and support is provided through digital interventions, with brief additional support provided by primary care staff.

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Conclusions: These findings add to the literature on how best to provide support alongside digital interventions, suggesting that although most practitioners cope well with a nondirective approach, a minority requires more training to feel confident in implementing this. This study suggests that the barriers to providing formal support to survivors of cancer in primary care could be successfully overcome with an approach such as *Renewed*, where a digital intervention provides most of the support and expertise, and health care practitioners provide additional brief human support to maximize engagement. Strategies to maximize the chances of successful implementation for this type of intervention are also discussed.

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KEYWORDS

process evaluation; digital intervention; primary care; health care professional; web-based; quality of life; posttreatment; oncology

Introduction

Background

In 2018, the total number of people alive within 5 years of a cancer diagnosis was estimated to be 43.8 million worldwide [1]. Currently, there are 2.5 million survivors in the United Kingdom, which is estimated to increase to 4 million by 2030 [2]. However, up to 86% of people who complete cancer treatment in the United Kingdom, Australia, and the United States experience enduring side effects [3-5], including fear of cancer recurrence, anxiety, depression, fatigue, and weight gain, contributing to a reduced quality of life (QoL) [4].

The rising cancer burden places a strain on health systems worldwide [6]. Health care professionals (HCPs) based in primary care are central to providing support for people who have had cancer after completion of their primary treatment (eg, chemotherapy). However, these services are becoming overstretched and are increasingly unable to meet the needs of survivors of cancer [7]. For instance, survivors of cancer have expressed a need for more support with the emotional effects of cancer and issues such as fatigue that can occur months or years after treatment [8]. Primary care staff describe a lack of clear guidance on how survivors of cancer should be supported [9]. Patients and oncologists have expressed concerns that primary care staff are not experts, and their busy workloads lead to deficiencies in the continuity of care [8,9], meaning that survivors of cancer may not receive access to appropriate support with their ongoing symptoms after cancer treatment. Therefore, there is a need for clearer, more effective, and cost-efficient means of providing support. Digital interventions, such as websites or mobile apps, offer the potential to help survivors of cancer improve their QoL [10]. The addition of brief human support can boost engagement with digital interventions [11,12]. Digital interventions combined with brief support from primary care staff may facilitate improved QoL after cancer treatment. It may provide efficient and low-cost models for delivering support without the need to accumulate expertise in the skills and knowledge needed to help patients make the behavioral changes needed to increase their QoL. However, the acceptability and feasibility of implementing digital interventions among survivors of cancer in primary care is still to be determined. An important aspect of this involves understanding the capability of HCPs to deliver brief support along with digital interventions.

Renewed [13-16] is a complex intervention designed to improve the QoL of survivors of cancer. It combines a digital intervention focused on changing key behaviors that can improve the QoL of survivors of cancer with brief support from a nurse or health care assistant to maximize engagement. *Renewed* was designed for implementation in primary care within the United Kingdom's National Health Service (NHS). *Renewed* is currently being tested in a randomized controlled trial (RCT) to determine its effectiveness and cost-effectiveness. In addition to determining the effectiveness and cost-effectiveness of an RCT, it is critical to examine whether an intervention might be implemented well in practice. Understanding barriers to and facilitators of implementation could help optimize the implementation of *Renewed Online* and also provide helpful insights for others developing digital interventions that include human support.

Objectives

National guidance recommends conducting process evaluations to identify how new interventions are implemented in practice, the likely mechanisms through which they might produce an effect, or factors in the health care environment that might stop an intervention from producing an effect [17]. This paper reports a process study exploring HCPs' perceptions of *Renewed*. Although the RCT of *Renewed* [13] is ongoing, as recommended by the Medical Research Council guidelines, qualitative process data are reported here before obtaining knowledge of the RCT outcomes to avoid biased interpretation [17]. This process study has been used to explore potential barriers to and facilitators of implementing *Renewed* in primary care and evaluate the acceptability of providing this type of support, which might contribute to the success (or not) of the intervention. Specifically, this study aims to explore (1) supporters' experiences of providing support to patients using the *Renewed Online* digital intervention (from hereon referred to as *Renewed Online*) and (2) barriers to and enablers of the successful implementation of *Renewed Online* in practice.

Methods

Study Design

The study design entailed a qualitative process evaluation of the *Renewed* intervention, which explored HCPs' perceptions of delivering support alongside *Renewed Online*. The COREQ (Consolidated criteria for Reporting Qualitative studies) checklist [18] guided the reporting (Multimedia Appendix 1 [18]). Participants in the RCT were randomized to (1) *Renewed Online*, (2) *Renewed Online* with brief human (HCP) support, or (3) usual care. For full details of the *Renewed* RCT, see the study by Krusche et al [13]. Briefly, survivors of cancer in the

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Renewed RCT (n=2712) had completed treatment for colon cancer (432/2712, 15.93%), breast cancer (1216/2712, 44.84%), or prostate cancer (864/2712, 31.86%). Mean years since the completion of treatment was 4 (SD 3.1) years; mean age was 64.5 (SD 10.9) years; and mean baseline QoL score was 72.4 (SD 11.9; as defined by scores <85 on the European Organization for Research and Treatment of Cancer measure [19]).

Ethics Approval

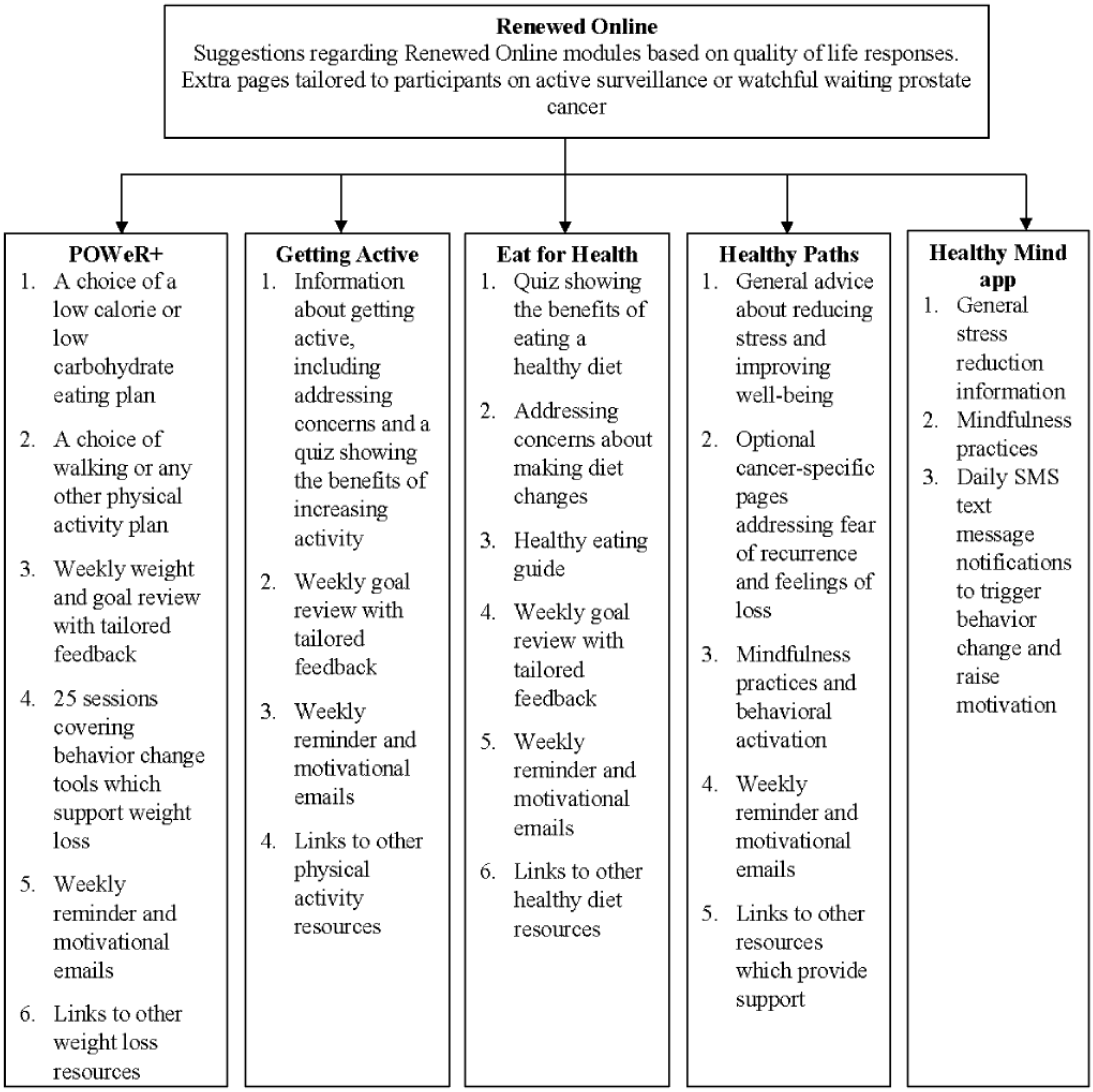
Ethical approval was granted by the University of Southampton (ERGO reference 31000.A8) and National Health Service (reference 18/NW/0013) ethics committees.

The Renewed Intervention

Overview

Renewed comprises a component website, *Renewed Online*, and brief HCP support. *Renewed Online* comprises an introductory session that provides an overview of what to expect from *Renewed*, brief advice on how to treat symptoms, and tailored recommendations about which components of the program would be most helpful based on the users' responses to the European Organization for Research and Treatment of Cancer measure [19]. Users can then choose to use *Getting Active* (support for increasing physical activity), *Eat for Health* (support with healthy eating), *POWeR* (an evidence-based weight loss program [11,20-23]), or *Healthy Paths* (support with reducing stress or difficult feelings [24]). A full description of *Renewed Online* is provided in Figure 1 [13], incorporating the TiDIER (Template for Intervention Description and Replication) guidelines (Multimedia Appendix 2) [25].

Figure 1. Renewed Online intervention (reproduced with permission from Krusche et al [13]).



HCP Support

HCP support was designed to boost adherence to both using the website and engaging with offline behavior changes (eg, physical activity) by promoting autonomous motivation. Survivors of cancer allocated to the *Renewed Online with brief human support group* were able to access support sessions provided by an HCP, delivered using the *congratulate, ask,*

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reassure, and encourage (CARE) approach [26]. CARE is based on the self-determination theory and aims to facilitate an autonomy-supportive relationship that promotes feelings of autonomy, competence, and relatedness [21], thus building internal motivation for change [27]. CARE was designed to be easy to deliver and fit within HCPs' busy schedules, without practitioners needing to become experts in a particular condition or way of treating that condition as this more detailed behavioral support was instead provided by the website.

Supporters were practice nurses, practice-based health care assistants, or clinical research nurses who were part of a comprehensive research network outside of general practitioner (GP) practices, a model representing delivery of care similar to that provided by private companies supporting digital interventions in the NHS, who tend to provide phone rather than in-person support and do not have access to patient records [28]. At the start of the study, supporters completed brief 15- to 20-minute web-based training outlining the study procedures and how to provide support to patients using the CARE approach. Before the sessions, the supporters were asked to send emails to patients 2 and 4 weeks after the patients began the study. Friendly email templates were provided, which were framed around the CARE approach, asking how patients were getting on and encouraging them to get in touch for a support session if they wished. Support sessions of 10 minutes were offered 2, 4, and 8 weeks after the patients had begun the study via telephone, email, or face to face. Textbox 1 shows a brief summary of the key messages from supporter training on how to provide support.

Textbox 1. Supporter training key messages.

Brief summary of the guidance given to supporters on how to provide support

Use the congratulate, ask, reassure, encourage approach with patients during support sessions

- Congratulate the patient; for example, "That's great that you want to get more active"
- Ask the patient; for example, "Have you decided to make any of the changes that Renewed suggested might be helpful?"
- Reassure the patient; for example, "Yes, doing more physical activity is safe and should help you to feel better."
- Encourage the patient; for example, "Keep going with that as it should start to help you to feel better soon."

Tips for providing support

- Be warm and friendly
- Praise any achievements
- Listen and show understanding

When sessions should take place

- 2, 4, and 8 weeks after the patient signs up for *Renewed*
- Send an encouraging email at 2 and 4 weeks using the supporter website; editable prewritten email templates are available
- Log all emails and appointments on the support log

If a patient does not contact for support

- Send an encouraging email

If you find it hard to talk to the patient for only 10 minutes

- Start the session by saying, "Nice to speak to you today. This is just a short appointment, we have around 10 minutes to talk. It would be great to hear how you're getting on with Renewed."
- In the last few minutes, say, "We are coming to towards the end of our time, is there anything else that you wanted to discuss quickly today?"
- Let the patient know that the session is about to end; say, "Thank you for your time, it's been nice to chat with you"

If the patient asks for advice

- Ask them what they think would work best for them or what they think would be best to do.
- It is okay to ask, "what does the website say to do in that situation?"
- If the patient is concerned about whether making a change is safe, you can reassure them that everything recommended on *Renewed* is safe.

Sampling and Recruitment

Supporters were identified for interviews through the *Renewed* supporter database and the study team's records of HCPs providing support as part of the RCT. Emails or phone calls were used to invite supporters to participate in a telephone interview about their experience of supporting patients using *Renewed Online*. In the early stages of recruitment, supporters were sampled purposively based on their job roles (practice nurse, practice-based health care assistant, or clinical research

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nurse); however, recruited supporters often had not undertaken any support sessions or only supported 1 patient. Supporters were then purposively sampled based on the number of patients they had supported to ensure the inclusion of those who had supported multiple patients to explore any variation in their experiences. Supporters were provided with a participant information sheet and asked to confirm their informed consent on the web after consideration.

Procedure

Interviews were conducted between September 2019 and January 2020, each lasting approximately 15 to 30 minutes, with a median of 21 minutes. A total of 2 (JS and JSB) researchers conducted the interviews. A semistructured interview schedule was developed by a qualitative researcher (JS) and experienced health psychologist (KB). The interview schedule explored supporters' experiences of providing support along with the digital intervention, perceptions of web-based supporter training, experiences of support appointments, perceptions of the CARE approach, and supporters' perceptions of the *Renewed* program.

Data Analysis

All interviews were audio recorded, transcribed verbatim, and then imported into NVivo 12 (QSR International) [29]. An inductive thematic analysis was performed based on aspects from the 6-step framework of Braun and Clark [30] and Joffe and Yardley [31]. JS familiarized herself with the data before coding the interviews. A coding manual was created and continually updated to reflect the ongoing analysis. The identification and validation of the developing themes were achieved through an iterative data analysis process with frequent discussions with KB, RE, and AR. Deviant cases were considered to ensure that minority views were not overlooked [32]. An audit trail and reflective log were completed to maintain rigor during the analysis. Constant comparison (a technique in which each interpretation and finding is compared with existing findings as it develops from data analysis [33]) was used to examine potential similarities or differences in the reported experiences of different types of supporters [34].

Results

Participant Characteristics

A total of 108 supporters were invited to participate in the interview, of whom 56 (51.9%) did not reply to invitations, 21 (19.4%) could not be interviewed as they had not undertaken any support sessions, 2 (1.9%) did not have the time to take part in an interview, and 1 (0.9%) could not accurately recall supporting patients. The final sample included 28 HCPs comprising 16 (57%) practice nurses, 6 (21%) clinical research nurses, and 6 practice-based health care assistants (21%) who provided support for patients at 45 GP practices in total. Almost all participants were female (27/28, 96%).

Themes

Overview

A total of 4 themes were developed that provided insights into supporters' experiences of providing support along with digital interventions and factors that hindered or enabled them to support patients as intended. The themes were (1) *Renewed Online* as an acceptable digital tool with some improvements, (2) confidence in enacting the supporter role, (3) practicalities of delivering support alongside a digital intervention, and (4) managing a patient-led approach. Each theme is outlined in the following sections, including representative quotes to illustrate key points. Participants are referred to by their identification number, role, and the number of patients they supported.

Renewed Online as an Acceptable Digital Tool With Some Improvements

Overall, supporters perceived *Renewed* as consistent with current practice, with the increasing use of web-based interventions. They could see how a digital tool such as *Renewed Online* would be useful for patients, especially as it allowed patients to work through rehabilitation at their own pace:

> *They're [GPs] signposting patients to online resources all the time more and more at the moment...So this [Renewed Online] is a similar thing. So I could see that it would be beneficial and would fit in.* [Participant 10, practice nurse, 2 patients]

Email support was also generally acceptable to supporters. However, a few worried that patients were not receiving emails from the supporter website; hence, they preferred to use their own email to contact patients.

A minority of supporters reported that their patients described the content of the information on the *Renewed Online* website as generic, not personal, and failing to provide anything new. These patients chose not to be part of the program:

> *He felt that the website was very generic and wasn't personal to him. He was like, "I already know all of that." he felt that it couldn't offer him any support at all...I couldn't then offer him any support with anything because he didn't want it. He said, "If you could give me advice on specific areas," which obviously we couldn't do.* [Participant 23, practice nurse, 1 patient]

Approximately 7% (2/28) of supporters raised concerns over the timing of providing *Renewed Online*. They suggested that it was important for *Renewed* to be introduced to patients when they first finish treatment and support from the hospital ends. At that point, they felt that *Renewed Online* could better support them and be more of a teachable moment before patients form their own habits for managing side effects or returning to old ones:

> *What would be brilliant, would be to get it in...very soon after they've finished their final treatment...because that's when they're perhaps the most vulnerable...giving them a tool where they can work out what's gonna benefit them in their life at that point. I think two, three years down the line, however they've got there, they've got there on their own without that [Renewed] kind of support.* [Participant 15, practice nurse, 4 patients]

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Confidence in Enacting the Supporter Role

Supporters received web-based training at the start of the study on how to provide support alongside digital interventions (Textbox 1). This explained how to use the CARE approach to support patients' engagement with *Renewed Online* and emphasized that the supporter did not need to be an expert in cancer. Most supporters reported that the length of training was adequate and provided clarity on what was needed for the role:

> *It was thorough, it explained everything really well I wasn't left with any questions. It was clear and easy to follow.* [Participant 13, clinical research nurse, 1 patient]

Some supporters possessed prior experience in cancer care and expressed confidence in their role supporting *Renewed Online*. Although not previously experienced in this area, others still expressed confidence but reported that this had grown as they gained experience in delivering the intervention. Although there appeared to be little substantive differences in the experiences of HCPs who supported multiple patients compared with 1 patient, the associated greater frequency of delivering support appeared to allow HCPs more opportunities to build confidence:

> *The more you do the calls, or the email correspondence...the much easier I feel it's become.* [Participant 1, clinical research nurse, 3 patients]

On the other hand, deviant case analysis highlighted that 33% (2/6) of health care assistants were the only supporters to report an initial lack of confidence based on preheld perceptions that they were unqualified for the supporter role. The first (participant 5, 2 patients) reported that the training did not prepare her for the role, expressing a lack of understanding of how to provide support and wanting to receive practical demonstrations of someone providing support. The second doubted her suitability for the role, initially being concerned that she was not an expert in cancer. However, these perceptions changed, and their confidence appeared to grow when actually delivering sessions, demonstrating that their initial concerns were perhaps unwarranted:

> *I felt like a bit of a fraud at the beginning, thinking am I really qualified to do this, I feel like the patient's phoning me up thinking I'm some sort of expert, but it wasn't like that at all.* [Participant 17, health care assistant, 2 patients]

Differences in where the supporters were based (either practice based or remote in the case of clinical research nurses) appeared important to their experiences in supporting patients. In particular, a few clinical research nurses felt disadvantaged based on the assumption that practice staff were probably more familiar with patients. They felt that this would facilitate rapport with patients and improve the quality of the support sessions:

> *It [Supporter role] would need to be somebody from the practice actually doing it who has access to their medical notes...just so that you're aware when you're listening to them, so you know what they're going through rather than being completely blind.* [Participant 8, clinical research nurse, 3 patients]

Practicalities of Delivering Support Alongside a Digital Intervention

Reflected in this theme is an exploration of the logistical problems supporters faced while delivering support to patients using *Renewed Online*.

Most of the current sample expressed difficulty in conducting sessions in the recommended 10 minutes, often reporting sessions of approximately 15 minutes. Sessions lasted >10 minutes for various reported reasons, including allowing time for introductions, the perception that patients felt lonely and were longing for someone to talk to, and not wanting the patient to feel rushed. In particular, the primary care staff expressed guilt about potentially rushing patients, considering that they had made an effort to come in for sessions. A clinical research nurse expressed difficulty in managing the 10-minute sessions as she was not used to working within this time limit:

> *I'd given myself longer than what was suggested because I knew from experience that if somebody is opening up to you about how they're feeling the worst possible thing that you can do is run out of time and have to end it.* [Participant 24, practice nurse, 2 patients]

A few supporters expressed a preference for lengthening sessions, particularly the first, to allow more time to get to know the patients and address any initial concerns. Relatedly, some clinical research nurses reported finding it challenging to build rapport with patients during the brief support sessions:

> *The appointment seemed very short. Especially on your initial one. I think your initial appointment should be twenty. So you can get to know the patient a bit before you bang straight into the CARE approach. Otherwise there's no real time to even introduce myself, introduce themselves.* [Participant 23, practice nurse, 1 patient]

HCPs viewed both face-to-face and telephone support as acceptable but with different benefits. Face-to-face sessions allowed them to read the patients' body language, whereas phone support was better for patients who may have difficulty in coming into a GP surgery because of travel disruptions, weather conditions, and location. In addition, phone sessions provided greater flexibility to supporters as it was easier to slot into their schedules:

> *That [phone sessions] works really well for me because it means that I can support patients when I'm not in the office...that's given me a greater flexibility with the patients.* [Participant 2, clinical research nurse, 5 patients]

Furthermore, phone sessions reportedly helped some supporters manage the length of sessions by preventing them from performing health care checks unrelated to *Renewed*. Supporters also expressed less *guilt* of having patients make the journey into practice.

Managing a Patient-Led Approach

Reflected in this theme were supporters' perceptions and experiences of using a patient-led approach and what they saw

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as helpful and found difficult. In this context, a patient-led approach refers to one in which an autonomy-supportive relationship was facilitated using CARE to support the digital intervention rather than giving advice, which was instead provided through the digital intervention. Most supporters reported that they liked the CARE approach and believed that it provided a useful prompt and session guide:

> *I liked that idea [CARE approach]. I thought that was really well planned and it's easy to remember...a good thing to just prompt you.* [Participant 26, practice nurse, 1 patient]

During sessions, patients would often discuss their behavior change goals and progress. Supporters expressed that it was initially a challenge not to give direct advice to patients during sessions. However, this reportedly became easier as they delivered more appointments. One of the supporters expressed that it was nice to see patients who were actively interested in improving their health:

> *It was refreshing to see them wanting to make life changes themselves rather than making lifestyle changes because they'd been advised to by a clinician.* [Participant 24, practice nurse, 2 patients]

In addition, some supporters expressed that not giving direct advice was a positive change and welcomed patients being more involved in their care:

> *It's all about them giving us the answers as opposed to the other way round, which I'm all for. I think that's better.* [Participant 23, practice nurse, 1 patient]

A few supporters' experiences portrayed a lack of understanding of the CARE approach and how to implement it, which caused some difficulty in delivering support alongside the digital intervention. For example, one of the supporters found it challenging to implement this approach when the patients went off on a tangent. She believed that this was because she viewed the CARE approach as a *script* to be followed strictly in a specific order, which made the conversation rigid:

> *I think that's why sometimes I didn't manage to get the CARE aspects in the way I'd like because sometimes you would start at one element of it, and you think, "Okay, I must make sure I go back to the C element or the A element..." And then I'd be like, "Well, how do I sort of interject that in now? Now we're kind of talking about something slightly different." I wanted it to more fluid.* [Participant 12, clinical research nurse, 1 patient]

This supporter viewing CARE as a script may reflect a more traditional understanding of HCP-patient relationships in which HCPs provide systematic education and instruction. However, CARE encourages an approach that prompts supporters to help patients decide what works best for them, perhaps indicating the supporter's misunderstanding or lack of familiarity with the CARE approach.

Relatedly, a practice nurse doubted the CARE approach as she perceived that patients wanted direct advice from her rather than just the website. Consequently, she felt quite limited in her supporter role.

Approximately 7% (2/28) of supporters highlighted that they would have liked to be able to review patients' *Renewed Online* activity so that they could be aware of what patients were referring to during appointments:

> *They would talk to me and I'm not completely sure I knew everything that they were covering [Renewed Online activity]...So that's something that I found difficult because they would talk away as if I knew what they were talking about.* [Participant 8, clinical research nurse, 3 patients]

Other supporters printed off pages from the *Renewed Online* demo and brought them into support sessions to overcome this.

Discussion

Principal Findings

This process evaluation used qualitative interviews to understand supporters' experiences of providing support to survivors of cancer alongside a digital intervention in primary care. Exploring supporters' experiences enabled the identification of possible factors that hindered or enabled support being delivered as intended alongside a digital intervention, highlighting lessons for future intervention development and implementation. Overall, supporters felt that they were able to follow the protocol and deliver support as needed; however, several issues were identified that might hamper implementation, and some minor alterations to *Renewed Online* would likely be required to ensure that the intervention is optimized for successful implementation in practice. Considering implementation theory in process evaluations can provide a framework for evaluating and explaining the success of implementation [35]. Therefore, the findings will be discussed in relation to the normalization process theory (NPT) [36], an implementation theory that explains the processes through which new practices of thinking, enacting, and organizing work are operationalized in health care [37]. An outline of the NPT, as described by McEvoy et al [38], is provided in Textbox 2.

The aspects of the intervention that supported implementation included the ease of training and the perceived similarity of *Renewed Online* to digital tools used in current practice. In relation to NPT, this demonstrates a high degree of *coherence* regarding the value of *Renewed Online*, which is needed for an intervention to be successfully implemented well in practice. Positive perceptions of the utility of an intervention have been shown to be key facilitators of implementation [39], and implementation failure occurred when HCPs did not perceive intervention use as a legitimate activity for patients or providers [40]. Previous literature has suggested that HCPs in primary care may not be well placed to provide support to survivors of cancer as they lack the expertise and time necessary to make these changes and desire clearer guidance on how to do so [8,9]. However, this study found that primary care staff felt that supporting survivors of cancer by using a digital intervention would be appropriate and beneficial. It is possible that this finding differs from previous literature as this is the first study to explore the views of primary care staff providing support *alongside* a digital intervention. In most cases, this format seemed to overcome concerns about the lack of expertise and

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time, as the digital intervention provided specific advice, avoiding the need to develop expertise, and vastly reduced the amount of input needed to support survivors of cancer to make behavioral changes. A minority of supporters initially believed that their perceived lack of expertise would affect their ability to support patients. However, their confidence in this approach improved once they began to support the patients, suggesting that this was not a significant barrier to implementation.

Previous research on digital interventions for other conditions has shown that primary care staff have reservations about providing phone support, viewing it as less effective than face-to-face support [21]. The acceptability of phone support seen in this study may reflect the fact that primary care is changing and is increasingly using phone appointments to manage increasing workloads [41]. This may normalize more rapidly in the current climate, as telemedicine is increasingly advocated for use in those with cancer during the COVID-19 pandemic to minimize the number of visits to health care settings and risk of exposure [42]. This increase in acceptability has implications for the implementation of future digital interventions using primary care staff to support digital intervention users, as phone support may provide similar effects and be more cost-effective [20].

Textbox 2. Normalization process theory outline.

Construct and definition

Coherence

The work individuals and organizations have to go through to understand a new practice to promote or inhibit it; these processes are energized by investments of meaning made by participants

Cognitive participation

The work individuals and organizations have to go through to enroll users and engage with a new practice; these processes are energized by investments of commitment made by participants

Collective action

The work individuals and organizations have to go through to enact a new practice; these processes are energized by investments of effort made by participants

Reflexive monitoring

The work of formal or informal appraising an intervention to develop participants' comprehension of the effects of the intervention; these processes are energized by investments in the appraisal made by participants

Most supporters successfully engaged with the CARE approach, with some noting that not giving direct advice was a positive change and welcomed patients being more involved in their care. This provided evidence of both *cognitive participation* and *collective action* and suggested that for most supporters, the CARE approach would likely normalize well in practice. However, a minority experienced difficulty adjusting to providing nondirective support and instead allowing the digital intervention to provide the advice. In terms of NPT, there was an apparent lack of *cognitive participation*, which suggests a potential challenge for successful implementation. In the wider literature, HCPs' difficulty in adjusting to not giving direct advice is a prevalent pattern. Encouraging health care workers to switch from a more traditional paternalistic approach, in which they hold all the knowledge and power and give it to the patient, to an equal relationship using nondirective support often requires intensive training, including reflective practices [43,44]. This is an issue that is pertinent to providing human support alongside many digital interventions, where health care workers are often employed to boost engagement but are not expected to be experts or to give advice [20,26]. It is possible that more intensive training might help the minority who struggle with the CARE approach. Alternatively, it may be that employing staff specifically to provide this support is more feasible than implementing more intensive training to change the behavior of health care workers whose daily work usually involves working in a directive way (eg, giving advice). Such an approach has been adopted successfully in a digital diabetes prevention program in which a commercial company (Changing Health) provides telephone support to NHS patients using digital services [28].

Some clinical research nurses perceived that not being based within GP practices was a barrier to delivering support as intended, as they did not have a pre-existing relationship with patients or access to their medical records and consequently reported finding it challenging to build rapport during 10-minute sessions. NPT would see this as a challenge to *collective action*, which examines the work HCPs have to do to enact a process [36]. This is an important issue, as the model of using research nurses adopted in this study is similar to that adopted within health care elsewhere, such as when private companies provide telephone support alongside digital interventions to patients in the United Kingdom's NHS (eg, the NHS digital diabetes prevention program); these workers do not have prior relationships with patients or access to their medical records. It may be that within such a context, a longer (perhaps double) appointment is needed to provide time to build rapport, as rapport building is considered crucial to quality health care support [41].

Some supporters suggested that *Renewed Online* should be offered to patients sooner after finishing treatment as this may be when patients are most vulnerable and motivated for behavior change. This demonstrates the NPT construct of *reflective monitoring*, whereby supporters' appraisal of *Renewed Online* considered the potential disadvantages and suggested how implementation may be improved in the future. In line with supporters' suggestions, previous research found that survivors

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of cancer described feeling the drive to adopt a healthier lifestyle to feel better and more empowered immediately after finishing treatment, and hence, it may be that this is the optimal *teachable moment* [15].

In light of the experiences of supporters and the barriers identified, several issues were identified, and potential plans for addressing these issues are presented in Table 1.

Table 1. Plans for addressing challenges faced by supporters.

Challenges faced by supporters	Plans for addressing those challenges
Many supporters were concerned that the 10-minute support sessions were too short.	Giving the option for the first session to be a double appointment should allow the time for initial introductions and addressing concerns.
Some clinical research nurses perceived that not knowing the patient before the first session was a disadvantage, as they had no existing rapport to build on.	Having the first session be an optional double appointment should allow time to build more rapport before beginning support.
Some HCPs[a] expressed a desire to see patients' activity on *Renewed* to enable easier and most salient conversations during sessions.	It may be useful to provide supporters with access to patients' *Renewed* activity.
Supporters suggested *Renewed* should be introduced at the point when patients are leaving cancer treatment as this is potentially when they are most in need of support.	Future implementation of *Renewed* may need to concentrate on patients who have finished treatment more recently instead of up to 10 years after treatment.
A few supporters were reluctant to use the CARE[b] approach as it was different from a traditional health care worker–patient relationship where the HCP is seen as having control and provides advice.	Training could be intensified for the minority who have concerns about not giving advice. This could include reflective practices, which have been shown to help people switch from a directive to nondirective approach [43,44].
A few supporters expressed a misunderstanding of how to use the CARE approach.	Update supporter training to include video demonstrations of how CARE can be delivered.
Some supporters expressed that delivering more support enabled them to build confidence.	Have fewer supporters so that they are able to support a greater number of patients, which could give them the opportunity to build confidence in delivering support.

[a]HCP: health care professional.

[b]CARE: congratulate, ask, reassure, and encourage.

Strengths and Limitations

The variation in HCP roles included in the study allowed the nuanced experience of those in different job roles to be explored. This study has several limitations. First, the data could not be analyzed iteratively during the interview period. This meant that the themes developed in early interviews could not be explored further in later ones, which can develop meaning and understanding [45]. Second, most (401/557, 71.9%) logged support sessions in the Renewed RCT were reported as sticking to 10 minutes within support sessions; however, those who consented to the interview gave patients 15 minutes on average within support sessions. It is difficult to know why this study's sample differs from the overall trial sample in this way and whether it might limit the transferability of results. This difference may be because of the use of paper self-report measures to collect the duration of support sessions within the trial, possibly resulting in a social desirability bias [46]. However, given the opportunity in an interview to discuss this in more detail, HCPs may have been more inclined to mention if they went over 10 minutes and why. Third, we were unable to record consultations with supporters within this study; hence, we could not corroborate supporters' reports on how they implemented the CARE approach. Further research exploring the recorded consultations of supporters using CARE would be useful. Finally, there was a low response rate to the interview invitations. There may be various reasons for such a low response, one of which may be the capacity for HCPs to conduct interviews because of busy schedules. The perceptions and experiences of implementing support alongside *Renewed* may have differed for those who did not accept an invitation to interview.

Conclusions

Our results suggest that HCPs generally found providing support alongside a digital intervention acceptable and were amenable to contributing to the delivery of support to survivors of cancer in primary care. Key factors that may support the successful implementation of this type of digital intervention in practice include the increasing acceptability of phone support and the utility and acceptability of nondirective support among most HCPs, such as the CARE approach. Challenges to implementing support alongside a digital intervention were also identified, including concerns about not having enough time during support sessions to build rapport and, in a minority, concerns about using a nondirective approach. This study shows that even when support for a digital intervention is designed to be brief, sufficient time needs to be allowed in the initial support sessions to allow practitioners to feel confident that rapport can be built. Further research is needed to explore whether additional training might be enough to support a minority of health care practitioners who were concerned about giving nondirective support to adopt this approach. If not, then primary care could consider employing other staff, such as social prescribers of health coaches, who work in a less directive way than nurses and health care assistants and who are now becoming increasingly common in the United Kingdom's NHS [47].

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There is a clear need for primary care to provide support to survivors of cancer [7]; however, previous research has suggested that lack of time and training on how to support this patient group are key barriers to providing this support [8,9]. This study showed that providing support alongside a digital intervention might be an acceptable way of overcoming these barriers, as only a small amount of support is required, and there is no need to develop cancer-specific expertise or behavior change skills. This approach of mixing digital and human support will likely be useful to others in developing and implementing interventions to support other aspects of care for survivors of cancer, which are not targeted within *Renewed Online*, such as support for sexual dysfunction, smoking cessation, alcohol consumption, returning to work, and lack of social connection and support.

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Authors' Contributions

JS, JSB, KB, AR, and LY contributed to the early conception of the qualitative process evaluation. JS and KB developed the interview schedule. JS and JSB collected the data. KB, LY, PL, JSB, and AWAG were involved in the development of *Renewed*. JS, RE, AR, and KB contributed to the analysis. JS wrote the initial draft of the manuscript. RE, KB, AR, and LY critically reviewed and edited the initial and subsequent drafts of the manuscript. CF, EW, CG, AWAG, and PL critically reviewed subsequent drafts of the manuscript. All authors read, critically revised, and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
COREQ (Consolidated Criteria for Reporting Qualitative studies): a 32-item checklist.
[DOCX File , 18 KB - cancer_v8i2e36364_app1.docx]

Multimedia Appendix 2
The TiDIER (Template for Intervention Description and Replication) checklist.
[DOCX File , 20 KB - cancer_v8i2e36364_app2.docx]

References

1. Latest global cancer data: cancer burden rises to 18.1 million new cases and 9.6 million cancer deaths in 2018. International Agency for Research on Cancer. 2018. URL: https://www.who.int/cancer/PRGlobocanFinal.pdf [accessed 2022-03-29]
2. Statistics fact sheet. Macmillan Cancer Support. 2021. URL: https://www.macmillan.org.uk/_images/cancer-statistics-factsheet_tcm9-260514.pdf [accessed 2022-03-29]
3. Mahumud RA, Alam K, Dunn J, Gow J. The burden of chronic diseases among Australian cancer patients: evidence from a longitudinal exploration, 2007-2017. PLoS One 2020;15(2):e0228744 [FREE Full text] [doi: 10.1371/journal.pone.0228744] [Medline: 32049978]
4. Cured - but at what cost? Long-term consequences of cancer and its treatment. Macmillan Cancer Support. 2013. URL: https://www.macmillan.org.uk/documents/aboutus/newsroom/consequences_of_treatment_june2013.pdf [accessed 2022-03-29]
5. Pearce A, Haas M, Viney R, Pearson SA, Haywood P, Brown C, et al. Incidence and severity of self-reported chemotherapy side effects in routine care: a prospective cohort study. PLoS One 2017;12(10):e0184360 [FREE Full text] [doi: 10.1371/journal.pone.0184360] [Medline: 29016607]

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6. Prager GW, Braga S, Bystricky B, Qvortrup C, Criscitiello C, Esin E, et al. Global cancer control: responding to the growing burden, rising costs and inequalities in access. ESMO Open 2018;3(2):e000285 [FREE Full text] [doi: 10.1136/esmoopen-2017-000285] [Medline: 29464109]
7. Adam R, Watson E. The role of primary care in supporting patients living with and beyond cancer. Curr Opin Support Palliat Care 2018;12(3):261-267. [doi: 10.1097/SPC.0000000000000369] [Medline: 30074923]
8. Khan NF, Evans J, Rose PW. A qualitative study of unmet needs and interactions with primary care among cancer survivors. Br J Cancer 2011;105 Suppl 1:S46-S51 [FREE Full text] [doi: 10.1038/bjc.2011.422] [Medline: 22048032]
9. Taylor S, Johnson H, Peat S, Booker J, Yorke J. Exploring the experiences of patients, general practitioners and oncologists of prostate cancer follow-up: a qualitative interview study. Eur J Oncol Nurs 2020;48:101820 [FREE Full text] [doi: 10.1016/j.ejon.2020.101820] [Medline: 32932010]
10. Roberts AL, Fisher A, Smith L, Heinrich M, Potts HW. Digital health behaviour change interventions targeting physical activity and diet in cancer survivors: a systematic review and meta-analysis. J Cancer Surviv 2017;11(6):704-719 [FREE Full text] [doi: 10.1007/s11764-017-0632-1] [Medline: 28779220]
11. Dennison L, Morrison L, Lloyd S, Phillips D, Stuart B, Williams S, et al. Does brief telephone support improve engagement with a web-based weight management intervention? Randomized controlled trial. J Med Internet Res 2014;16(3):e95 [FREE Full text] [doi: 10.2196/jmir.3199] [Medline: 24681761]
12. Yardley L, Spring BJ, Riper H, Morrison LG, Crane DH, Curtis K, et al. Understanding and promoting effective engagement with digital behavior change interventions. Am J Prev Med 2016;51(5):833-842. [doi: 10.1016/j.amepre.2016.06.015] [Medline: 27745683]
13. Krusche A, Bradbury K, Corbett T, Barnett J, Stuart B, Yao GL, et al. Renewed: protocol for a randomised controlled trial of a digital intervention to support quality of life in cancer survivors. BMJ Open 2019;9(3):e024862 [FREE Full text] [doi: 10.1136/bmjopen-2018-024862] [Medline: 30826763]
14. Corbett T, Singh K, Payne L, Bradbury K, Foster C, Watson E, et al. Understanding acceptability of and engagement with web-based interventions aiming to improve quality of life in cancer survivors: a synthesis of current research. Psychooncology 2018;27(1):22-33. [doi: 10.1002/pon.4566] [Medline: 29044832]
15. Corbett T, Cheetham T, Müller AM, Slodkowska-Barabasz J, Wilde L, Krusche A, et al. Exploring cancer survivors' views of health behaviour change: "Where do you start, where do you stop with everything?". Psychooncology 2018;27(7):1816-1824. [doi: 10.1002/pon.4732] [Medline: 29645327]
16. Bradbury K, Steele M, Corbett T, Geraghty AW, Krusche A, Heber E, et al. Developing a digital intervention for cancer survivors: an evidence-, theory- and person-based approach. NPJ Digit Med 2019;2:85 [FREE Full text] [doi: 10.1038/s41746-019-0163-4] [Medline: 31508496]
17. Moore GF, Audrey S, Barker M, Bond L, Bonell C, Hardeman W, et al. Process evaluation of complex interventions: medical research council guidance. BMJ 2015;350:h1258 [FREE Full text] [doi: 10.1136/bmj.h1258] [Medline: 25791983]
18. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care 2007;19(6):349-357. [doi: 10.1093/intqhc/mzm042] [Medline: 17872937]
19. Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. J Natl Cancer Inst 1993;85(5):365-376. [doi: 10.1093/jnci/85.5.365] [Medline: 8433390]
20. Little P, Stuart B, Hobbs FR, Kelly J, Smith ER, Bradbury KJ, et al. An internet-based intervention with brief nurse support to manage obesity in primary care (POWeR+): a pragmatic, parallel-group, randomised controlled trial. Lancet Diabetes Endocrinol 2016;4(10):821-828 [FREE Full text] [doi: 10.1016/S2213-8587(16)30099-7] [Medline: 27474214]
21. Smith E, Bradbury K, Scott L, Steele M, Little P, Yardley L. Providing online weight management in primary care: a mixed methods process evaluation of healthcare practitioners' experiences of using and supporting patients using POWeR. Implement Sci 2017;12(1):69 [FREE Full text] [doi: 10.1186/s13012-017-0596-6] [Medline: 28545538]
22. Little P, Stuart B, Hobbs FR, Kelly J, Smith ER, Bradbury KJ, et al. Randomised controlled trial and economic analysis of an internet-based weight management programme: POWeR+ (Positive Online Weight Reduction). Health Technol Assess 2017;21(4):1-62 [FREE Full text] [doi: 10.3310/hta21040] [Medline: 28122658]
23. Yardley L, Williams S, Bradbury K, Garip G, Renouf S, Ware L, et al. Integrating user perspectives into the development of a web-based weight management intervention. Clin Obes 2012;2(5-6):132-141. [doi: 10.1111/cob.12001] [Medline: 25586248]
24. Geraghty AW, Muñoz RF, Yardley L, Mc Sharry J, Little P, Moore M. Developing an unguided internet-delivered intervention for emotional distress in primary care patients: applying common factor and person-based approaches. JMIR Ment Health 2016;3(4):e53 [FREE Full text] [doi: 10.2196/mental.5845] [Medline: 27998878]
25. Hoffmann TC, Glasziou PP, Boutron I, Milne R, Perera R, Moher D, et al. Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. BMJ 2014;348:g1687. [doi: 10.1136/bmj.g1687] [Medline: 24609605]
26. Bradbury K, Morton K, Band R, May C, McManus R, Little P, et al. Understanding how primary care practitioners perceive an online intervention for the management of hypertension. BMC Med Inform Decis Mak 2017;17(1):5 [FREE Full text] [doi: 10.1186/s12911-016-0397-x] [Medline: 28069041]

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27. Koponen AM, Simonsen N, Suominen S. Quality of primary health care and autonomous motivation for effective diabetes self-management among patients with type 2 diabetes. Health Psychol Open 2017;4(1):2055102917707181 [FREE Full text] [doi: 10.1177/2055102917707181] [Medline: 28567300]
28. Service evaluation of the changing health structured education and lifestyle behaviour change coaching programme for prevention of diabetes. Changing Health. 2012. URL: https://www.changinghealth.com/wp-content/uploads/2019/02/Marketing-Pilot-Paper-Draft-220119.pdf [accessed 2022-03-29]
29. Nvivo 12 for Windows. QSR International. 2018. URL: https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home [accessed 2022-03-29]
30. Braun C, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
31. Marks DF, Yardley L. Content and thematic analysis. In: Research methods for clinical and health psychology. Thousand Oaks, CA: Sage Research Methods; 2004.
32. Seale C. Ensuring rigour in qualitative research. Eur J Public Health 1997;7(4):379-384. [doi: 10.1093/eurpub/7.4.379]
33. Lewis-Beck MS, Bryman A, Futing Liao T. The SAGE encyclopedia of social science research methods. Thousand Oaks, CA: Sage Research Methods; 2004.
34. Glaser BG, Strauss AL. The discovery of grounded theory: strategies for qualitative research. New Brunswick, NJ: Aldine Transcation; 1967.
35. Ross J, Stevenson F, Dack C, Pal K, May C, Michie S, et al. Developing an implementation strategy for a digital health intervention: an example in routine healthcare. BMC Health Serv Res 2018;18(1):794 [FREE Full text] [doi: 10.1186/s12913-018-3615-7] [Medline: 30340639]
36. May C, Finch T. Implementing, embedding, and integrating practices: an outline of normalization process theory. Sociology 2009;43(3):535-554. [doi: 10.1177/0038038509103208]
37. Huddlestone L, Turner J, Eborall H, Hudson N, Davies M, Martin G. Application of normalisation process theory in understanding implementation processes in primary care settings in the UK: a systematic review. BMC Fam Pract 2020;21(1):52 [FREE Full text] [doi: 10.1186/s12875-020-01107-y] [Medline: 32178624]
38. McEvoy R, Ballini L, Maltoni S, O'Donnell CA, Mair FS, Macfarlane A. A qualitative systematic review of studies using the normalization process theory to research implementation processes. Implement Sci 2014;9:2 [FREE Full text] [doi: 10.1186/1748-5908-9-2] [Medline: 24383661]
39. Anrys P, Strauven G, Boland B, Dalleur O, Declercq A, Degryse JM, et al. Collaborative approach to Optimise MEdication use for older people in nursing homes (COME-ON): study protocol of a cluster controlled trial. Implement Sci 2016;11:35 [FREE Full text] [doi: 10.1186/s13012-016-0394-6] [Medline: 26968520]
40. Kennedy A, Rogers A, Chew-Graham C, Blakeman T, Bowen R, Gardner C, et al. Implementation of a self-management support approach (WISE) across a health system: a process evaluation explaining what did and did not work for organisations, clinicians and patients. Implement Sci 2014;9:129 [FREE Full text] [doi: 10.1186/s13012-014-0129-5] [Medline: 25331942]
41. Baird B, Charles A, Honeyman M, Maguire D, Das P. Understanding pressures in general practice. TheKingsFund. 2016. URL: https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/Understanding-GP-pressures-Kings-Fund-May-2016.pdf [accessed 2022-03-29]
42. Al-Shamsi HO, Alhazzani W, Alhuraiji A, Coomes EA, Chemaly RF, Almuhanna M, et al. A practical approach to the management of cancer patients during the novel coronavirus disease 2019 (COVID-19) pandemic: an international collaborative group. Oncologist 2020;25(6):e936-e945 [FREE Full text] [doi: 10.1634/theoncologist.2020-0213] [Medline: 32243668]
43. Davies F, Wood F, Bullock A, Wallace C, Edwards A. Shifting mindsets: a realist synthesis of evidence from self-management support training. Med Educ 2018;52(3):274-287. [doi: 10.1111/medu.13492] [Medline: 29314172]
44. Kulnik ST, Pöstges H, Brimicombe L, Hammond J, Jones F. Implementing an interprofessional model of self-management support across a community workforce: a mixed-methods evaluation study. J Interprof Care 2017;31(1):75-84. [doi: 10.1080/13561820.2016.1246432] [Medline: 27922290]
45. Srivastava P, Hopwood N. A practical iterative framework for qualitative data analysis. Int J Qual Methods 2009;8(1):76-84. [doi: 10.1177/160940690900800107]
46. Grimm P. Social desirability bias. In: Wiley International Encyclopedia of Marketing. Hoboken, NJ: Wiley Online Library; 2010.
47. Drinkwater C, Wildman J, Moffatt S. Social prescribing. BMJ 2019;364:l1285. [doi: 10.1136/bmj.l1285] [Medline: 30923039]

Abbreviations

CARE: congratulate, ask, reassure, and encourage
COREQ: Consolidated Criteria for Reporting Qualitative studies
GP: general practitioner
HCP: health care professional

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NHS: National Health Service
NIHR: National Institute for Health Research
NPT: normalization process theory
QoL: quality of life
RCT: randomized controlled trial
TiDIER: Template for Intervention Description and Replication

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Original Paper

The Acceptability of an Electronically Delivered Acceptance- and Mindfulness-Based Physical Activity Intervention for Survivors of Breast Cancer: One-Group Pretest-Posttest Design

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Abstract

Background: Survivors of breast cancer can face internal barriers to physical activity, such as uncertainty and frustration stemming from physical limitations, decreased physical functioning, fatigue, and pain. Interventions that draw from the principles of Acceptance and Commitment Therapy (ACT) may help survivors of breast cancer overcome some of the internal barriers associated with physical activity.

Objective: The primary aim of this study was to investigate the acceptability of an electronically delivered physical activity intervention for survivors of breast cancer, centered on ACT processes.

Methods: This study used a 1-group pretest-posttest design. We recruited 80 insufficiently active female survivors of breast cancer using a web-based recruitment strategy. The 8-week intervention consisted of weekly modules that featured didactic lessons and experiential exercises targeting key ACT processes in the context of physical activity promotion (namely, values, committed action, acceptance, defusion, and contacting the present moment). We determined intervention acceptability according to study retention (≥70%), adherence rates (≥75% of the participants completing ≥50% of the modules), and posttest survey scores reflecting the perceived ease of use, perceived usefulness, and interest and enjoyment of the intervention (≥5 on a 7-point Likert-type scale). We also evaluated changes in self-reported aerobic and muscle strengthening–physical activity, physical activity acceptance, physical activity regulation, and health-related outcomes.

Results: The retention rate (61/80, 76%), adherence rate (60/80, 75%), average perceived ease of use (6.17, SD 1.17), perceived usefulness (5.59, SD 1.40), and interest and enjoyment scores (5.43, SD 1.40) met the acceptability criteria. Participants increased their self-reported aerobic physical activity (Cohen d=1.04), muscle strengthening–physical activity (Cohen d=1.02), physical activity acceptance (cognitive acceptance: Cohen d=0.35; behavioral commitment: Cohen d=0.51), physical activity regulation (identified regulation: Cohen d=0.37; integrated regulation: Cohen d=0.66), increased their ability to participate in social roles and activities (Cohen d=0.18), and reported less fatigue (Cohen d=0.33) and sleep disturbance (Cohen d=0.53).

Conclusions: Electronically delivered acceptance- and mindfulness-based interventions may be useful for promoting physical activity in survivors of breast cancer. Further research is needed to refine these approaches and evaluate their effectiveness.

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KEYWORDS

cancer survivors; exercise; mindfulness; Acceptance and Commitment Therapy; behavioral sciences

Introduction

Background

Despite the well-documented benefits of physical activity, most survivors of breast cancer do not meet the nationally recommended physical activity guidelines [1,2]. This population may encounter challenges in meeting the recommended levels of physical activity common to the general US population, along with barriers attributable to cancer and its treatment. These can include uncertainty and frustration stemming from physical limitations, decreased physical functioning, fatigue, and pain associated with physical activity [3-6].

Behavioral interventions based on the principles of Acceptance and Commitment Therapy (ACT) may be useful in helping survivors of breast cancer increase physical activity. This is partly because many of the barriers to physical activity attributable to cancer and its treatment are internal in nature and are not necessarily amenable to immediate problem solving. ACT is an approach to behavioral therapy that supplements behavioral skill building with techniques centered on developing *psychological flexibility*: the ability to be aware of, accept, and proceed with gentle persistence despite uncomfortable sensations, thoughts, and feelings that may accompany behaviors consistent with personal values [7]. It encourages individuals to set goals and take committed action in the service of clearly defined values. Rather than identifying and seeking to change problematic thoughts, emotions, and physical sensations that can stand in the way of valued living, ACT focuses on changing how individuals relate to these thoughts and feelings. Compelling evidence demonstrates that ACT is effective in bringing about a broad range of psychological and behavioral outcomes [8,9] and has shown promise for helping cancer survivors cope with negative internal experiences that can accompany cancer diagnosis and treatment [10,11].

Although ACT is typically delivered face-to-face by trained mental health professionals in clinical settings, ACT principles and skills are increasingly being applied remotely to promote behavior change for public health priorities, such as smoking cessation, weight management, diabetes management, and physical activity [12-16]. A recent systematic review and meta-analysis concluded that interventions based on ACT principles hold promise for increasing physical activity, but their application to this end is nascent [17]. The degree to which this approach to physical activity promotion, delivered electronically, may be appropriate and useful for survivors of breast cancer is unknown.

Objectives

The primary aim of this study was to investigate the acceptability of the ACTive program, an electronically delivered acceptance- and mindfulness-based physical activity intervention designed for survivors of breast cancer. This research corresponds to *phase IIa: Proof-of-Concept* of the Obesity-Related Behavioral Intervention Trials model for developing behavioral treatments [18]. It follows formative qualitative research [19] and systematic intervention development and refinement [20]. Our primary hypothesis was that female survivors of breast cancer exposed to the ACTive program would rate it as acceptable, as defined by study retention, program adherence, and ratings of perceived ease of use (PEOU), usefulness, and intrinsic motivation. Exploratory aims were to evaluate changes in participants' physical activity, related cognition, and health-related outcomes associated with receiving the behavioral intervention.

Methods

Recruitment

Eligibility criteria included that the participants be female adults with a history of breast cancer diagnosis who were not undergoing chemotherapy or irradiation treatment and were not planning on or preparing for surgery. Furthermore, participants were not eligible for inclusion if upon eligibility screening their modified Physical Activity Readiness Questionnaire [21] score indicated that unsupervised physical activity may not be safe, or the modified Godin Leisure-Time Exercise Questionnaire [21] indicated that they tended to engage in ≥150 minutes of moderate intensity aerobic exercise per week (or ≥75 minutes of vigorous intensity aerobic exercise per week or an equivalent combination of physical activity volume).

We recruited participants using the services of the Love Research Army of the Dr Susan Love Research Foundation. The recruitment material was emailed to a large listserv consisting of approximately 79,000 individuals who had signed up to receive information about breast cancer–related research studies. Interested participants provided their contact information. The study staff contacted interested individuals via telephone to assess eligibility and engage in the informed consent process.

Study Design

This study used a 1-group pretest-posttest design. Participants were recruited in September 2020 and completed a baseline survey about demographic information, physical activity levels, physical activity acceptance, physical activity regulation, and quality of life. The intervention content was delivered over the course of 8 weeks, starting in the last week of September 2020. All participants started the intervention simultaneously. A week after completing the intervention, participants completed a follow-up survey gathering information about the acceptability of the intervention, physical activity levels, physical activity acceptance, physical activity regulation, and quality of life. Surveys were delivered via REDCap (Research Electronic Data Capture; Vanderbilt University).

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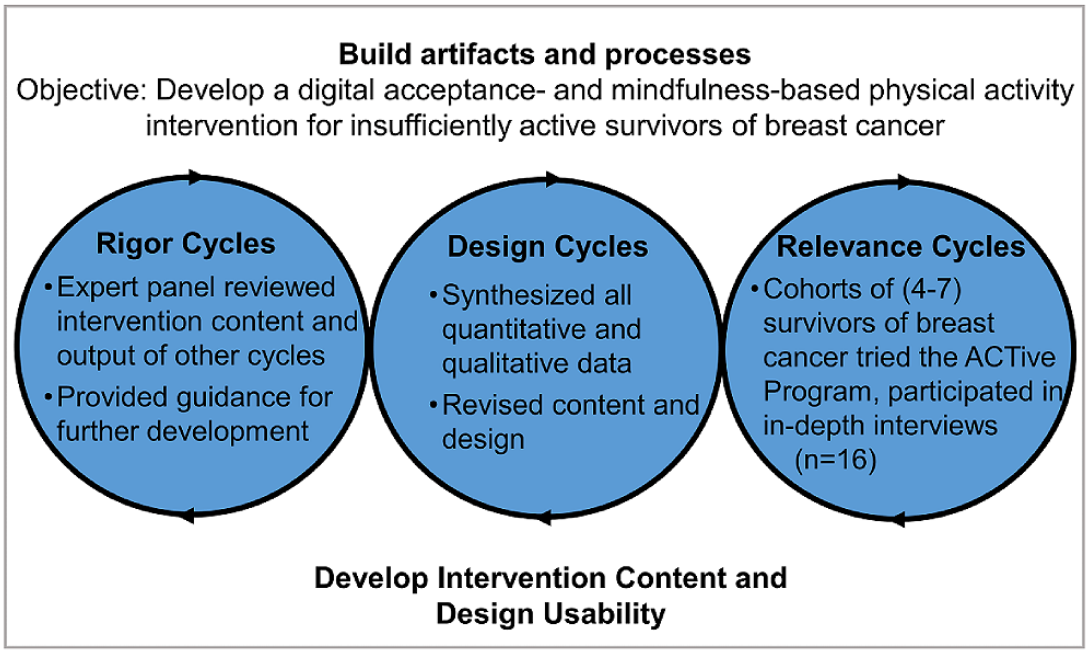
Ethics Approval

All study procedures were approved by the University of Texas School of Public Health Committee for the Protection of Human Subjects (HSC-SPH-18-1025). All participants provided informed consent for participation before taking part in the study.

Intervention Development

Before this study, we developed the ACTive program using an iterative design process. We used an existing manual to guide the application of ACT principles to help insufficiently active individuals increase physical activity [22]. To frame the intervention development process, we used the Information Systems Research framework [23]. This approach frames intervention development in three cycles (ie, *design*, *rigor*, and *relevance* cycles), which are iteratively repeated (Figure 1). Throughout this process, we included insights from individuals from the target population (30/80, 37% of the participants met the aforementioned eligibility criteria and were recruited using the same methods). The lead author (MCR) conducted individual interviews with participants after they experienced the development of intervention content and revised the intervention based on the findings from these interviews. The results of qualitative analyses are presented in the qualitative study by Robertson et al [20]. Throughout this process, we identified and iteratively tested the practical aspects of the ACTive program design. For example, we found REDCap to be an intervention delivery modality that could securely deliver intervention content (including potentially sensitive information) in a way that was perceived as simple and easy to navigate. Furthermore, we included mixed types of media (eg, short videos and audio files, images, text, and documents) and added components that participants requested, such as resources with instructions on how to safely engage in muscle strengthening–physical activity and gentle yoga classes.

Figure 1. Information Systems Research iterative design framework for the intervention.



Intervention

The ACTive program (Textbox 1) [24] was designed to help insufficiently active survivors of breast cancer meet the 2018 aerobic- and muscle strengthening–physical activity guidelines for Americans according to their own physical activity–related preferences and abilities. Target guidelines included engaging in 150 minutes of moderate intensity aerobic physical activity per week (or 75 minutes of vigorous intensity aerobic physical activity per week or an equivalent combination of both exercise intensities), engaging in at least two bouts of muscle strengthening–physical activity that targeted all major muscle groups per week [25].

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Textbox 1. Template for Intervention Description and Replication checklist for the present intervention.

The ACTive program briefs and description

- Why?
  - Despite the well-documented benefits, most survivors of breast cancer do not meet nationally recommended physical activity guidelines. Behavioral interventions based on the Acceptance and Commitment Therapy principles may be useful for helping survivors of breast cancer to increase physical activity. Digital behavior change interventions minimize barriers to access that can undermine traditional behavioral interventions.
- What (materials)?
  - The ACTive program consisted of 9 modules that featured didactic lessons and experiential exercises targeting key Acceptance and Commitment Therapy processes (Table 1). In addition, the ACTive program featured cancer survivor–specific resources for engaging in aerobic- and muscle strengthening–physical activity and delivered behavior change techniques for safely increasing physical activity. See the Methods section for more details and references to external content.
- What (procedures)?
  - The ACTive program was designed to help insufficiently active survivors of breast cancer gradually strive toward meeting the 2018 physical activity guidelines for Americans in accordance with their own physical activity–related preferences and abilities. The participants were sent intervention content weekly. They were encouraged to view all intervention content and provide responses to all queries before the next weekly module was sent.
- Who provided?
  - All intervention content was created or curated by the principal investigator of the study (MCR), a doctoral student with an Master's in Public Health studying behavioral science. See the Methods section for more details and references to external content.
- How?
  - The intervention was delivered via REDCap (Research Electronic Data Capture). REDCap was also used to periodically send participants emails from the principal investigator's (MCR) email address acknowledging the participants' effort and responses (eg, providing participants with their statements of values, goals, and committed action).
- Where?
  - The intervention content was delivered via the internet to participants throughout the United States.
- When and how much?
  - The ACTive program was delivered over the course of 8 weeks, starting from the last week of September 2020. Per week, 1 module was sent (the first week additionally contained a brief Getting Started module).
- Tailoring:
  - The participants were regularly reminded of their previous responses and were prompted to build upon them (eg, in week 3, participants were presented with the personal values they identified in week 2 and asked to set corresponding goals and engage in action planning). The intervention also provided optional resources, and individuals were encouraged to use those that they found to be personally relevant (eg, information pertaining to physical activity and lymphedema).
- How well?
  - All intervention content was successfully sent to participants' preferred email addresses. Study retention and intervention adherence are the end points detailed in the Results section of this paper.

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Table 1. ACTive program module topics and featured behavior change techniques (BCTs).

Module	Main topic (with the Acceptance and Commitment Therapy processes)	BCTs for physical activity promotion[a]
1	Introductory session: introduces study staff; establishes expectations	Motivational interviewing (confidence ruler to elicit positive change talk); time management
2	The benefits of physical activity: relevant scientific literature on physical activity; ways to gauge intensity	Provide information on consequences of behavior *in general*; environmental restructuring; provide instructions on how to perform the behavior; demonstrate the behavior
3	Values: identifying and clarifying personal values; how adherence to physical activity may support these values; increasing motivation	Stress management and emotional control training; prompt self-monitoring of behavior; provide instructions on how to perform the behavior; demonstrate the behavior
4	Goals and committed action: identifying goals consistent with values, including at least one physical activity–related goal; taking committed action to accomplish goals; distinguishing internal and external barriers to physical activity	Stress management and emotional control training; prompt self-monitoring of behavior; goal setting (behavior); action planning; provide instructions on how to perform the behavior; demonstrate the behavior
5	Acceptance: increasing acceptance as it applies to distress tolerance and physical activity; discriminating between acknowledgment and avoidance of internal discomfort; also included a *creative hopelessness* exercise	Stress management and emotional control training; prompt self-monitoring of behavior; goal setting (behavior); set graded tasks; provide rewards contingent on successful behavior; barrier identification and problem solving[a]; provide instructions on how to perform the behavior; demonstrate the behavior
6	Cognitive defusion: breaking the link between thoughts and behavior; becoming more aware of thoughts that may interfere with exercise plans	Stress management and emotional control training; prompt self-monitoring of behavior; goal setting (behavior); set graded tasks; provide rewards contingent on successful behavior; barrier identification and problem solving[b]; provide instructions on how to perform the behavior; demonstrate the behavior
7	Mindfulness: contacting the present moment; being present; allowing negative internal events to pass without disrupting committed action; engaging in nonjudgmental contact with psychological and physical events that occur; increasing awareness during physical activity	Stress management and emotional control training; prompt self-monitoring of behavior; goal setting (behavior); set graded tasks; provide rewards contingent on successful behavior; provide instructions on how to perform the behavior; demonstrate the behavior
8	Review: review and integrate key concepts	Stress management and emotional control training; prompt self-monitoring of behavior; goal setting (behavior); set graded tasks; provide rewards contingent on successful behavior; provide instructions on how to perform the behavior; demonstrate the behavior
9	Maintenance: how to maintain adherence to physical activity; navigating lapses; preventing relapse	Plan social support or social change; relapse prevention and coping planning; stress management and emotional control training; prompt self-monitoring of behavior; provide rewards contingent on successful behavior; provide instructions on how to perform the behavior; demonstrate the behavior

[a]On the basis of the Michie taxonomy [26].

[b]Problem solving was applied to external problems that may be readily amenable to change, but acceptance was applied to internal problems that may be more resistant to short term changes.

The intervention consisted of 9 modules that featured didactic lessons and experiential exercises targeting key ACT processes (namely, values, committed action, acceptance, defusion, and contacting the present moment) in the context of physical activity promotion for cancer survivors (Table 1). Sessions began with a mindfulness exercise designed to focus participants' attention in preparation for lesson content and foster the initiation of a mindfulness practice. Didactic lessons typically consisted of multiple 3- to 5-minute video and audio files narrated by the principal investigator of the study (MCR); these were supplemented by outside sources from ACT experts (eg, videos created by Dr Russ Harris [27,28]). Sessions also featured workbook-type activities and exercises designed to apply didactic content to their lives (eg, having participants identify their personally held values).

In addition to acceptance- and mindfulness-based content, the ACTive program featured resources for engaging in physical activity and applying commonly used behavior change techniques for physical activity promotion (Table 1) [26]. These resources included cancer survivor–specific how-to videos for engaging in muscle strengthening–physical activity (eg, embedded links to the Oncology, Nutrition and Exercise Group exercise videos by PennState [29], a video on proper walking posture by an exercise physiologist, and recorded yoga sessions for cancer survivors) as well as other audiovisual components (eg, images with supportive messages or inspirational quotes) and supporting documents (eg, a habit tracker and a printable calendar). The participants were prompted to report their weekly physical activity levels to facilitate self-monitoring. If participants (1) reported meeting the recommended guidelines for aerobic physical activity or muscle strengthening exercise,

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(2) met their own personally set physical activity–related goals, or (3) improved their aerobic physical activity from the week before, they were immediately rewarded with celebratory images and statements acknowledging the achievement (no additional content was added if participants did not meet any of these criteria).

The intervention was delivered in an automated fashion via REDCap, which sent surveys containing all intervention content through a dedicated study email address. To facilitate a sense of supportive accountability [30], REDCap was used to automatically send participants emails from the principal investigator's (MCR) email address upon completion of various aspects of the intervention. These emails acknowledged participation and provided participants with their own responses for their records (eg, providing participants with their values, goals, and statements of committed action). Further, the REDCap surveys were programmed to automatically provide reminders of previous input responses so that participants could build upon them (eg, participants were presented with what they put as their values upon being prompted to engage in goal setting and action planning).

Measures

Acceptability

Our conceptualization of the ACTive program's *acceptability* was based on study retention and adherence rates and the Integrated Model of Technology Acceptance (IMTA). [31,32]. We calculated the ACTive program's *retention* rate as the percentage of participants who completed the follow-up survey. We calculated the *adherence* rate from the percentage of modules completed by each participant as indicated by the REDCap system use data. IMTA is a measurement model for eHealth technology acceptance. It unifies previous lines of research of information systems acceptance and posits that technology adoption is best predicted by PEOU, perceived usefulness (PU), and intrinsic motivation [31,32]. To measure these constructs, we used the PEOU scale [31,32], the PU scale [31,32], and the interest/enjoyment subscale of the Intrinsic Motivation Inventory (IMIe) [33] (Table 2). The PEOU and PU scales consist of six 7-point Likert-type items (eg, "Learning to operate this intervention would be easy for me" and "I would find this intervention to be useful for being more physically active," respectively), with responses ranging from *Extremely unlikely* to *Extremely likely*. A psychometric analysis of these scales found evidence of reliability (Cronbach α of .98 for PU and .94 for PEOU) and convergent, discriminant, and factorial validity [34]. The IMIe scale consists of seven 7-point Likert-type items (eg, "I enjoyed doing this activity very much"), with responses ranging from *1 (Not at all true)* to *7 (very true)*. This subscale has demonstrated good internal consistency and test-retest reliability in diverse populations [33,35,36].

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Table 2. Summary of operationalizing measures.

Construct and component	Operationalization	Internal reliability[a]	Example item
Acceptability			
Retention	Percentage of participants who completed the follow-up survey	N/A[b]	N/A
Adherence	Percentage of modules completed	N/A	N/A
Ease of use	Perceived ease of use scale [31,32]	.95	"Learning to operate this intervention would be easy for me."
Usefulness	Perceived usefulness scale [31,32]	.97	"I would find this intervention to be useful for being more physically active."
Enjoyability	Interest and enjoyment subscale of the Intrinsic Motivation Inventory [33]	.92	"I enjoyed doing this activity very much."
Physical activity			
Leisure-time aerobic physical activity	Godin Leisure-Time Exercise Questionnaire [37]	N/A	"During a typical 7-d period (a week), how many times on average do you do the following kinds of exercise for more than 15 minutes during your free time? Moderate Exercise (not exhausting; eg, fast walking, baseball, tennis, easy bicycling, volleyball, badminton, easy swimming, alpine skiing, popular and folk dancing)."
Muscle strengthening–physical activity	Modified Godin Leisure-Time Exercise Questionnaire [38,39]	N/A	"In a typical week, outside of your job or work around the house, how many days do you do leisure-time physical activities specifically designed to strengthen your muscles such as lifting weights, circuit training, or resistance bands? (Do not include cardio/aerobic types of exercise)."
Physical activity acceptance			
Cognitive acceptance	Cognitive acceptance subscale of PAAQ[c]	.75	"I need to concentrate on getting rid of my urges to stop exercising or put off exercise."
Behavioral commitment	Behavioral commitment subscale of PAAQ	.81	"I am committing to being physically active no matter what feels uncomfortable or challenging about that."
Physical activity motivation			
Amotivation	Amotivation subscale of BREQ-3[d]	.84	"I don't see why I should have to exercise."
External regulation	External regulation subscale of BREQ-3	.86	"I exercise because other people say I should."
Introjected regulation	Introjected regulation subscale of BREQ-3	.84	"I feel guilty when I don't exercise."
Identified regulation	Identified regulation subscale of BREQ-3	.79	"It's important to me to exercise regularly."
Integrated regulation	Integrated regulation subscale of BREQ-3	.88	"I exercise because it is consistent with my life goals."
Intrinsic regulation	Intrinsic regulation subscale of BREQ-3	.93	"I exercise because it's fun."
Health-related outcomes			
Physical function	Physical function subscale of PROMIS-29[e]	.78	"Are you able to do chores such as vacuuming or yard work?"
Anxiety	Anxiety subscale of PROMIS-29	.89	"In the past 7 days...I felt fearful."
Depressive symptoms	Depressive symptoms subscale of PROMIS-29	.87	"In the past 7 days...I felt worthless."
Fatigue	Fatigue subscale of PROMIS-29	.94	"In the past 7 days...how run-down did you feel on average?"
Sleep disturbance	Sleep disturbance subscale of PROMIS-29	.88	"In the past 7 days...I had difficulty falling asleep..."
Ability to participate in social roles and activities	Ability to participate in social roles and activities subscale of PROMIS-29	.90	"I have trouble doing all of the activities with friends that I want to."
Pain interference	Pain interference subscale of PROMIS-29	.94	"In the past 7 days...how much did pain interfere with your day to day activities?"

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[a]Cronbach α at follow-up of this study.

[b]N/A: not applicable.

[c]PAAQ: Physical Activity Acceptance Questionnaire [40].

[d]BREQ-3: Behavioral Regulation for Exercise Questionnaire-3 [41].

[e]PROMIS-29: Patient-Reported Outcomes Measurement Information System-29 profile measure (version 2.1) [42].

Physical Activity

To assess physical activity levels, the Godin Leisure-Time Exercise Questionnaire was administered. This questionnaire has been shown to have good retest reliability (reliability coefficient=0.81) and convergent validity with measures of fitness such as maximum rate of oxygen consumption during intense exercise [37] and has been identified as a useful measure for understanding physical activity patterns in survivors of breast cancer [43]. We modified the Godin Leisure-Time Exercise Questionnaire to add an item measuring muscle strengthening–physical activity as has been done elsewhere in populations of cancer survivors [38,39]. This item reads, "In a typical week, outside of your job or work around the house, how many days do you do leisure-time physical activities specifically designed to strengthen your muscles such as lifting weights, circuit training, or resistance bands? (Do not include cardio/aerobic types of exercise)" and response options ranged from 0 to 7.

Physical Activity Acceptance

A central construct targeted by the ACTive program is experiential acceptance, defined as the propensity to acknowledge negative internal experiences rather than avoid them. We operationalized this construct using the Physical Activity Acceptance Questionnaire (PAAQ) [40]. This questionnaire consists of two subscales, *cognitive acceptance* (eg, "I need to concentrate on getting rid of my urges to stop exercising or put off exercise") and *behavioral commitment* (eg, "I am committing to being physically active no matter what feels uncomfortable or challenging about that."). Responses ranged from *1 (Never true)* to *7 (Always true)*. This questionnaire has demonstrated sound psychometric properties in survivors of breast cancer, with high internal validity (Cronbach α=.89), test-retest reliability, and convergent validity with established measures of mindfulness and physical activity (both self-reported and accelerometer-measured) [40].

Physical Activity Motivation

A recent meta-analysis and systematic review revealed that mindfulness can have marked effects on motivation for health-related behaviors (as conceptualized by Self-Determination Theory) [44]. To investigate this link in the context of this study, we evaluated the participants' physical activity–related motivation at baseline and after the intervention. To do so, we administered the 24-item Behavioral Regulation for Exercise Questionnaire-3 (BREQ-3) [41]. This questionnaire contains 5 subscales that operationalize Self-Determination Theory constructs of *amotivation*, *external regulation*, *introjected regulation*, *identified regulation*, *integrated regulation*, and *intrinsic regulation* (eg, "It's important to me to exercise regularly"). Responses ranged from *0 (Not true for me)* to *4 (very true for me)*. This questionnaire was found to have acceptable internal consistency in a sample of 414 survivors of colorectal cancer [45].

Health-Related Outcomes

To measure quality of life and physical functioning, we administered the Patient-Reported Outcomes Measurement Information System-29 profile measure (version 2.1; PROMIS-29) [42]. The PROMIS initiative is a National Institutes of Health initiative that aims to create psychometrically sound self-report measures designed to assess well-being in various domains of human health [46]. PROMIS-29 includes eight subscales, seven of which (physical function, anxiety, depressive symptoms, fatigue, sleep disturbance, ability to participate in social roles and activities, and pain interference) have 4 items with 5 Likert-type responses each (eg, ranging from *Not at all* to *very much*). The final subscale (pain intensity) has 1 item with responses ranging from *0 (No Pain)* to *10 (Worst pain imaginable)*. Scores were coded and summed such that higher scores indicate more of the concept being measured (ie, higher scores for physical function are favorable, but higher scores for anxiety are not favorable). Raw scores were then converted to *T*-scores using standardized PROMIS tables [42], which were rescaled such that the mean was 50 and the SD was 10. This questionnaire has demonstrated strong psychometric properties across a variety of populations, including cancer survivors [42,47-49].

Data Analysis

We computed participants' average PEOU, PU, and IMIe scores in accordance with their recommended scoring procedures. We calculated the average weekly moderate to vigorous physical activity using the Godin Leisure-Time Exercise Questionnaire [37] and the average subscale scores for the PAAQ and BREQ-3, following the scoring instructions. We followed the recommended PROMIS procedures to calculate the *T*-score metrics from the participant responses. We used listwise deletion to handle missing data, which assumes that missing data are completely missing at random [50]. We set the nominal α to .05 and used R (version 4.0.3) [51] and the tidyverse package [52] to conduct the data analysis.

Following the CONSORT (Consolidated Standards of Reporting Trials) guidelines [53], we determined the a priori criteria upon which to base our decision regarding the acceptability of the ACTive program. These were based on retention rate, adherence rate, and IMTA-based acceptability questionnaire data. As has been done elsewhere, we set the criteria for an acceptable *retention rate* of ≥70% [54,55]. Our criterion for the *adherence rate* was that ≥75% of participants completed at least four of the modules, which is comparable with other digital behavior change interventions (DBCIs) for cancer survivors [55-57]. Finally, our acceptability criteria included that the average scores of PEOU, PU, and IMIe were ≥5 (out of the 7 points of the Likert-type scales) [58]. To pursue exploratory aims, we

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conducted 2-tailed, paired sample *t* tests (or paired sample Wilcoxon signed-rank test, as appropriate) and computed Cohen effect size values [59] for pre- and postintervention Godin Leisure-Time Exercise Questionnaire, PAAQ, BREQ-3, and PROMIS-29 subscale scores.

Results

Overview

We attempted to contact 134 participants who expressed interest in the study and met the prescreening eligibility criteria. Of the 134 participants, a total of 91 (67.9%) participants were formally screened. Of the 91 participants, 9 (10%) were found not eligible to participate (in most cases, because they were taking drugs for a heart condition), and 2 (2%) were found to be eligible but did not subsequently take part in the study. We engaged in an informed consent process with 90% (82/91) of participants, all of whom agreed to participate in the study. Of these 82 participants, 2 (2%) did not complete the baseline survey or receive any intervention content. Thus, 80 participants were included in the study's analytic sample.

Participant Characteristics

The mean age of the sample was 57.5 (SD 11.4, range 31-79) years, and the median time since breast cancer diagnosis was 7 (IQR 3-12) years. The study sample was relatively well-educated (64/80, 80% college graduates), mostly non-Hispanic White (58/80, 73%), and mostly either overweight or obese (58/79, 73%; Table 3).

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Table 3. Participant characteristics (N=80).

Characteristic and category	Values, n (%)
Education level	
Some college	16 (20)
Bachelor's degree	36 (45)
Graduate school degree	28 (35)
Employment status	
Employed full time	41 (51)
Employed part-time	9 (11)
Retired	20 (25)
Other	10 (13)
Marital status	
Single	12 (15)
Married	58 (73)
Living with significant other	1 (1)
Divorced	5 (6)
Widowed	3 (4)
Race	
American Indian, Alaska Native, or other	1 (1)
Asian	4 (5)
Black or African American	7 (9)
White	65 (83)
Ethnicity	
Hispanic	7 (9)
Non-Hispanic	72 (91)
Stage of breast cancer at diagnosis	
1	33 (44)
2	30 (40)
3	10 (13)
4	2 (3)
BMI status	
Underweight	1 (1)
Normal	20 (25)
Overweight	34 (43)
Obese	24 (30)

Acceptability

Of the 80 participants in the analytic sample, 61 (76%) completed the follow-up survey after the 8-week intervention, yielding a *retention rate* of 76.3%. The participants completed 71.5% of all modules in total, and the *adherence rate* (percentage of participants who completed at least 4 modules) was 75% (60/80; Figure 2). The participants' average PEOU, PU, and IMIe scores were 6.17 (SD 1.17), 5.59 (SD 1.40), and 5.43 (SD 1.40), respectively (Figure 3). The retention rate, adherence rate, and IMTA-based acceptability scores met the predetermined acceptability criteria.

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Figure 2. Participant completion of intervention modules.

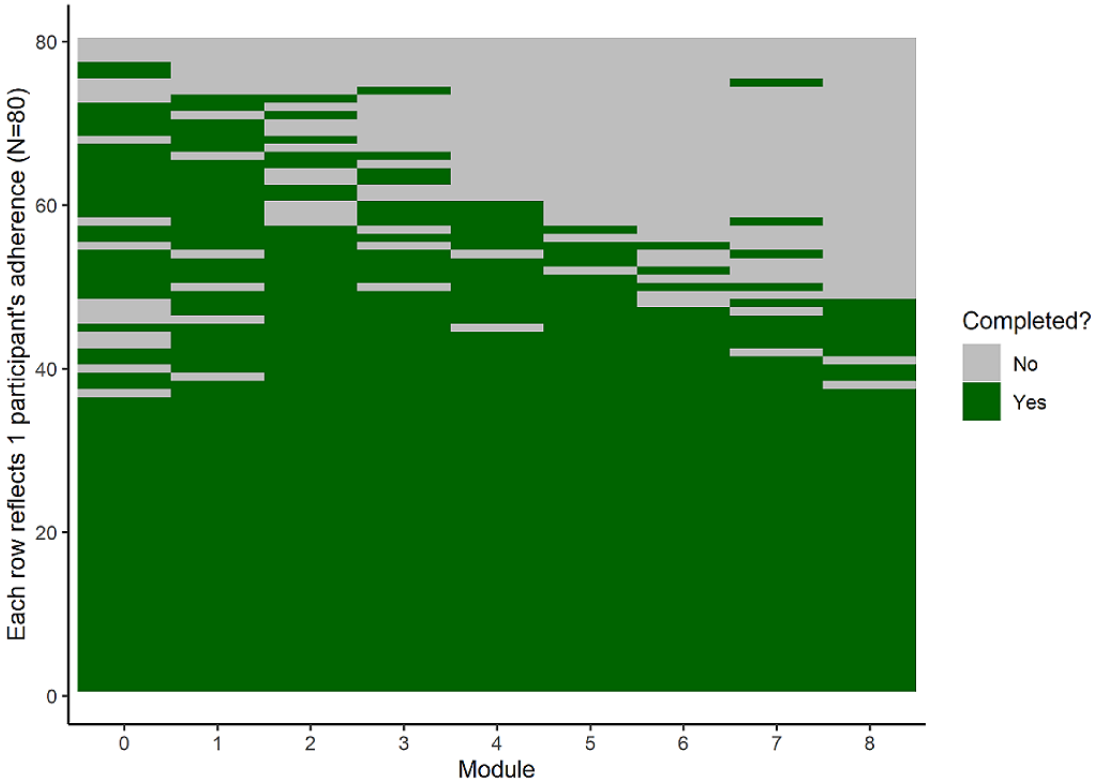

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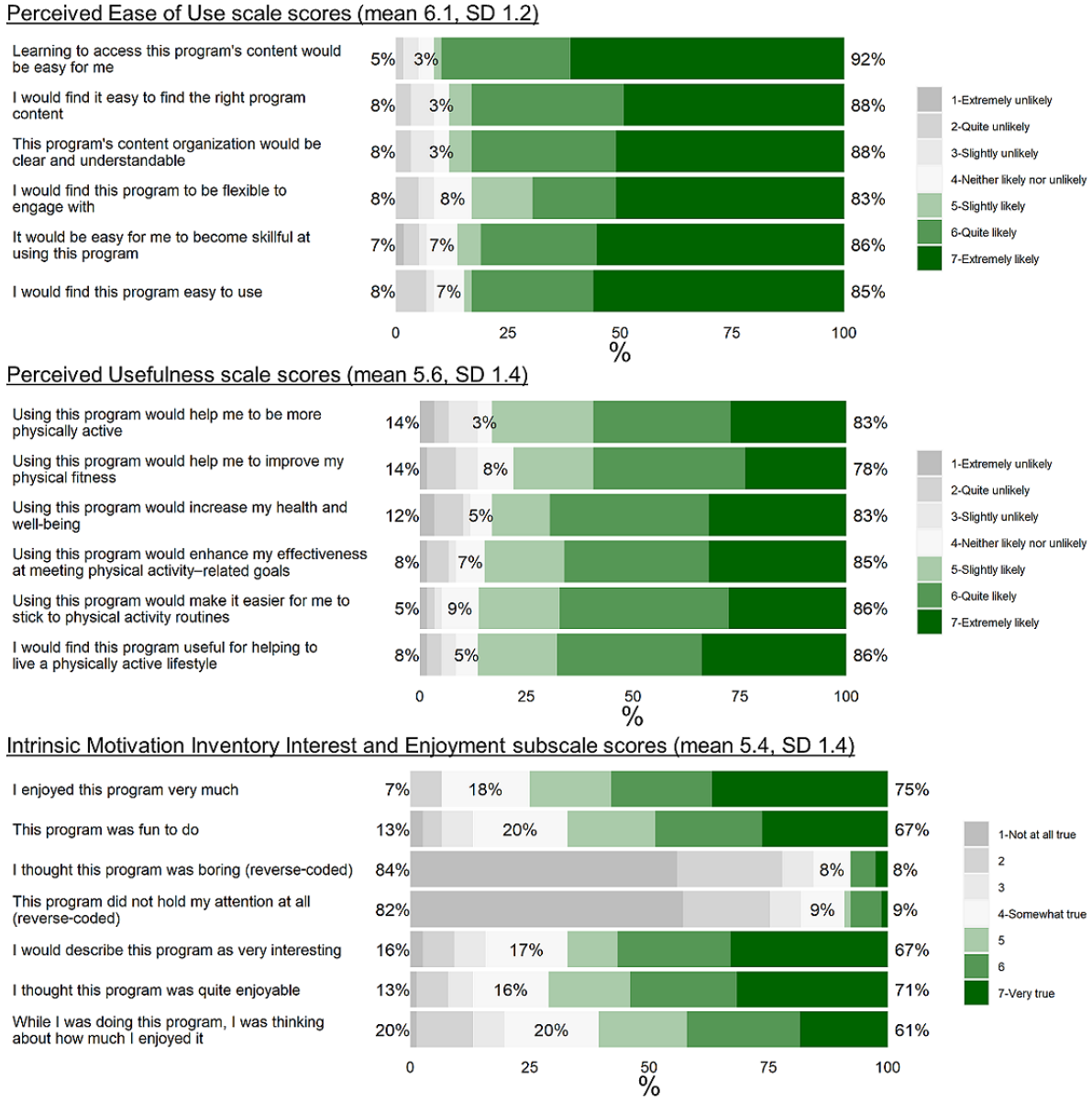
Figure 3. Acceptability scores. Inconsistencies in the sum of percentages is due to the rounding of the percentages.



Exploratory Outcomes

Table 4 presents the results of the exploratory analyses. On average, participating in the ACTive program was associated with an increase in nearly 90 minutes of self-reported moderate to vigorous intensity aerobic physical activity per week (Cohen *d*=1.04; Table 4; Figure 4) and 1.3 additional bouts of muscle strengthening–physical activity per week (Cohen *d*=1.02; Table 4; Figure 5). The participants exhibited statistically significant increases in scores for both the *cognitive acceptance* (Cohen *d*=0.35) and *behavioral commitment* subscales (Cohen *d*=0.51) of the PAAQ as well as for the *identified regulation* (Cohen *d*=0.37) and *integrated regulation* (Cohen *d*=0.66) subscales of the BREQ-3. There was no statistically significant increase in the *intrinsic regulation* subscale of the BREQ-3. Finally, participants exhibited decreased PROMIS-29 scores for *fatigue* (Cohen *d*=−0.33) and *sleep disturbance* (Cohen *d*=−0.53), and increased scores for ability to participate in social roles and activities (Cohen *d*=0.18) over the course of the study. The changes in the other PROMIS-29 subscales were not statistically significant (Table 4).

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Table 4. Changes in exploratory outcomes associated with the ACTive program (n=59).

Questionnaire and construct or subscale	Baseline score, mean (SD)	Follow-up score, mean (SD)	Change, mean (SD)	*P* value
Godin Leisure-Time Physical Activity Questionnaire				
Average weekly minutes of moderate to vigorous aerobic physical activity	36.2 (69.2)	127.4 (111.1)	91.6 (114.1)	<.001[a]
Average weekly bouts of muscle strengthening–physical activity	0.3 (0.8)	1.6 (1.6)	1.3 (1.6)	<.001[a]
Physical Activity Acceptance Questionnaire				
Cognitive acceptance	18.9 (6.9)	20.4 (6.0)	2.3 (6.9)	.01[b]
Behavioral commitment	21.3 (5.5)	23.8 (4.7)	2.5 (5.2)	<.001[a]
Behavioral Regulation for Exercise Questionnaire-3				
Identified regulation	2.5 (0.9)	2.8 (0.8)	0.3 (0.6)	<.001[a]
Integrated regulation	1.5 (1.1)	2.1 (1.0)	0.7 (0.9)	<.001[a]
Intrinsic regulation	1.7 (1.0)	1.9 (1.1)	0.2 (0.9)	.07[b]
Patient-Reported Outcomes Measurement Information System-29 profile measure (version 2.1; *T*-scores)				
Physical function	53.1 (6.4)	53.3 (5.6)	0.2 (7.0)	.95[a]
Anxiety	54.5 (9.1)	52.9 (8.6)	−0.6 (7.4)	.51[b]
Depressive symptoms	51.1 (7.0)	49.8 (7.1)	−1.2 (5.6)	.11[a]
Fatigue	53.3 (8.6)	50.2 (8.9)	−2.9 (9.2)	.02[b]
Sleep disturbance	53.0 (7.8)	48.8 (8.0)	−4.2 (7.1)	<.001[b]
Ability to participate in social roles and activities	52.1 (7.5)	53.5 (7.3)	1.3 (5.5)	.03[a]
Pain interference	49.7 (7.8)	50.2 (8.2)	0.5 (8.1)	.69[a]
Pain intensity (raw score)	3.5 (2.0)	3.5 (1.9)	0.08 (2.1)	.60[a]

[a]Paired-sample Wilcoxon signed-rank test.

[b]2-tailed, paired sample *t* test.

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Figure 4. Pre- to postintervention change in average weekly moderate to vigorous physical activity as measured by the Godin Leisure-Time Physical Activity Questionnaire.

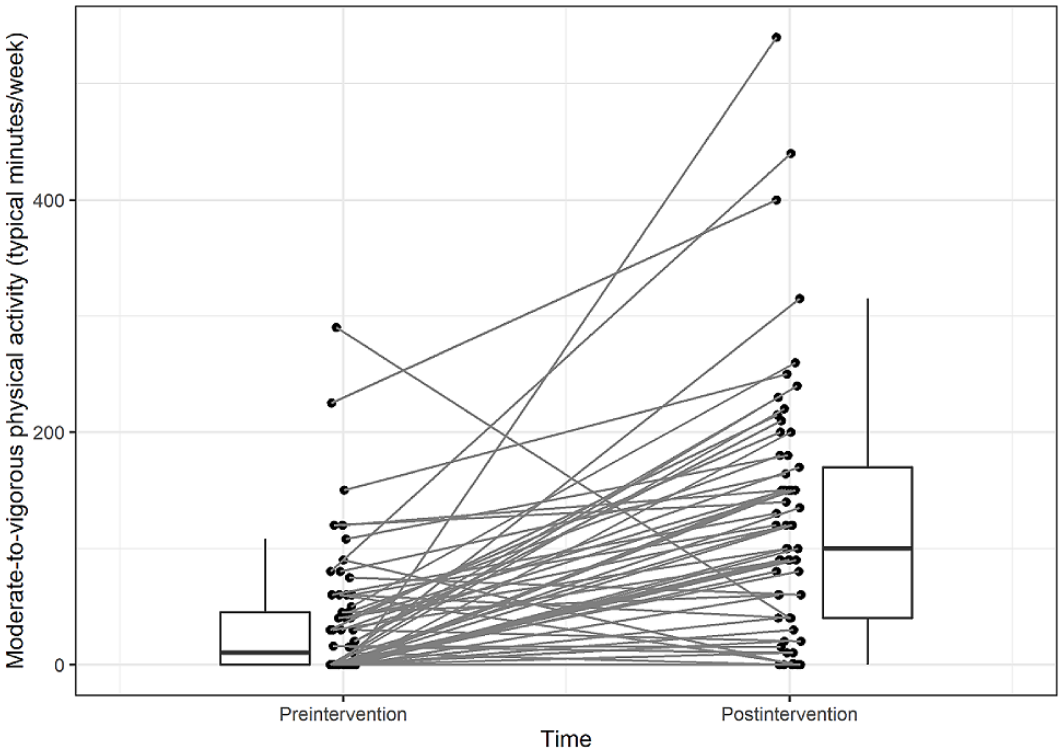
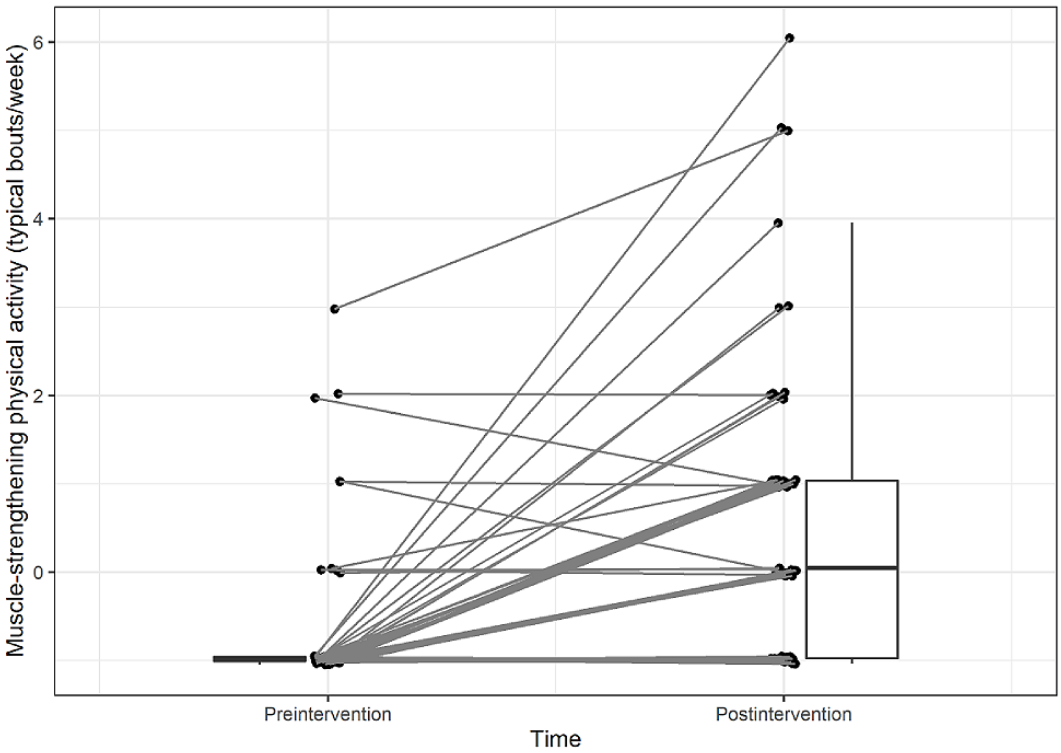


Figure 5. Pre- to postintervention changes in the average number of days participants engaged in muscle strengthening–physical activity as measured by the modified Godin Leisure-Time Physical Activity Questionnaire.



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Discussion

Principal Findings

In this study, we evaluated the acceptability of the ACTive program, an acceptance- and mindfulness-based physical activity DBCI for insufficiently active survivors of breast cancer. The 8-week electronically delivered intervention was centered on the application of ACT principles to increase psychological flexibility and acceptance in the context of physical activity. The study retention rate; participant adherence rate; and PEOU, PU, and IMIe scores supported the acceptability of this approach for promoting physical activity in survivors of breast cancer. Exploratory findings suggest that participation in the program was associated with increased aerobic- and muscle strengthening–physical activity, physical activity acceptance, identified and integrated regulation of physical activity, and decreased fatigue and sleep disturbance.

Although it met the threshold we determined to be acceptable for this early phase of research, the retention rate for this study (74%) was relatively low. High attrition is a challenge commonly encountered in physical activity–related DBCIs [60], but our retention rate was modestly lower than some other studies in cancer survivors [61] and the general population [62]. In addition to extraneous factors such as the possibility of reduced participation because of the COVID-19 pandemic [63], this may be in part because of a relatively high participant burden. Full participation in the ACT-derived content featured in this study required a considerable degree of concentration and reflective thought. It may have been that participants who were lost to follow-up were not able to do so because of competing demands for time and energy. Future studies should investigate which subpopulations of survivors of breast cancer are most amenable to this unique approach to promote physical activity. Adaptive interventions may feature acceptance- and mindfulness-based modules for those who may benefit from this content the most.

Study adherence, operationalized in this study as the completion of the weekly modules, was relatively high. This is another known challenge to remotely deliver digital health studies; the participants commonly cease interacting with DBCI-related content in health-related studies in less than a week [64]. In this study, participation was close to 100% for approximately half of the participants (48/80, 60%) and gradually tapered off over time for the other half (32/80, 40%; Figure 2). Evidence suggests that physician referral is associated with markedly increased adherence to digital health studies and may be a way to improve adherence to empirically supported DBCIs [64]. Physical activity–related DBCIs may be a useful tool to supplement health care providers' physical activity counseling, which has been shown to be effective but is often limited by time constraints [65]. Although the default assumption may be that more interactions with DBCI content is necessarily better, there is increasing recognition of the importance of parsing from intervention interaction that might constitute *effective engagement* or the level and type of engagement that is linked to key outcomes of interest [66]. The ACTive program was structured such that each module generally targeted specific ACT processes. It may be that some processes should be prioritized in the context of physical activity promotion if they predict a disproportionate amount of variance in physical activity–related outcomes. Future studies designed to evaluate intervention effectiveness should investigate what constitutes effective engagement with physical activity interventions centered on ACT principles. Furthermore, it may be useful to investigate the optimal constitution of ACT-based programs for promoting physical activity.

Findings pertaining to PEOU, PU, and IMIe scores indicated that the ACTive program was well received. These constructs predict the use and appraisal of web-based learning platforms [34,67-69] and the likelihood of cancer survivors sharing health-related information with others [70]. In this study, PEOU scores were particularly high (Figure 3). This finding supports the delivery of ACT-derived content to promote physical activity via digital means. This is a noteworthy finding, because to date, most physical activity interventions derived from ACT concepts have been conducted in person [17]. The findings suggest that this approach to physical activity promotion may be extended using DBCI technologies to increase public health impact. In this study, we used the REDCap survey delivery system. Although audiovisual program delivery is not its primary purpose, it seems to be useful for developing and evaluating beginning stage behavioral interventions. Furthermore, this may be a particularly attractive option when privacy and data security are paramount.

High PU and IMIe scores suggest that participating survivors of breast cancer felt that the application of acceptance- and mindfulness-based techniques to increase physical activity was relevant and enjoyable. This is an important finding given the marked heterogeneity of motivations for physical activity, physical abilities, and the range of desired DBCI features found in survivors of breast cancer [71]. This study is among the first to evaluate the use of acceptance- and mindfulness-based techniques for physical activity promotion in cancer survivors; although, ACT is increasingly being used to inform physical activity promotion interventions in other groups [17] and has been recommended as a useful therapeutic modality for cancer survivors [10,11]. The paradigm shifting emphasis to *change your relationship* with problematic thoughts and feelings, rather than changing the thoughts and feelings themselves, appears to resonate with insufficiently active survivors of breast cancer. High ratings of the PU of the intervention suggest that participants felt the program was effective at increasing their physical activity levels, and this notion was supported by exploratory findings.

The study participants tended to report substantial increases in aerobic- and muscle strengthening–physical activity levels from before the intervention to after the intervention. The participants averaged approximately 90 minutes per week increases in moderate to vigorous intensity aerobic physical activity and an approximately 1.3 bouts per week increase in muscle strengthening–physical activity. Given the dose response, negative association between physical activity and overall and cancer-specific mortality in survivors of breast cancer [72-75] and recommended guidelines for cancer survivors [76-78], these increases are clinically meaningful. The results are in accordance

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with a recent systematic review and meta-analysis that concluded that interventions based on ACT principles hold promise for increasing physical activity [17] and are supported by both high PU ratings and corresponding increases in PAAQ scores. Given the importance of long-term adherence to physical activity, future research is needed to evaluate the effectiveness of acceptance- and mindfulness-based interventions for both initiation and long-term maintenance of physical activity in survivors of breast cancer.

We observed small and medium effect sizes for changes in the PAAQ subscales of *cognitive acceptance* and *behavioral commitment*, respectively. This suggests that the participants experienced increases in both their experiential acceptance of physical activity–related internal experiences (eg, sensations, cognitions, and emotions) and their behavioral commitment to engaging in physical activity. This has implications for long-term change; increases in *cognitive acceptance* have been found to be associated with long-term changes in objectively measured physical activity [40]. As ACT is centered on increasing *psychological flexibility*, and in the context of physical activity promotion, this is perhaps most clearly manifested as *physical activity acceptance*, it may be that effective physical activity interventions derived from ACT tenets are partly mediated by this construct. Future studies should investigate this possibility in survivors of breast cancer.

Participants tended to report an increase in both *identified regulation* and *integrated regulation* of physical activity from before the intervention to after the intervention. These constructs are held by Self-Determination Theory to reflect autonomous forms of extrinsic regulation and have been shown to be consistently predictive of physical activity [79]. The findings of this study are concordant with the literature that has found mindfulness interventions to be associated with increases in autonomous motivation [44]. Practicing mindfulness exercises, such as engaging in mindful walking, might be theorized to increase the interest or enjoyment derived from physical activity and thus, engender increases in *intrinsic regulation* [44]. As changes in this study were observed for *identified regulation* and *integrated regulation* for physical activity but not *for intrinsic regulation*, it may have been that participants' reflection on the benefits of physical activity alongside value clarification exercises caused them to value physical activity more deeply and increasingly identify as someone who prioritizes it. Future research should investigate this notion and how Self-Determination Theory and ACT may inform behavior change interventions in tandem.

Finally, sleep disturbance, fatigue, and the ability to participate in social roles and activities are challenges faced by cancer survivors that can begin with primary treatment and persist long into survivorship [80-82]. In this study, participants tended to report clinically meaningful decreases in these issues from before the intervention to after the intervention [83]. This finding is in accordance with the literature that has found effective physical activity interventions to impact these health-related outcomes in cancer survivors [84,85]. Indeed, the American College of Sports Medicine guidelines for cancer survivors provide specific physical activity recommendations for achieving improvements in these domains [77], and such changes may occur relatively quickly with increasing physical activity levels [86,87]. Other mean changes in health-related outcomes were not statistically significant; although, there were trends toward a reduction in depressive symptoms. However, the interpretation of changes in PROMIS-29 health-related needs to be considered in light of the COVID-19 pandemic and its societal ramifications, which may have influenced these variables.

Strengths and Limitations

The findings of this study must be considered in the context of its limitations. The generalizability of this study is limited by convenience sampling methods that yielded a relatively well-educated sample and limited diversity in terms of race and ethnicity. Furthermore, participants who responded to the recruitment material may have been particularly motivated to increase their physical activity. The COVID-19 pandemic precluded more active forms of recruitment that may have yielded a more diverse sample, but our recruitment methods allowed individuals from all over the United States to participate. The study's high attrition rate has potential implications for the findings regarding the acceptability of the intervention. It may have been that those who were lost to follow-up produced lower ratings. However, the results met the a priori criteria for determining the acceptability. Our study design was centered on investigating the acceptability of the ACTive program and precluded making causal inferences regarding the efficacy of the intervention. We observed that changes in reported physical activity along with high ratings of PU of the intervention and concomitant changes in theorized determinants and outcomes linked to physical activity are somewhat encouraging, but alternate explanations may account for these observations. Salient threats to internal validity include history (particularly given the COVID-19 pandemic), potential reactivity to the experimental situation, regression to the mean, and self-reported assessment of physical activity (which is prone to social desirability and recall bias). There is also an inflated chance of type 1 error given that we conducted multiple statistical tests (eg, evaluating changes in all survey subscales individually). We did not adjust the *P* values given the exploratory nature of this investigation. The strengths of this study include the use of a theory-based intervention that can be implemented with high fidelity and has potential for scalability, acceptability testing informed by the Obesity-Related Behavioral Intervention Trials model for intervention development, and predetermined thresholds to ascertain intervention acceptability. Another strength of this project was the parsimony of design and low cost of the intervention. The study was conducted with minimal resource expenditure using in-house scripting or video and leveraging extant resources (eg, REDCap). This low-end development was used to achieve considerable positive impact and demonstrated the ability to compile meaningful, theory-based applications for increased reach, fidelity, and acceptability.

Conclusions

We conclude that electronically delivered acceptance- and mindfulness-based physical activity approaches to physical activity promotion represent potentially well-received and useful

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intervention option for insufficiently active survivors of breast cancer. Metrics pertaining to study retention, program adherence, and ratings of PEOU, usefulness, and intrinsic motivation all met the predetermined criteria for success. Receipt of the intervention was associated with increases in reported aerobic- and muscle strengthening–physical activity, physical activity acceptance, identified and integrated regulation of physical activity, and decreases in fatigue and sleep disturbance. More research is needed to further develop this approach to promote physical activity and formally evaluate its potential efficacy in pilot-testing with randomized designs.

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Conflicts of Interest

None declared.

References

1. Blanchard CM, Courneya KS, Stein K, American Cancer Society's SCS-II. Cancer survivors' adherence to lifestyle behavior recommendations and associations with health-related quality of life: results from the American Cancer Society's SCS-II. J Clin Oncol 2008 May 01;26(13):2198-2204. [doi: 10.1200/JCO.2007.14.6217] [Medline: 18445845]
2. Tarasenko Y, Chen C, Schoenberg N. Self-reported physical activity levels of older cancer survivors: results from the 2014 National Health Interview Survey. J Am Geriatr Soc 2017 Feb;65(2):e39-e44. [doi: 10.1111/jgs.14589] [Medline: 27943255]
3. Milne HM, Guilfoyle A, Gordon S, Wallman KE, Courneya KS. Personal accounts of exercise and quality of life from the perspective of breast cancer survivors. Qual Life Res 2007 Nov;16(9):1473-1481. [doi: 10.1007/s11136-007-9251-z] [Medline: 17717726]
4. Smith-Turchyn J, Richardson J, Tozer R, McNeely M, Thabane L. Physical activity and breast cancer: a qualitative study on the barriers to and facilitators of exercise promotion from the perspective of health care professionals. Physiother Can 2016;68(4):383-390 [FREE Full text] [doi: 10.3138/ptc.2015-84] [Medline: 27904238]
5. Smith L, Croker H, Fisher A, Williams K, Wardle J, Beeken R. Cancer survivors' attitudes towards and knowledge of physical activity, sources of information, and barriers and facilitators of engagement: a qualitative study. Eur J Cancer Care (Engl) 2017 Jul;26(4):e12641. [doi: 10.1111/ecc.12641] [Medline: 28135016]
6. Cummins C, Kayes NM, Reeve J, Smith G, MacLeod R, McPherson KM. Navigating physical activity engagement following a diagnosis of cancer: a qualitative exploration. Eur J Cancer Care (Engl) 2017 Jul;26(4):e12608. [doi: 10.1111/ecc.12608] [Medline: 27925326]
7. Hayes SC. Acceptance and commitment therapy, relational frame theory, and the third wave of behavioral and cognitive therapies - republished article. Behav Ther 2016 Nov;47(6):869-885. [doi: 10.1016/j.beth.2016.11.006] [Medline: 27993338]
8. A-Tjak JG, Davis ML, Morina N, Powers MB, Smits JA, Emmelkamp PM. A meta-analysis of the efficacy of acceptance and commitment therapy for clinically relevant mental and physical health problems. Psychother Psychosom 2015;84(1):30-36. [doi: 10.1159/000365764] [Medline: 25547522]
9. Smout MF, Hayes L, Atkins PW, Klausen J, Duguid JE. The empirically supported status of acceptance and commitment therapy: an update. Clinical Psychologist 2020 Nov 09;16(3):97-109. [doi: 10.1111/j.1742-9552.2012.00051.x]
10. Hulbert-Williams NJ, Storey L, Wilson KG. Psychological interventions for patients with cancer: psychological flexibility and the potential utility of Acceptance and Commitment Therapy. Eur J Cancer Care (Engl) 2015;24(1):15-27. [doi: 10.1111/ecc.12223] [Medline: 25100576]
11. Mosher CE, Secinti E, Li R, Hirsh AT, Bricker J, Miller KD, et al. Acceptance and commitment therapy for symptom interference in metastatic breast cancer patients: a pilot randomized trial. Support Care Cancer 2018 Jun;26(6):1993-2004 [FREE Full text] [doi: 10.1007/s00520-018-4045-0] [Medline: 29327085]
12. Bricker JB, Mull KE, Kientz JA, Vilardaga R, Mercer LD, Akioka KJ, et al. Randomized, controlled pilot trial of a smartphone app for smoking cessation using acceptance and commitment therapy. Drug Alcohol Depend 2014 Oct 01;143:87-94 [FREE Full text] [doi: 10.1016/j.drugalcdep.2014.07.006] [Medline: 25085225]
13. Ivanova E, Jensen D, Cassoff J, Gu F, Knäuper B. Acceptance and commitment therapy improves exercise tolerance in sedentary women. Med Sci Sports Exerc 2015 Jun;47(6):1251-1258. [doi: 10.1249/MSS.0000000000000536] [Medline: 25290743]
14. Moffitt R, Mohr P. The efficacy of a self-managed Acceptance and Commitment Therapy intervention DVD for physical activity initiation. Br J Health Psychol 2015 Feb;20(1):115-129. [doi: 10.1111/bjhp.12098] [Medline: 24698135]

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15. Cardel MI, Ross KM, Butryn M, Donahoo WT, Eastman A, Dillard JR, et al. Acceptance-based therapy: the potential to augment behavioral interventions in the treatment of type 2 diabetes. Nutr Diabetes 2020 Jan 21;10(1):3 [FREE Full text] [doi: 10.1038/s41387-020-0106-9] [Medline: 32066659]
16. Forman EM, Butryn ML. A new look at the science of weight control: how acceptance and commitment strategies can address the challenge of self-regulation. Appetite 2015 Jan;84:171-180 [FREE Full text] [doi: 10.1016/j.appet.2014.10.004] [Medline: 25445199]
17. Pears S, Sutton S. Effectiveness of Acceptance and Commitment Therapy (ACT) interventions for promoting physical activity: a systematic review and meta-analysis. Health Psychol Rev 2021 Mar;15(1):159-184. [doi: 10.1080/17437199.2020.1727759] [Medline: 32036768]
18. Czajkowski SM, Powell LH, Adler N, Naar-King S, Reynolds KD, Hunter CM, et al. From ideas to efficacy: the ORBIT model for developing behavioral treatments for chronic diseases. Health Psychol 2015 Oct;34(10):971-982 [FREE Full text] [doi: 10.1037/hea0000161] [Medline: 25642841]
19. Robertson MC, Tsai E, Lyons EJ, Srinivasan S, Swartz MC, Baum ML, et al. Mobile health physical activity intervention preferences in cancer survivors: a qualitative study. JMIR Mhealth Uhealth 2017 Jan 24;5(1):e3 [FREE Full text] [doi: 10.2196/mhealth.6970] [Medline: 28119278]
20. Robertson M, Cox-Martin E, Liao Y, Flores SA, Shegog R, Markham CM, et al. Acceptance- and mindfulness-based techniques for physical activity promotion in breast cancer survivors: a qualitative study. Support Care Cancer 2022 Jan;30(1):465-473 [FREE Full text] [doi: 10.1007/s00520-021-06428-x] [Medline: 34313858]
21. Thomas S, Reading J, Shephard RJ. Revision of the Physical Activity Readiness Questionnaire (PAR-Q). Can J Sport Sci 1992 Dec;17(4):338-345. [Medline: 1330274]
22. Martin EC, Galloway-Williams N, Cox MG, Winett RA. Pilot testing of a mindfulness- and acceptance-based intervention for increasing cardiorespiratory fitness in sedentary adults: a feasibility study. J Contextual Behav Sci 2015 Oct;4(4):237-245 [FREE Full text] [doi: 10.1016/j.jcbs.2015.10.005] [Medline: 27104134]
23. Hevner A. A three cycle view of design science research. Scand J Inf Syst 2007 Jan 01;19(2):4.
24. Hoffmann TC, Glasziou PP, Boutron I, Milne R, Perera R, Moher D, et al. Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. BMJ 2014 Mar 07;348:g1687. [doi: 10.1136/bmj.g1687] [Medline: 24609605]
25. Physical Activity Guidelines for Americans, 2nd edition. US Dept of Health and Human Services. 2018. URL: https://health.gov/sites/default/files/2019-09/Physical_Activity_Guidelines_2nd_edition.pdf [accessed 2022-03-26]
26. Michie S, Richardson M, Johnston M, Abraham C, Francis J, Hardeman W, et al. The behavior change technique taxonomy (v1) of 93 hierarchically clustered techniques: building an international consensus for the reporting of behavior change interventions. Ann Behav Med 2013 Aug;46(1):81-95. [doi: 10.1007/s12160-013-9486-6] [Medline: 23512568]
27. Harris R. The Happiness Trap. Free Resources. URL: https://thehappinesstrap.com/free-resources/ [accessed 2020-10-22]
28. Harris R. An Easy-to-Read Primer on Acceptance and Commitment Therapy. Oakland, CA, USA: New Harbinger Publications; Jun 27, 2019.
29. The ONE Group: Oncology - Nutrition - Exercise - Exercise videos. Penn State College of Medicine Research. URL: https://research.med.psu.edu/oncology-nutrition-exercise/videos/ [accessed 2020-10-22]
30. Mohr DC, Cuijpers P, Lehman K. Supportive accountability: a model for providing human support to enhance adherence to eHealth interventions. J Med Internet Res 2011 Mar 10;13(1):e30 [FREE Full text] [doi: 10.2196/jmir.1602] [Medline: 21393123]
31. Venkatesh V. Creation of favorable user perceptions: exploring the role of intrinsic motivation. MIS Q 1999 Jun;23(2):239. [doi: 10.2307/249753]
32. Venkatesh V, Speier C, Morris MG. User acceptance enablers in individual decision making about technology: toward an integrated model. Decis Sci 2002;33(2):297-316. [doi: 10.1111/j.1540-5915.2002.tb01646.x Copy DOI]
33. McAuley E, Duncan T, Tammen VV. Psychometric properties of the Intrinsic Motivation Inventory in a competitive sport setting: a confirmatory factor analysis. Res Q Exerc Sport 1989 Mar;60(1):48-58. [doi: 10.1080/02701367.1989.10607413] [Medline: 2489825]
34. Davis FD, Bagozzi RP, Warshaw PR. User acceptance of computer technology: a comparison of two theoretical models. Manag Sci 1989 Aug;35(8):982-1003. [doi: 10.1287/mnsc.35.8.982]
35. Choi J, Mogami T, Medalia A. Intrinsic motivation inventory: an adapted measure for schizophrenia research. Schizophr Bull 2010 Sep;36(5):966-976 [FREE Full text] [doi: 10.1093/schbul/sbp030] [Medline: 19386577]
36. Siu K, Lopez V. Intrinsic Motivation Inventory: translation and validation in Chinese women with urinary incontinence. Int J Urol Nurs 2010;4(1):39-46. [doi: 10.1111/j.1749-771X.2010.01086.x]
37. Shephard R. Godin leisure-time exercise questionnaire. Med Sci Sports Exerc 1997 Jun;29(6):S36-S38 [FREE Full text]
38. Vallerand JR, Rhodes RE, Walker GJ, Courneya KS. Correlates of meeting the combined and independent aerobic and strength exercise guidelines in hematologic cancer survivors. Int J Behav Nutr Phys Act 2017 Mar 28;14(1):44 [FREE Full text] [doi: 10.1186/s12966-017-0498-7] [Medline: 28351397]

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39. Parker NH, Basen-Engquist K, Rubin ML, Li Y, Prakash L, Ngo-Huang A, et al. Factors influencing exercise following pancreatic tumor resection. Ann Surg Oncol 2021 Apr;28(4):2299-2309. [doi: 10.1245/s10434-020-09062-9] [Medline: 32886288]
40. Butryn ML, Arigo D, Raggio GA, Kaufman AI, Kerrigan SG, Forman EM. Measuring the ability to tolerate activity-related discomfort: initial validation of the Physical Activity Acceptance Questionnaire (PAAQ). J Phys Act Health 2015 May;12(5):717-716 [FREE Full text] [doi: 10.1123/jpah.2013-0338] [Medline: 25106049]
41. Wilson PM, Rodgers WM, Loitz CC, Scime G. "It's who I am … really!' The importance of integrated regulation in exercise contexts 1. J Appl Biobehav Res 2006;11(2):79-104. [doi: 10.1111/j.1751-9861.2006.tb00021.x]
42. Cella D, Riley W, Stone A, Rothrock N, Reeve B, Yount S, PROMIS Cooperative Group. The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005-2008. J Clin Epidemiol 2010 Nov;63(11):1179-1194 [FREE Full text] [doi: 10.1016/j.jclinepi.2010.04.011] [Medline: 20685078]
43. Amireault S, Godin G, Lacombe J, Sabiston CM. Validation of the Godin-Shephard Leisure-Time Physical Activity Questionnaire classification coding system using accelerometer assessment among breast cancer survivors. J Cancer Surviv 2015 Sep;9(3):532-540. [doi: 10.1007/s11764-015-0430-6] [Medline: 25666749]
44. Donald JN, Bradshaw EL, Ryan RM, Basarkod G, Ciarrochi J, Duineveld JJ, et al. Mindfulness and its association with varied types of motivation: a systematic review and meta-analysis using self-determination theory. Pers Soc Psychol Bull 2020 Jul;46(7):1121-1138. [doi: 10.1177/0146167219896136] [Medline: 31884892]
45. Peddle CJ, Plotnikoff RC, Wild TC, Au HJ, Courneya KS. Medical, demographic, and psychosocial correlates of exercise in colorectal cancer survivors: an application of self-determination theory. Support Care Cancer 2008 Jan;16(1):9-17. [doi: 10.1007/s00520-007-0272-5] [Medline: 17569994]
46. Broderick JE, DeWitt EM, Rothrock N, Crane PK, Forrest CB. Advances in patient-reported outcomes: the NIH PROMIS(®) measures. EGEMS (Wash DC) 2013;1(1):1015 [FREE Full text] [doi: 10.13063/2327-9214.1015] [Medline: 25848562]
47. Tang E, Ekundayo O, Peipert JD, Edwards N, Bansal A, Richardson C, et al. Validation of the Patient-Reported Outcomes Measurement Information System (PROMIS)-57 and -29 item short forms among kidney transplant recipients. Qual Life Res 2019 Mar;28(3):815-827. [doi: 10.1007/s11136-018-2058-2] [Medline: 30467780]
48. Jensen RE, Potosky AL, Reeve BB, Hahn E, Cella D, Fries J, et al. Validation of the PROMIS physical function measures in a diverse US population-based cohort of cancer patients. Qual Life Res 2015 Oct;24(10):2333-2344 [FREE Full text] [doi: 10.1007/s11136-015-0992-9] [Medline: 25935353]
49. Quach CW, Langer MM, Chen RC, Thissen D, Usinger DS, Emerson MA, et al. Reliability and validity of PROMIS measures administered by telephone interview in a longitudinal localized prostate cancer study. Qual Life Res 2016 Nov;25(11):2811-2823 [FREE Full text] [doi: 10.1007/s11136-016-1325-3] [Medline: 27240448]
50. Allison PD. Missing Data. Thousand Oaks, CA, USA: Sage Publications; 2001:6-8.
51. R: a language and environment for statistical computing. R Foundation for Statistical Computing. 2020. URL: https://www.R-project.org/ [accessed 2022-03-26]
52. Wickham H, Averick M, Bryan J, Chang W, McGowan L, François R, et al. Welcome to the Tidyverse. J Open Source Softw 2019 Nov;4(43):1686. [doi: 10.21105/joss.01686]
53. Eldridge SM, Chan CL, Campbell MJ, Bond CM, Hopewell S, Thabane L, PAFS consensus group. CONSORT 2010 statement: extension to randomised pilot and feasibility trials. BMJ 2016 Oct 24;355:i5239. [doi: 10.1136/bmj.i5239] [Medline: 27777223]
54. Lee MK, Yun YH, Park H, Lee ES, Jung KH, Noh DY. A web-based self-management exercise and diet intervention for breast cancer survivors: pilot randomized controlled trial. Int J Nurs Stud 2014 Dec;51(12):1557-1567. [doi: 10.1016/j.ijnurstu.2014.04.012] [Medline: 24856854]
55. Forbes CC, Blanchard CM, Mummery WK, Courneya KS. Feasibility and preliminary efficacy of an online intervention to increase physical activity in Nova Scotian cancer survivors: a randomized controlled trial. JMIR Cancer 2015 Nov 23;1(2):e12 [FREE Full text] [doi: 10.2196/cancer.4586] [Medline: 28410166]
56. Short CE, Rebar A, James EL, Duncan MJ, Courneya KS, Plotnikoff RC, et al. How do different delivery schedules of tailored web-based physical activity advice for breast cancer survivors influence intervention use and efficacy? J Cancer Surviv 2017 Feb;11(1):80-91. [doi: 10.1007/s11764-016-0565-0] [Medline: 27498099]
57. Kanera IM, Bolman CA, Willems RA, Mesters I, Lechner L. Lifestyle-related effects of the web-based Kanker Nazorg Wijzer (Cancer Aftercare Guide) intervention for cancer survivors: a randomized controlled trial. J Cancer Surviv 2016 Oct;10(5):883-897 [FREE Full text] [doi: 10.1007/s11764-016-0535-6] [Medline: 26984534]
58. Short CE, DeSmet A, Woods C, Williams SL, Maher C, Middelweerd A, et al. Measuring engagement in eHealth and mHealth behavior change interventions: viewpoint of methodologies. J Med Internet Res 2018 Nov 16;20(11):e292 [FREE Full text] [doi: 10.2196/jmir.9397] [Medline: 30446482]
59. Cohen J. Statistical Power Analysis for the Behavioral Sciences. Cambridge, MA, USA: Academic Press; 1977:20-27.
60. Eysenbach G. The law of attrition. J Med Internet Res 2005 Mar 31;7(1):e11 [FREE Full text] [doi: 10.2196/jmir.7.1.e11] [Medline: 15829473]

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61. Kuijpers W, Groen WG, Aaronson NK, van Harten WH. A systematic review of web-based interventions for patient empowerment and physical activity in chronic diseases: relevance for cancer survivors. J Med Internet Res 2013 Feb 20;15(2):e37 [FREE Full text] [doi: 10.2196/jmir.2281] [Medline: 23425685]
62. Davies CA, Spence JC, Vandelanotte C, Caperchione CM, Mummery WK. Meta-analysis of internet-delivered interventions to increase physical activity levels. Int J Behav Nutr Phys Act 2012 Apr 30;9:52 [FREE Full text] [doi: 10.1186/1479-5868-9-52] [Medline: 22546283]
63. Cardel M, Manasse S, Krukowski R, Ross K, Shakour R, Miller DR, et al. COVID-19 impacts mental health outcomes and ability/desire to participate in research among current research participants. Obesity (Silver Spring) 2020 Dec;28(12):2272-2281 [FREE Full text] [doi: 10.1002/oby.23016] [Medline: 32845582]
64. Pratap A, Neto EC, Snyder P, Stepnowsky C, Elhadad N, Grant D, et al. Indicators of retention in remote digital health studies: a cross-study evaluation of 100,000 participants. NPJ Digit Med 2020;3:21 [FREE Full text] [doi: 10.1038/s41746-020-0224-8] [Medline: 32128451]
65. Fong AJ, Faulkner G, Jones JM, Sabiston CM. A qualitative analysis of oncology clinicians' perceptions and barriers for physical activity counseling in breast cancer survivors. Support Care Cancer 2018 Sep;26(9):3117-3126. [doi: 10.1007/s00520-018-4163-8] [Medline: 29574619]
66. Yardley L, Spring BJ, Riper H, Morrison LG, Crane DH, Curtis K, et al. Understanding and promoting effective engagement with digital behavior change interventions. Am J Prev Med 2016 Nov;51(5):833-842. [doi: 10.1016/j.amepre.2016.06.015] [Medline: 27745683]
67. Pal D, Vanijja V. Perceived usability evaluation of Microsoft Teams as an online learning platform during COVID-19 using system usability scale and technology acceptance model in India. Child Youth Serv Rev 2020 Dec;119:105535 [FREE Full text] [doi: 10.1016/j.childyouth.2020.105535] [Medline: 33020676]
68. Yi MY, Hwang Y. Predicting the use of web-based information systems: self-efficacy, enjoyment, learning goal orientation, and the technology acceptance model. Int J Hum Comput Stud 2003 Oct;59(4):431-449. [doi: 10.1016/s1071-5819(03)00114-9]
69. Dickinger A, Arami M, Meyer D. The role of perceived enjoyment and social norm in the adoption of technology with network externalities. Eur J Inf Syst 2017 Dec 19;17(1):4-11. [doi: 10.1057/palgrave.ejis.3000726]
70. Mao B, Morgan SE, Peng W, McFarlane SJ, Occa A, Grinfeder G, et al. What motivates you to share? The effect of interactive tailored information aids on information sharing about clinical trials. Health Commun 2021 Oct;36(11):1388-1396. [doi: 10.1080/10410236.2020.1754588] [Medline: 32345059]
71. Corbett T, Singh K, Payne L, Bradbury K, Foster C, Watson E, et al. Understanding acceptability of and engagement with web-based interventions aiming to improve quality of life in cancer survivors: a synthesis of current research. Psychooncology 2018 Jan;27(1):22-33. [doi: 10.1002/pon.4566] [Medline: 29044832]
72. Geidl W, Schlesinger S, Mino E, Miranda L, Pfeifer K. Dose-response relationship between physical activity and mortality in adults with noncommunicable diseases: a systematic review and meta-analysis of prospective observational studies. Int J Behav Nutr Phys Act 2020 Aug 26;17(1):109 [FREE Full text] [doi: 10.1186/s12966-020-01007-5] [Medline: 32843054]
73. Li T, Wei S, Shi Y, Pang S, Qin Q, Yin J, et al. The dose-response effect of physical activity on cancer mortality: findings from 71 prospective cohort studies. Br J Sports Med 2016 Mar;50(6):339-345. [doi: 10.1136/bjsports-2015-094927] [Medline: 26385207]
74. Spei ME, Samoli E, Bravi F, La Vecchia C, Bamia C, Benetou V. Physical activity in breast cancer survivors: a systematic review and meta-analysis on overall and breast cancer survival. Breast 2019 Apr;44:144-152. [doi: 10.1016/j.breast.2019.02.001] [Medline: 30780085]
75. McTiernan A, Friedenreich C, Katzmarzyk P, Powell KE, Macko R, Buchner D, 2018 PHYSICAL ACTIVITY GUIDELINES ADVISORY COMMITTEE*. Physical activity in cancer prevention and survival: a systematic review. Med Sci Sports Exerc 2019 Jun;51(6):1252-1261 [FREE Full text] [doi: 10.1249/MSS.0000000000001937] [Medline: 31095082]
76. Schmitz KH, Campbell AM, Stuiver MM, Pinto BM, Schwartz AL, Morris GS, et al. Exercise is medicine in oncology: engaging clinicians to help patients move through cancer. CA Cancer J Clin 2019 Nov;69(6):468-484 [FREE Full text] [doi: 10.3322/caac.21579] [Medline: 31617590]
77. Campbell KL, Winters-Stone KM, Wiskemann J, May AM, Schwartz AL, Courneya KS, et al. Exercise guidelines for cancer survivors: consensus statement from international multidisciplinary roundtable. Med Sci Sports Exerc 2019 Nov;51(11):2375-2390 [FREE Full text] [doi: 10.1249/MSS.0000000000002116] [Medline: 31626055]
78. Patel A, Friedenreich C, Moore S, Hayes SC, Silver JK, Campbell KL, et al. American College of Sports Medicine Roundtable Report on physical activity, sedentary behavior, and cancer prevention and control. Med Sci Sports Exerc 2019 Nov;51(11):2391-2402 [FREE Full text] [doi: 10.1249/MSS.0000000000002117] [Medline: 31626056]
79. Teixeira PJ, Carraça EV, Markland D, Silva MN, Ryan RM. Exercise, physical activity, and self-determination theory: a systematic review. Int J Behav Nutr Phys Act 2012 Jun 22;9:78 [FREE Full text] [doi: 10.1186/1479-5868-9-78] [Medline: 22726453]
80. Savard J, Morin CM. Insomnia in the context of cancer: a review of a neglected problem. J Clin Oncol 2001 Feb 01;19(3):895-908. [doi: 10.1200/JCO.2001.19.3.895] [Medline: 11157043]

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81. Humpel N, Iverson DC. Sleep quality, fatigue and physical activity following a cancer diagnosis. Eur J Cancer Care (Engl) 2010 Nov;19(6):761-768. [doi: 10.1111/j.1365-2354.2009.01126.x] [Medline: 19832890]
82. Bower JE, Meyerowitz BE, Desmond KA, Bernaards CA, Rowland JH, Ganz PA. Perceptions of positive meaning and vulnerability following breast cancer: predictors and outcomes among long-term breast cancer survivors. Ann Behav Med 2005 Jun;29(3):236-245. [doi: 10.1207/s15324796abm2903_10] [Medline: 15946118]
83. Yost KJ, Eton DT, Garcia SF, Cella D. Minimally important differences were estimated for six Patient-Reported Outcomes Measurement Information System-Cancer scales in advanced-stage cancer patients. J Clin Epidemiol 2011 May;64(5):507-516 [FREE Full text] [doi: 10.1016/j.jclinepi.2010.11.018] [Medline: 21447427]
84. Serdà I Ferrer BC, van Roekel E, Lynch BM. The role of physical activity in managing fatigue in cancer survivors. Curr Nutr Rep 2018 Sep;7(3):59-69. [doi: 10.1007/s13668-018-0234-1] [Medline: 30094747]
85. Roveda E, Vitale JA, Bruno E, Montaruli A, Pasanisi P, Villarini A, et al. Protective effect of aerobic physical activity on sleep behavior in breast cancer survivors. Integr Cancer Ther 2017 Mar;16(1):21-31 [FREE Full text] [doi: 10.1177/1534735416651719] [Medline: 27252076]
86. Kredlow MA, Capozzoli MC, Hearon BA, Calkins AW, Otto MW. The effects of physical activity on sleep: a meta-analytic review. J Behav Med 2015 Jun;38(3):427-449. [doi: 10.1007/s10865-015-9617-6] [Medline: 25596964]
87. Puetz TW. Physical activity and feelings of energy and fatigue: epidemiological evidence. Sports Med 2006;36(9):767-780. [doi: 10.2165/00007256-200636090-00004] [Medline: 16937952]

Abbreviations

ACT: Acceptance and Commitment Therapy
BREQ-3: Behavioral Regulation for Exercise Questionnaire-3
CONSORT: Consolidated Standards of Reporting Trials
DBCI: digital behavior change intervention
IMIe: interest/enjoyment subscale of the Intrinsic Motivation Inventory
IMTA: Integrated Model of Technology Acceptance
PAAQ: Physical Activity Acceptance Questionnaire
PEOU: perceived ease of use
PROMIS-29: Patient-Reported Outcomes Measurement Information System-29 profile measure (version 2.1)
PU: perceived usefulness
REDCap: Research Electronic Data Capture

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Original Paper

Barriers to Clinical Trial Participation: Comparative Study Between Rural and Urban Participants

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Abstract

Background: The National Clinical Trials Network program conducts phase 2 or phase 3 treatment trials across all National Cancer Institute's designated cancer centers. Participant accrual across these clinical trials is a critical factor in deciding their success. Cancer centers that cater to rural populations, such as The University of Kansas Cancer Center, have an additional responsibility to ensure rural residents have access and are well represented across these studies.

Objective: There are scant data available regarding the factors that act as barriers to the accrual of rural residents in these clinical trials. This study aims to use electronic screening logs that were used to gather patient data at several participating sites in The Kansas University of Cancer Center's Catchment area.

Methods: Screening log data were used to assess what clinical trial participation barriers are faced by these patients. Additionally, the differences in clinical trial participation barriers were compared between rural and urban participating sites.

Results: Analysis revealed that the hospital location rural urban category, defined as whether the hospital was in an urban or rural setting, had a medium effect on enrolment of patients in breast cancer and lung cancer trials (Cohen d=0.7). Additionally, the hospital location category had a medium effect on the proportion of recurrent lung cancer cases at the time of screening (d=0.6).

Conclusions: In consideration of the financially hostile nature of cancer treatment as well as geographical and transportation barriers, clinical trials extended to rural communities are uniquely positioned to alleviate the burden of nonmedical costs in trial participation. However, these options can be far less feasible for patients in rural settings. Since the number of patients with cancer who are eligible for a clinical trial is already limited by the stringent eligibility criteria required of such a complex disease, improving accessibility for rural patients should be a greater focus in health policy.

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KEYWORDS

rural residents; clinical trials; screening; cancer; patients; lung cancer; health policy epidemiology; cancer patients; electronic screening logs; electronic screening

Introduction

There are numerous barriers for rural residents to obtain health care. Some of the barriers include but are not limited to lack of facilities, lack of infrastructure, inability to travel, lack of specialists, financial barriers, and limited access to clinical trials [1]. Consequently, patients may avoid or delay care, resulting in more severe clinical outcomes [2,3].

Within this field, there are several environmental risk factors such as sun exposure, pesticide exposure, and risk of injury from farming equipment [4,5]. Among these risks, pesticides and other chemicals may lead to an increased cancer incidence among rural populations [6]. Given the nature of cancer, without early diagnosis, the patient might be left with fewer treatment options or may even run out of treatment options. Moreover, treatments for battling cancer are very expensive as they require

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multiple sessions over a long period of time [7,8]. The medications involved with cancer treatment are also expensive, and not all are covered through medical insurance leaving the patient to pay for it [9]. Given most of the rural residents are either self-employed or employed through small companies, typically their insurance coverage is very minimal [10]. A lack of insurance coverage or gaps in insurance coverage can add to the difficulty of the treatment process for rural patients. In many cases, these patients must choose between skipping treatment or taking on debt [9]. In consideration of these obstacles, clinical trials may represent an underutilized avenue of affordable treatment for rural patients. However, the availability of these trials to rural patients is limited by the logistic difficulty of bringing expensive medical devices involved in cancer treatment to isolated health centers in nonmetro areas.

The Masonic Cancer Alliance (MCA), which serves as the outreach network for the University of Kansas Cancer Center (KUCC), already has a great relationship with most of the rural hospitals and clinics in the catchment area. The KUCC launched this network to extend clinical trials at these hospitals and clinics in rural and health professional shortage areas. The majority of trials made available to the MCA sites are the National Cancer Institute's National Clinical Trials Network studies. To better understand the volume and patient cohort availability, all of the screening information gathered at these locations was documented at each of the sites under a screening log database. These community sites span across the state of Kansas, covering the majority of KUCC's catchment area.

The National Clinical Trials Network (NCTN) program is aimed to motivate like-minded people across North America and internationally to coordinate and support cancer clinical trials that are funded by the National Cancer Institute. The trials that were part of the NCTN program were used as potential trials available for patients who received care at 9 community sites. The community site information is summarized in Table 1, including the county and state these sites are located, as well as their Rural Urban Continuum Codes (RUCC) classification, which designates counties as rural or urban depending on population and urbanization.

KUCC, in collaboration with MCA, launched clinical trial screening at the 9 community sites that are located across the KUCC catchment area for the NCTN trials. Figure 1 provides a geographical representation of where these sites are located.

Table 1. Community partner sites where participants were screened

Site name	County, state (population)	RUCC[a] classification	Health professional shortage areas (primary care)
Hays Medical Center	Ellis County, KS (28,553)	Rural (5)	No
Heartland Cancer Center	Finney County, KS (36,467)	Rural (5)	Yes
Newman Regional Center	Lyon County, KS (33,195)	Rural (4)	Yes
Olathe Medical Center	Johnson County, KS (602,401)	Urban (1)	No
Salina Regional Health Center	Saline County, KS (54,224)	Rural (5)	Yes
St. Catherine Hospital	Finney County, KS (36,467)	Rural (5)	Yes
St. Francis Comprehensive Medical Center	Shawnee County, KS (176,875)	Urban (3)	Yes
Truman Medical Center	Jackson County, MO (703,011)	Urban (1)	No
Via Christi Hospital	Crawford County, KS (38,818)	Rural (4)	Yes

[a]RUCC: Rural Urban Continuum Codes.

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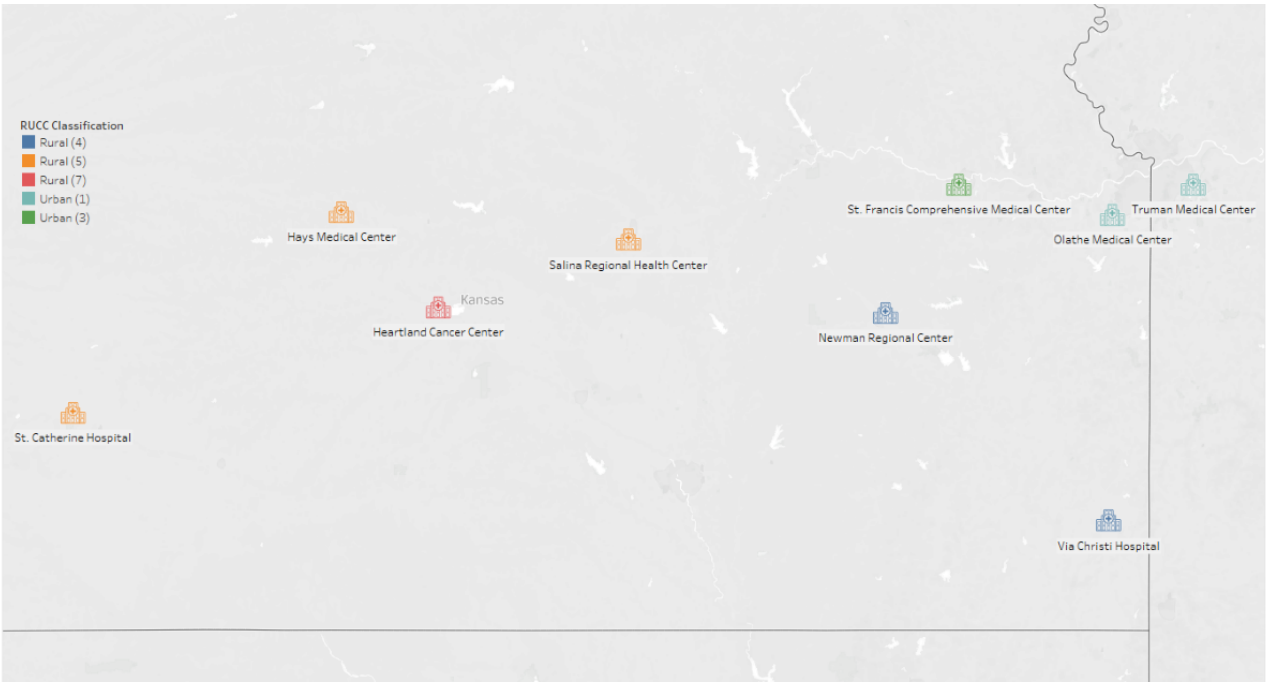
Figure 1. Geographical location of the clinical trial screening sites. RUCC: Rural Urban Continuum Codes. ©Mapbox ©OpenStreetMap.



Methods

Screening Methodology

The MCA, in conjunction with the Biostatistics and Informatics Shared Resources, have built a screening log survey using REDCap (Research Electronic Data Capture) [11]. The screening log was targeted to capture high-level information about participants who were screened at these community sites. The screening log captured information such as whether there was a trial available based on the community cancer center's clinical trials portfolio. If a potential trial was currently available for a participant's cancer type, the participants were screened and screening information was documented. Documented screening information for these patients included cancer disease type, stage, and recurrence. The screening log is attached as a supplementary document listing all the questions that were captured during the screening. If a patient was found to be ineligible for a trial after screen, the corresponding reasons were also documented. If a patient was eligible for a trial but chose not to take part, their reasons were also documented. Multiple disease trials were considered to be available trials for both patients with lung cancer and patients with breast cancer.

The University of Kansas Medical Center Institutional Review Board's approval was given to capture the participants screening information across the 9 community sites in October 2014. Since then, information has been captured under the REDCap screening log project. The data dictionary depicting the screening information that was captured has been attached as a supplementary document (Multimedia Appendix 1). The number of clinical trials that were available across these 9 sites is illustrated as a bar chart in Figure 2. These results are stratified by year, and different colors represent the type of disease the trial was targeting (breast, lung, or multiple disease). The multiple disease trials are broader studies that allowed screening for both breast and lung but also other common cancer types.

The 9 sites involved in the screening process span across the state of Kansas and are described in Table 1. Based on the RUCC, these sites were classified as Rural (RUCC 4-9) or Urban sites (RUCC 1-3). For the purposes of this study, we used hospital location to categorize rural or urban status to compare factors in breast cancer and lung cancer between the rural and urban groups. These factors include clinical trial availability, barriers to treatment, and disease characteristics.

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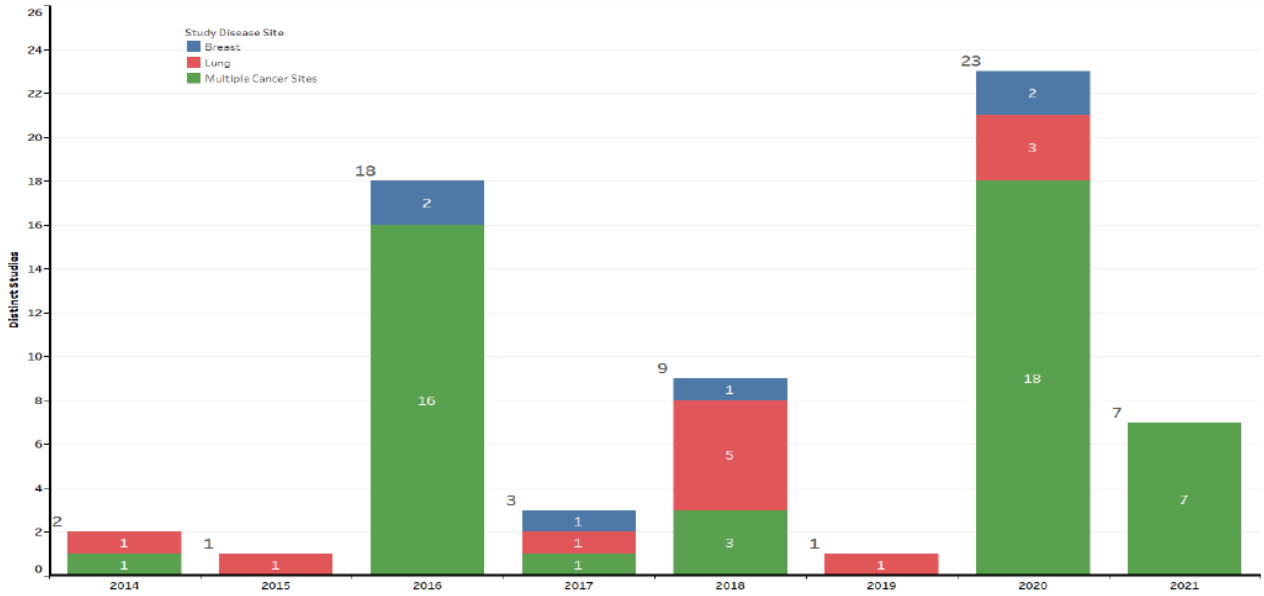
Figure 2. Clinical trials actively screening during the calendar year.



Statistical Analysis

The data capture for screening were developed with a pure intention of operational goals, and consequently there was not a formal study design to determine the sample size for each of these sites. Moreover, the screening process of clinical trials is hard to predict, and there is always an ebb and flow with screening both in urban and rural areas. Due to these sampling issues, the Fisher exact test *P* value was determined to be an insufficient method for comparing rural participants to urban participants. Additionally, in consideration of the fact that significant *P* values are also likely to be found in large sample sizes even when the size of the effect is negligible, Cohen *d* was used to calculate effect size instead [12]. To obtain the Cohen *d*, a log odds ratio was calculated and then converted [13]. A Cohen *d* value of [0;0.2) implies negligible effect; [0.2; 0.5) implies small effect; [0.5; 0.8) implies medium effect; and [0.8; infinity) implies large effect [14].

Cohen d Calculation

Cohen *d* is calculated using the following standard formula:

Variables included for analysis included the rural-urban category, with outcomes including the disease-specific information gathered during the screening process. Among the disease-specific information, variables varied between patients who had breast cancer and those diagnosed with lung cancer.

Outcome variables for patients with breast cancer included clinical trial availability, whether they were a new or existing patient at diagnosis, tumor stage, histology of the breast, nodal breast status, metastatic status, recurrence status, stage of breast, and hormone of the breast. Clinical trial availability was recorded as yes or no depending on whether a clinical trial was available. Metastatic status was recorded as yes or no. Recurrence status was recorded as recurrent or nonrecurrent. Tumor stage was recorded as T1, T2, T3, or T4. Histology of the breast was recorded as ductal carcinoma in situ (invasive carcinoma), or inflammatory carcinoma. Nodal breast status was recorded as either positive or negative. Stage of breast was recorded as 0, I, II, III, or IV. Lastly, the hormone of the breast was recorded as ER/PR+ (estrogen receptor/progesterone receptor) HER2+ (human epidermal growth factor receptor 2), ER/PR+ HER2–, ER/PR– HER2+, or ER/PR– HER2–.

Outcome variables for patients with lung cancer included clinical trial availability, whether they were a new or existing patient at diagnosis, tumor stage, histology of the lung, nodal lung status, metastatic status, and recurrence status. Clinical trial availability was recorded as yes or no depending on whether a clinical trial was available. Metastatic status was recorded as yes or no. Recurrence status was recorded as recurrent or nonrecurrent. Lung histology was recorded as adenocarcinoma, bronchoalveolar, squamous cell carcinoma, small-cell carcinoma, or mesothelioma. Tumor stage was recorded as T0, T1, T2, T3, or T4. Lastly, nodal lung status was recorded either positive or negative.

Ethics Approval

The University of Kansas Medical Center granted approval under a central IRB with reliance by the other institutions (STUDY00002341).

Results

A total of 2258 patients with breast cancer and 1347 patients diagnosed with lung cancer were screened across 9 sites from October of 2014 to December of 2020. Some common reasons why patients were not able to participate in clinical trials are described in Multimedia Appendix 2. As stated previously, we sought to assess the relative availability of clinical trials between rural and urban patients. Additionally, we analyzed the relative incidence of certain cancer disease features between these two

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populations. These results are detailed in Multimedia Appendix 3.

Among patients with breast cancer, we noted significant differences in clinical trial availability between rural-urban categories. For urban residents, 177 (18.7%) of the 945 patients with breast cancer were eligible for a clinical trial based on their portfolio. Compare this to rural residents, where 79 (6.01%) of 1313 patients were eligible for a clinical trial. A Cohen *d* value of 0.7 represents a medium effect between the rural and urban groups when it comes to clinical trial availability. Using the Cohen *d* calculation formula, this would mean that an urban patient who has breast cancer would be 3.56 more likely to have an available clinical trial for their cancer type compared to a rural patient with breast cancer. This suggests that an urban participant diagnosed with breast cancer had higher odds of finding a potential clinical trial compared to a rural patient diagnosed with the same condition. Hospital Location Rural-Urban Category (HLRUC) had a small effect on whether a patient was a new or existing patient at the time of diagnosis (Cohen *d*=0.2), suggesting slightly higher odds that a rural patient would be a new patient at the time of diagnosis. Health risk control did not display an effect on either the stage of breast cancer or breast histology. For both outcomes, the Cohen *d* was 0.1. Health risk control displayed a small effect size (Cohen *d*=0.2-0.4) on nodal breast status, metastatic status, recurrence status, stage of breast, and hormone of breast. This suggests slightly higher odds for the incidence of these outcomes among rural patients diagnosed with breast cancer.

Among patients with lung cancer, there was a similar disparity in clinical trial availability. For rural patients with lung cancer, 84 (10.5%) of 798 patients had an available clinical trial. For urban patients with lung cancer, 140 (43%) of 325 patients had an available clinical trial. The residence category resulted in a Cohen *d* of 0.8, which would mean that urban patients with lung cancer were 4.268 times more likely to have an available clinical trial. HLRUC had a small effect on the incidence of lung histology categories including adenocarcinoma, bronchoalveolar, small-cell carcinoma, and mesothelioma. HLRUC did not influence the lung histology category of squamous cell carcinoma. HLRUC had a small effect on incidence of the T1 stage of lung cancer (Cohen *d*=0.2) but had no effect on the incidence of other stages. HLRUC had no effect on nodal status (Cohen *d*=0.1), and a small effect on metastatic status (Cohen *d*=0.2). HLRUC had a medium effect on recurrent status of patients with lung cancer (Cohen *d*=0.6), suggesting a higher odds of recurrent lung cancer among rural patients.

Discussion

Key Findings

Our results suggest that clinical trial availability was greater for urban patients with breast cancer and lung cancer than it was for their rural counterparts. It stands to reason that the benefit of expanding clinical trial availability to rural patients could be significant for an already underserved population. Since the screening was a part of the data gathering process, the effect size could also potentially be due to fewer study options that are available at the rural sites. Stringent eligibility criteria are a long-standing barrier in cancer trial participation, and there have been recent initiatives to reevaluate and broaden clinical trial availability [15,16]. Broadening the criteria has multiple benefits such as improved clinical trial participation, reflecting larger patient population and increasing patient access to new investigational treatment [17]. Even after initial prescreening, the participants might have to undergo a set of labs before they are officially enrolled into the clinical trial. Costs for these additional labs or exams might not be covered by the clinical trial sponsor and might discourage participants from even entertaining the idea of participation into these trials [18]. Subsequent studies should consider barriers to clinical trial participation in the context of cancer stage as well as current factors. In cases where the participants' diagnosis is in an advanced stage, they have very fewer clinical trial opportunities because of fewer advanced stage trials and the aggressive nature of the disease [19]. The time-sensitive nature of advanced stage cancer incentivizes physicians to begin treatment as quickly as possible instead of searching for potential clinical trials. When there are additional barriers complicating clinical trial participation, this could make clinical trials particularly unavailable for patients in an advanced cancer stage.

Apart from the clinical trial availability metric, our keen focus was to assess if patients who seek care in rural areas might differ in care, which could potentially lead to malignancy of cancer or a diagnosis of a late stage. Our analysis indicated that the prevalence of certain cancer features was similar between populations seeking care at rural and urban centers. However, the limited sample size of patients at rural locations could affect the interpretation of these results. More data from rural populations, as well as the inclusion of additional factors in the screening process, will be required for future analysis.

Recent studies suggest that involving primary care physicians in the conversation of clinical trial participation can encourage rural patients to see cancer trials as a treatment option [20]. For rural participants who are diagnosed with cancer for the first time, they may lack the experience and information to decide what treatment options suit them. This can exacerbate the already present barriers to clinical trial participation for these patients. If information on clinical trial options is provided to them by a primary care physician or other familiar health care worker, they may be more receptive to alternate treatment options such as clinical trial participation [21]. In this way, some of the individual and personal barriers to clinical trial participation can be alleviated.

Multimedia Appendix 2 illustrates some of the common reasons why participants were not able to find an appropriate clinical trial that suits their profile. Additionally, if they were qualified for study participation and decided not to participate, those reasons have been documented as well. Among both the breast and the lung cancer group, the major screening failure reason has been the performance status or the ECOG (Eastern Cooperative Oncology Group) status. The ECOG status is a frequently used measure in clinical trial planning, which details a patient's ability to care for themselves, as well as their mobility and activity levels. Typically, most trials under their inclusion criteria look for participants who have a lower performance

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status; a higher performance status would mean they are limited self-care or need additional support [22].

As mentioned previously, multiple disease trials were considered to be available trials for patients with lung cancer and those with breast cancer. While the lack of specificity in these trials allows for greater accessibility, the broadness of their typical premise means the potential benefits of participation are limited.

Some of the common reasons why the patient decided not to participate includes "time concern," "travel concern," "insurance denial," "study logistics," "language barrier," "social," and "physician didn't offer." One of the low hanging fruits that can be easily addressed from the above barriers is to educate the physicians at these sites and provide them with a comprehensive list of studies that suits their patient's profile. For this very reason, KUCC has developed a mobile app also known as "Clinical Trial Finder App" that can be used by any physician to easily screen or refer a patient while the patient is in the clinic with them [23,24].

Limitations

Due to the data limitation, we are unable to assess if the screening rate varies by site or based on race or ethnicity. As a future project, our team proposes to find ways to collaborate with these sites to gain additional demographics and clinical information to dive deeper into understanding the various trends. Another major limitation of the study was that hospital location was used as a surrogate for patient residence. In future studies, it would be beneficial to gather data on actual patient residence in order to determine urban or rural residence categories. The screening estimates might be on the lower end, as some of the screened patients who did not follow the standard screening procedures could have been excluded from the data capture system.

Conclusion

Even in this day and age, we continue to observe barriers that discourage participants from participating in clinical trials. Additionally, the health care availability gap between rural and urban participants is widening, which limits the generalizability of clinical trials for rural participants. Technological, therapeutic, and medical practice advances have had very little impact on reducing these barriers. A few of the notable barriers include lack of personnel to screen participants, lack of technology, commuting issues, and differences among the population characteristics. We as a cancer center strive to continue educating our clinical teams at the rural sites about the potential referral opportunities. Future policy makers must consider more targeted programs that facilitate the participation of rural patients. This approach must be multifaceted, involving earning the trust of rural patients, providing resource to facilitate clinical trial participation, disseminating the right information, and continuing to engage and adapt to the dynamic rural environment. Additional support must be provided to encourage clinical trial participation through resources such as transportation, childcare, and tax credits, among others.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Survey template.
[PDF File (Adobe PDF File), 56 KB - cancer_v8i2e33240_app1.pdf]

Multimedia Appendix 2
Screen failure reason and qualified participants reason to decline trial participation.
[DOCX File , 17 KB - cancer_v8i2e33240_app2.docx]

Multimedia Appendix 3
Comparison of rural versus urban participants based on the participants' screening characteristics.
[DOCX File , 40 KB - cancer_v8i2e33240_app3.docx]

References

1. Charlton M, Schlichting J, Chioreso C, Ward M, Vikas P. Challenges of rural cancer care in the United States. Oncology (Williston Park) 2015 Sep;29(9):633-640 [FREE Full text] [Medline: 26384798]
2. Spleen AM, Lengerich EJ, Camacho FT, Vanderpool RC. Health care avoidance among rural populations: results from a nationally representative survey. J Rural Health 2014 Jun 24;30(1):79-88 [FREE Full text] [doi: 10.1111/jrh.12032] [Medline: 24383487]
3. Prentice JC, Pizer SD. Delayed access to health care and mortality. Health Serv Res 2007 Apr;42(2):644-662 [FREE Full text] [doi: 10.1111/j.1475-6773.2006.00626.x] [Medline: 17362211]

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4. Damalas C, Koutroubas S. Farmers' exposure to pesticides: toxicity types and ways of prevention. Toxics 2016 Jan 08;4(1):1 [FREE Full text] [doi: 10.3390/toxics4010001] [Medline: 29051407]
5. Damroth K, Damroth R, Chaudhary A, Erickson A, Heneghan L, Hellenthal N, et al. Farm injuries: animal most common, machinery most lethal: an NTDB study. The American Surgeon 2020 Jun 17;85(7):752-756. [doi: 10.1177/000313481908500737]
6. Rathinam X, Kota R, Thiyagar N. Farmers and formulations--rural health perspective. Med J Malaysia 2005 Mar;60(1):118-24; quiz 125 [FREE Full text] [Medline: 16250298]
7. Diaby V, Tawk R, Sanogo V, Xiao H, Montero AJ. A review of systematic reviews of the cost-effectiveness of hormone therapy, chemotherapy, and targeted therapy for breast cancer. Breast Cancer Res Treat 2015 May;151(1):27-40 [FREE Full text] [doi: 10.1007/s10549-015-3383-6] [Medline: 25893588]
8. Paul C, Carey M, Anderson A, Mackenzie L, Sanson-Fisher R, Courtney R, et al. Cancer patients' concerns regarding access to cancer care: perceived impact of waiting times along the diagnosis and treatment journey. Eur J Cancer Care (Engl) 2012 May;21(3):321-329 [FREE Full text] [doi: 10.1111/j.1365-2354.2011.01311.x] [Medline: 22111696]
9. Zafar S, Peppercorn JM, Schrag D, Taylor DH, Goetzinger AM, Zhong X, et al. The financial toxicity of cancer treatment: a pilot study assessing out-of-pocket expenses and the insured cancer patient's experience. Oncologist 2013;18(4):381-390 [FREE Full text] [doi: 10.1634/theoncologist.2012-0279] [Medline: 23442307]
10. Gong G, Phillips SG, Hudson C, Curti D, Philips BU. Higher US rural mortality rates linked to socioeconomic status, physician shortages, and lack of health insurance. Health Aff (Millwood) 2019 Dec 01;38(12):2003-2010. [doi: 10.1377/hlthaff.2019.00722] [Medline: 31794316]
11. Harris PA, Taylor R, Minor BL, Elliott V, Fernandez M, O'Neal L, REDCap Consortium. The REDCap consortium: Building an international community of software platform partners. J Biomed Inform 2019 Jul;95:103208 [FREE Full text] [doi: 10.1016/j.jbi.2019.103208] [Medline: 31078660]
12. Sullivan GM, Feinn R. Using effect size-or why the P value is not enough. J Grad Med Educ 2012 Sep;4(3):279-282 [FREE Full text] [doi: 10.4300/JGME-D-12-00156.1] [Medline: 23997866]
13. Borenstein M. Introduction to Meta-Analysis. Chichester, UK: Wiley; 2009.
14. McLeod S. What does effect size tell you? Simply Psychology. 2019. URL: https://www.simplypsychology.org/effect-size.html#:~:text=What%20is%20effect%20size%3F,the%20relationship%20between%20two%20variables [accessed 2022-04-05]
15. Kim ES, Bernstein D, Hilsenbeck SG, Chung CH, Dicker AP, Ersek JL, et al. Modernizing eligibility criteria for molecularly driven trials. JCO 2015 Sep 01;33(25):2815-2820. [doi: 10.1200/jco.2015.62.1854]
16. George SL. Reducing patient eligibility criteria in cancer clinical trials. JCO 1996 Apr;14(4):1364-1370. [doi: 10.1200/jco.1996.14.4.1364]
17. Jin S, Pazdur R, Sridhara R. Re-evaluating eligibility criteria for oncology clinical trials: analysis of investigational new drug applications in 2015. JCO 2017 Nov 20;35(33):3745-3752. [doi: 10.1200/jco.2017.73.4186]
18. Nipp RD, Hong K, Paskett ED. Overcoming barriers to clinical trial enrollment. American Society of Clinical Oncology Educational Book 2019 May(39):105-114. [doi: 10.1200/edbk_243729]
19. Phases of Clinical Trials. National Cancer Institute. URL: https://www.cancer.gov/about-cancer/treatment/clinical-trials/what-are-trials/phases [accessed 2022-04-05]
20. Virani S, Burke L, Remick SC, Abraham J. Barriers to recruitment of rural patients in cancer clinical trials. JOP 2011 May;7(3):172-177. [doi: 10.1200/jop.2010.000158]
21. Lawrence RA, McLoone JK, Wakefield CE, Cohn RJ. Primary care physicians' perspectives of their role in ccncer care: a systematic review. J Gen Intern Med 2016 Oct 24;31(10):1222-1236 [FREE Full text] [doi: 10.1007/s11606-016-3746-7] [Medline: 27220499]
22. Sok M, Zavrl M, Greif B, Srpčič M. Objective assessment of WHO/ECOG performance status. Support Care Cancer 2019 Oct 5;27(10):3793-3798. [doi: 10.1007/s00520-018-4597-z] [Medline: 30721369]
23. Cancer Center Launches Clinical Trial Finder App. The University of Kansas Cancer Center. 2020 Dec 04. URL: https://www.kucancercenter.org/news-room/news/2020/12/cancer-center-launches-clinical-trial-finder-app?reloadts=1626134088690 [accessed 2022-04-05]
24. Mudaranthakam DP, Alsup AM, Murakonda V, Lin T, Thompson J, Gajewski B, et al. Accelerating cancer patient recruitment through a mobile application (clinical trial finder). Cancer Inform 2022 Jan 25;21:11769351211073114 [FREE Full text] [doi: 10.1177/11769351211073114] [Medline: 35095270]

Abbreviations

ECOG: Eastern Cooperative Oncology Group
ER/PR: estrogen receptor/progesterone receptor
HER2: human epidermal growth factor receptor 2
HLRUC: Hospital Location Rural-Urban Category
KUCC: University of Kansas Cancer Center
MCA: Masonic Cancer Alliance

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NCTN: National Clinical Trials Network
REDCap: Research Electronic Data Capture
RUCC: Rural Urban Continuum Codes

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Original Paper

Patient and Provider Perspectives on Enrollment in Precision Oncology Research: Qualitative Ethical Analysis

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Abstract

Background: The genomic frontier continues to revolutionize the practice of oncology. Advances in cancer biology from tumorigenesis to treatment resistance are driven by the molecular underpinnings of malignancy. The framing of precision oncology as both a clinical and research tool is constantly evolving and directly influences conversations between oncologists and their patients. Prior research has shown that patient-participants often have unmet or unrealistic expectations regarding the clinical utility of oncology research and genomic sequencing. This indicates the need for more in-depth investigation of how and why patients choose to participate in such research.

Objective: This study presents a qualitative ethical analysis to better understand patient and provider perspectives on enrollment in precision oncology research.

Methods: Paired semistructured interviews were conducted with patient-participants enrolled in a prospective head and neck precision oncology research platform, along with their oncology providers, at a National Cancer Institute–designated academic cancer center.

Results: There were three major themes that emerged from the analysis. (1) There are distinct and unique challenges with informed consent to precision medicine, chiefly involving the ability of both patient-participants and providers to effectively understand the science underlying the research. (2) The unique benefits of precision medicine enrollment are of paramount importance to patients considering enrollment. (3) Patient-participants have little concern for the risks of research enrollment, particularly in the context of a low-burden protocol.

Conclusions: Patient-participants and their providers offer complementary and nuanced perspectives on their motivation to engage in precision oncology research. This reflects both the inherent promise and enthusiasm within the field, as well as the limitations and challenges of ensuring that both patient-participants and clinicians understand the complexities of the science involved.

(JMIR Cancer 2022;8(2):e35033) doi:10.2196/35033

KEYWORDS

oncology research platform; precision oncology; head and neck oncology; academic cancer center; semistructured interview; patient-provider dyads; oncology; interview; ethical analysis; patient; provider

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Introduction

The genomic frontier continues to revolutionize the practice of oncology. Advances in cancer biology from tumorigenesis to treatment resistance are driven by the molecular underpinnings of malignancy, and the framing of precision oncology as both a clinical and research tool is constantly evolving. Introspection is warranted to examine how conversations between oncologists and their patients may be affected.

Studies have assessed the motivations of research participants enrolling in genome sequencing research, such as the HealthSeq [1] and ClinSeq [2] projects, and reflected the tension between the risk and potential reward that these platforms offer. Additional studies have explored the perspectives of patient-participants enrolled in precision oncology studies, many of whom reported unfilled expectations [3]. These patient-participants also reported a higher level of perceived utility of the study at the time of enrollment than after enrollment. Specifically, their expectations that participation in a genome sequencing study would affect future health and medication decisions were not frequently met [4].

These studies all indicate the need for more nuanced questions and perspectives. As one study states, "Further evaluation of whether and how family members and close contacts were involved in the patient's decision to pursue or decline sequencing, and any discussion with family members and friends preceding sequencing, may help to elucidate how these dynamics affect decision-making" [5]. A key component when asking these questions is to address the unique concerns in this field of research. For example, precision oncology has a more established clinical utility in certain cancers than others. Moreover, the role of germline mutations is de-emphasized in many cancers, which may confuse how patients consider the issues of heritability and familial risk. In addition, cancer stage, prognosis, and recurrence will all invariably impact how patients, many of whom are affected by cancers considered to be terminal, will consider the prospect of using "cutting edge science" to save their lives. This is particularly true when most precision oncology platforms to date have had, at best, modest impact on survival outcomes.

Our aim is to better understand patient and provider perspectives related to the decision to enroll in a low-burden precision oncology protocol. In this study, we employed a qualitative embedded ethics protocol involving semistructured interviews of both adult patients with head and neck cancer enrolled in precision medicine research and their clinicians. This study was nested within a prospective precision oncology study at one institution, a National Cancer Institute–designated academic cancer center. Two other articles have been derived from the interview data set, one focused on patient and provider perspectives on enrolling in head and neck cancer research [6] and the other on commercialization of cancer genomic data [7]. Herein, we focus specifically on patient and provider perspectives on enrollment in precision oncology itself.

Methods

Overarching Study Design

This inquiry ran alongside the overarching study, "Developing Precision Medicine Protocols for Head and Neck Cancer MiOtoSeq (Michigan Otolaryngology and Translational Oncology Sequencing Center)," an institutional review board–approved precision medicine study in the Michigan Medicine Department of Otolaryngology-Head and Neck Surgery [8]. Patient-participants enrolled in MiOtoSeq were adults with biopsy-confirmed cancer of the head and neck who were counseled and consented to participate in upfront, targeted genomic research sequencing of their tumors and germline tissues. In conjunction with the MiOtoSeq study, we embedded this qualitative ethics protocol to better understand and compare perspectives on their involvement in precision oncology research. Specifically, we were interested in the motivations of patients and providers to enroll in the research.

Interviews

A subset of the MiOtoSeq patient-participants were purposively sampled for interviews based on demographic and clinical factors to ensure a diverse variety of experiences. All patients participated in a 1-hour interview conducted by researchers trained in semistructured interviewing techniques [9]. All interviews were conducted in 2018.

The interviews were audiorecorded, transcribed by a third-party service, and deidentified. All interview files were stored on an institutionally supported secure storage platform. In these interviews, participating patients and clinicians were asked a variety of questions related to the goals of precision medicine research, the risks and benefits as they perceived them, and their experience with the MiOtoSeq enrollment and consent process.

This analysis includes responses from a total of 20 interviews from 10 patients and 8 clinicians. In the cases of 2 physicians, each had treated 2 patients and we conducted 2 separate interviews with the physicians to focus on each patient. Patient-participants were recruited until thematic saturation was achieved [10] and then their physician was recruited for comparison purposes. One of the clinicians is an author of this analysis, and his interview responses were excluded from quotation. Once the interviews were underway, team members (KSB and MK) iteratively developed the codebook [9]. Transcripts were inductively and deductively double-coded (by MK and CK) and discordances were reconciled (KSB). Please refer to our previous publication for more detail regarding these methods [6]. For the purposes of this article, gender pronouns for clinicians and patient-participants were randomly selected for additional privacy.

Ethics Approval and Consent to Participate

Approval was obtained from the ethics committee of the University of Michigan (HUM00085888). The procedures used in this study adhere to the tenets of the Declaration of Helsinki. Informed consent was obtained from all individual participants included in the study.

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Results

Theme 1: Challenges With Informed Consent to Precision Medicine

Many patient-participants stated that their background knowledge of genetics came from media or television. For example, several patient-participants cited the movie Jurassic Park, coverage of "test tube babies," or the Discovery Channel as their main source of genetic information. As one patient-participant put it, their awareness began "when Francis (or was it Crick?) first started the Human Genome Project" (Patient [P] 05). As one clinician aptly joked, "I think most patients don't understand [genetics], because I barely do in a lot of ways" (Clinician [C] 10).

Many clinicians were concerned that the patients' lack of understanding of genetics, and research in general, might lead to conflations between clinical care and enrollment in a precision medicine protocol. For patients without a strong grasp of the basics of genetics, the nuanced potential benefit of precision oncology—where clinical care and research may be blurred—was complex to understand. For example, the doctor of one of the patient-participants who said he had learned about genetics from Jurassic Park admitted that although he explained to the patient that this was not a therapeutic trial, "…maybe he didn't get that. I don't know [laughs]" (C02). Another doctor added, "I don't know if [my patient] actually understood, because patients express understanding of almost *everything* I say…" (CO3). Other clinicians seemed reassured that patients at least understood that the research would not change their clinical care or help them directly. However, despite one clinician stating that he thinks "the personal reward for any individual patient is very low" (C11), his patient stated that her expectation from participating in the study was that it "might save my life" (P11).

Other clinicians emphasized the inherent vulnerability of patients in a clinical oncology visit and how that might compound confusion or inadvertent exploitation. Of note, although the clinicians were MiOtoseq coinvestigators, consent for enrollment into the study was obtained by a dedicated study coordinator. One clinician described her realization that "most patients don't understand genetic sequencing and simply sign something because we give [it to] them in a very vulnerable situation" (C07). She went on to describe asking patients to enroll in research during a clinical care visit as "really not an informed consent process." Another clinician agreed that his patients were "more worried about not passing away from [the cancer] as opposed to having their sequencing done" (C10). As a patient affirmed, "In the whirlwind of things…I really didn't think about [enrolling in research] too much…I just consented" (P11). However, a different patient-participant described the benefit of learning about precision medicine in the clinical context: "Wow, you know, I'd like to know more about myself…and my genetic makeup and kind of what went wrong…" (P08).

Theme 2: Unique Benefits of Precision Medicine Enrollment

Many patient-participants were excited about the promise of precision medicine research specifically, referring to current cancer treatment options as "archaic." They described precision medicine as "the future," and several expressed hope for finding a cure for cancer.

> *I think that we have no idea of what we're doing right now. We're dabbling a foot in the pool, but once we get all the way into that pool, I think we're going to have some serious answers.* [P07]

Patient-participants were less clear about potential benefits to themselves in enrolling in precision medicine research. Although the majority noted that they realized the research was not primarily for their own benefit, many held out hope for the "teeny, teeny, teeny, teeny possibility [that] it could help me" (P07). Several patient-participants specifically described hoping that the research could help them if their cancer came back in the future. Clinicians appeared generally aware of their patients' aspirations to have their cancer cured, which one described as a "common coping strategy" (C07). Although, as one clinician said, he explains to patients that the research could not possibly affect their clinical course, "when it takes 14 months to get the sequencing back!" (C02).

More uniquely related to a precision medicine protocol than other types of clinical research, many patient-participants also described that research participation might help their blood relatives in the future and protect them from "what is inside me that came from my ancestors…" (P04). Almost all spoke about protecting their family and children through research enrollment, with one patient-participant stating that they "would do anything to make sure they [their children] don't go through this" (P08). Another described this altruistic legacy as "a way for me watching out for my family later on when I'm gone" (P07). Another added: "I would hope that this could help, you know, my family first and then out into other people" (P09). Notably, some of these themes might relate to other novel cancer research platforms and are not necessarily specific to precision oncology itself.

Theme 3: Risks of Research Enrollment

Although patient-participants overwhelmingly spoke of hope and the potential benefits of precision medicine research, the majority of those who spoke of risks only brought them up to dismiss them. Many discussed how enrolling in a precision medicine protocol had no additional risk or burden to themselves and did not involve much effort or downside: "If there's something that really doesn't cause you any…discomfort, really takes up very little of your time, if down the road 30 or 40 years from now, that could really affect peoples' lives, you know, why wouldn't you want to do that?" (P09). One patient-participant also discussed the convenience of being able to complete everything in the same visit; he said that if the trial required extra visits, he probably would not have enrolled.

If patient-participants or their clinicians mentioned specific risks that concerned them, the most common was finding out information that the patients might not want to know. One

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patient-participant described these potential secondary findings as both "a shield and a sword" (P05). She added, "I can't see that ignorance could possibly benefit you…other than a bit of bliss I suppose." Another patient-participant dismissed the risk of finding out unwanted information this way: "Life has twists and turns. We don't have a clue what's going to happen, but are we going to hold back positive for the thought of a negative?" (P07). Another concluded that he was already 70 years old, so he did not need to worry about genetic discrimination or being fired from his job. This common dismissal of the risks of research enrollment might relate to the general lack of understanding of genetics as highlighted in Theme 1.

Interestingly, the most common risk described by clinicians was not related to stumbling upon an affirmative genetic finding that patients might not want to know about, but quite the opposite—that of not understanding what an abnormal variant meant for their patients in the first place. This relates to an altogether different category of risk related to transgressions of professional duty. One clinician described precision medicine research as having to be "comfortable with that uncertainty" (C08). Another clinician bemoaned that scientific advancement regrettably may lead to recognition of missed diagnoses, if they "look back in 5 years, and you didn't even know the germline mutation that was bad was a bad one then, right?...Even if you didn't know it was bad, should you have told them that something could be there?" (C10).

Discussion

This analysis uniquely matches the perspectives of patient-participants with their corresponding clinicians, offering insight into the influence of the doctor-patient relationship on precision oncology research enrollment and satisfaction. Our findings highlighted nuanced challenges with informed consent to precision medicine, uniquely perceived benefits of precision oncology, and relatively discounted risks related to genomic discovery.

One key component of our findings relates to ensuring that patients have the capacity to fully understand the research to which they are being asked to consent. Specifically, although many patient-participants stated that they understood the basics of the science, the background they cited was limited to popular media and fictionalized interpretations, indicating low true genomic health literacy (defined as "the capacity to obtain, process, understand, and use genomic information for health-related decision making" [11]). The relative lack of genomic health literacy among patient-participants raises concerns for the maintenance of their underlying autonomy throughout the enrollment process and beyond.

A component of this genomic health literacy important to the process of informed consent is understanding the limitations of genome sequencing, a competency that has been associated with high levels of education [12]. For example, there is still a lack of common understanding of the term "actionable," and there are differences in understanding "between patients and clinicians, with patients expecting more personal benefits to come from actionable results" [13]. Actionability generally relates to recognition of a germline mutation with implications for relatives, as well as identifying clinically prognostic biomarkers and biological targets to be used in the patient's treatment. In head and neck precision oncology both remain rather rare; thus, there are more nebulous outcomes than direct benefits of enrollment at this stage.

Of the patients that do experience decisional conflict when enrolling in genomic sequencing, this phenomenon is associated with lower health literacy and a lack of experience with prior genetic testing [14]. Unfortunately, disparities in baseline genomic knowledge often persist longitudinally, despite the offering of educational materials and genetic counseling opportunities [15]. In this study, clinicians noted several times that the inherent vulnerability of their patients to both structural and individual coercion, or at least undue influence, to enroll in research was tied closely to clinical caregiving. Past research has demonstrated that framing potential benefits as aspirational, direct, and collateral can help clarify the otherwise complex relationship between research and clinical care in this space [16,17]. Our findings are consistent with these, confirming the need for better strategies to educate and counsel patients and participants alike.

The benefits of obtaining high genomic health literacy are that greater baseline knowledge of genomics has been associated with lower levels of distress related to participating in a genome sequencing study and higher levels of understanding of the study. Ensuring that both clinicians and patient-participants understand the risks and benefits of research participation can serve to clarify decisions and better enable prospective participants to honor their autonomy.

Although informed consent has been shown to improve knowledge about both the limitations and benefits of genome sequencing in a variety of settings [4,12], many oncologists have little familiarity with newer genetic technologies and have a low level of genomic literacy themselves, as several of our clinician interviewees admitted [18]. Clinicians without backgrounds in genetics also report difficulty understanding and communicating genomic terminology and the volume of complex information yielded from genomic sequencing studies [19]. If clinicians have a limited understanding of genetic sequencing studies, they may be uncomfortable communicating the goals or results of these studies to their patients. This could lead to lower levels of physician satisfaction and less participation in future studies [18]. This tension was noted by the clinicians interviewed herein as well, despite the fact that they are all engaged in academic research in this field.

The theme of altruism is also prominent in studies exploring subjects' motivations to engage in genetic research [20]. In the broadest lens, this reflects contributing to the generation of generalizable knowledge to help future patients—the cornerstone of clinical research itself. However, this concept is far more nuanced when considering the distinctions between germline and somatic mutations [21]. In this study, in which somatic mutations are far more common than germline mutations in a head and neck cancer cohort, the likelihood of family members benefitting directly from the research is lower. An intriguing ethical analysis reconceptualizes participation in precision

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medicine "as inextricable from social relationships and their ongoing ethical obligations. Going beyond altruism, reframing biospecimen and data collection in terms of socially regulated gift-giving recovers questions of responsibility and care…and underscores ethical commitments to reciprocity and responsibility" [22].

In summary, patient-participants and their providers offered complementary and nuanced perspectives on their motivation to engage in precision head and neck oncology research. It is important to note that the findings reported here represent the views of a specific group of clinicians and their patient-participants. Further research is warranted to generalize their experiences. Nevertheless, this study reflects the participants' excitement to be a part of cutting-edge research, as well as their inherent altruistic tendencies. This enthusiasm should still be tempered with realistic expectations, and better systems should be created to educate cancer patients turned participants about the precision medicine.

Acknowledgments

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Authors' Contributions

AGS, JCB, and PLS substantially contributed to conception and design. MK and CB substantially contributed to the acquisition of data. All authors substantially contributed to the analysis or interpretation of data. KSB and AGS drafted the article. All authors revised the article critically for important intellectual content and granted final approval of the version to be published.

Conflicts of Interest

None declared.

References

1. Sanderson SC, Linderman MD, Suckiel SA, Diaz GA, Zinberg RE, Ferryman K, et al. Motivations, concerns and preferences of personal genome sequencing research participants: baseline findings from the HealthSeq project. Eur J Hum Genet 2016 Jan;24(1):14-20 [FREE Full text] [doi: 10.1038/ejhg.2015.118] [Medline: 26036856]
2. Facio FM, Brooks S, Loewenstein J, Green S, Biesecker LG, Biesecker BB. Motivators for participation in a whole-genome sequencing study: implications for translational genomics research. Eur J Hum Genet 2011 Dec;19(12):1213-1217 [FREE Full text] [doi: 10.1038/ejhg.2011.123] [Medline: 21731059]
3. Roberts JS, Gornick MC, Le LQ, Bartnik NJ, Zikmund-Fisher BJ, Chinnaiyan AM, MI-ONCOSEQ Study team. Next-generation sequencing in precision oncology: patient understanding and expectations. Cancer Med 2019 Jan;8(1):227-237 [FREE Full text] [doi: 10.1002/cam4.1947] [Medline: 30600607]
4. Roberts JS, Robinson JO, Diamond PM, Bharadwaj A, Christensen KD, Lee KB, MedSeq Project team. Patient understanding of, satisfaction with, and perceived utility of whole-genome sequencing: findings from the MedSeq Project. Genet Med 2018 Sep;20(9):1069-1076 [FREE Full text] [doi: 10.1038/gim.2017.223] [Medline: 29300387]
5. Hull LE, Vassy JL. Toward greater understanding of patient decision-making around genome sequencing. Per Med 2018 Jan;15(1):57-66. [doi: 10.2217/pme-2017-0037] [Medline: 29714114]
6. Shuman AG, Gornick MC, Brummel C, Kent M, Spector-Bagdady K, Biddle E, et al. Patient and provider perspectives regarding enrollment in head and neck cancer research. Otolaryngol Head Neck Surg 2020 Jan;162(1):73-78 [FREE Full text] [doi: 10.1177/0194599819889976] [Medline: 31818193]
7. Spector-Bagdady K, Krenz CD, Brummel C, Brenner JC, Bradford CR, Shuman AG. "My research is their business, but I'm not their business": patient and clinician perspectives on commercialization of precision oncology data. Oncologist 2020 Jul;25(7):620-626 [FREE Full text] [doi: 10.1634/theoncologist.2019-0863] [Medline: 32167617]
8. Precision medicine for head and neck cancer. Michigan Medicine, University of Michigan: Otolaryngology-Head and Neck Surgery. 2021. URL: https://medicine.umich.edu/dept/otolaryngology/research/head-neck-cancer-research/precision-medicine-head-neck-cancer [accessed 2022-04-19]
9. Giacomini MK, Cook DJ. Users' guides to the medical literature: XXIII. Qualitative research in health care A. Are the results of the study valid? Evidence-Based Medicine Working Group. JAMA 2000 Jul 19;284(3):357-362. [doi: 10.1001/jama.284.3.357] [Medline: 10891968]
10. Crabtree BF, Miller WL, editors. Doing Qualitative Research. 2nd ed. Thousand Oaks, CA: Sage; 1999.
11. Hurle B, Citrin T, Jenkins JF, Kaphingst KA, Lamb N, Roseman JE, et al. What does it mean to be genomically literate?: National Human Genome Research Institute meeting report. Genet Med 2013 Aug;15(8):658-663 [FREE Full text] [doi: 10.1038/gim.2013.14] [Medline: 23448722]

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12. Kaphingst KA, Facio FM, Cheng M, Brooks S, Eidem H, Linn A, et al. Effects of informed consent for individual genome sequencing on relevant knowledge. Clin Genet 2012 Nov;82(5):408-415 [FREE Full text] [doi: 10.1111/j.1399-0004.2012.01909.x] [Medline: 22694298]
13. Gornick MC, Ryan KA, Scherer AM, Scott Roberts J, De Vries RG, Uhlmann WR. Interpretations of the term "actionable" when discussing genetic test results: what you mean is not what I heard. J Genet Couns 2019 Apr;28(2):334-342. [doi: 10.1007/s10897-018-0289-6] [Medline: 30964581]
14. Pacyna JE, Radecki Breitkopf C, Jenkins SM, Sutton EJ, Horrow C, Kullo IJ, et al. Should pretest genetic counselling be required for patients pursuing genomic sequencing? results from a survey of participants in a large genomic implementation study. J Med Genet 2019 May;56(5):317-324 [FREE Full text] [doi: 10.1136/jmedgenet-2018-105577] [Medline: 30580287]
15. Rini C, Henderson GE, Evans JP, Berg JS, Foreman AKM, Griesemer I, et al. Genomic knowledge in the context of diagnostic exome sequencing: changes over time, persistent subgroup differences, and associations with psychological sequencing outcomes. Genet Med 2020 Jan;22(1):60-68 [FREE Full text] [doi: 10.1038/s41436-019-0600-4] [Medline: 31312045]
16. Chae BJ, Lee J, Lee SK, Shin H, Jung S, Lee JW, et al. Unmet needs and related factors of Korean breast cancer survivors: a multicenter, cross-sectional study. BMC Cancer 2019 Aug 27;19(1):839 [FREE Full text] [doi: 10.1186/s12885-019-6064-8] [Medline: 31455311]
17. Strzebonska K, Waligora M. Umbrella and basket trials in oncology: ethical challenges. BMC Med Ethics 2019 Aug 23;20(1):58 [FREE Full text] [doi: 10.1186/s12910-019-0395-5] [Medline: 31443704]
18. Chow-White P, Ha D, Laskin J. Knowledge, attitudes, and values among physicians working with clinical genomics: a survey of medical oncologists. Hum Resour Health 2017 Jun 27;15(1):42 [FREE Full text] [doi: 10.1186/s12960-017-0218-z] [Medline: 28655303]
19. Arora NS, Davis JK, Kirby C, McGuire AL, Green RC, Blumenthal-Barby JS, MedSeq Project. Communication challenges for nongeneticist physicians relaying clinical genomic results. Per Med 2016 Sep;14(5):423-431 [FREE Full text] [doi: 10.2217/pme-2017-0008] [Medline: 29181085]
20. Scherr CL, Aufox S, Ross AA, Ramesh S, Wicklund CA, Smith M. What people want to know about their genes: a critical review of the literature on large-scale genome sequencing studies. Healthcare (Basel) 2018 Aug 08;6(3):96 [FREE Full text] [doi: 10.3390/healthcare6030096] [Medline: 30096823]
21. Garg R, Vogelgesang J, Kelly K. Impact of genetic counseling and testing on altruistic motivations to test for BRCA1/2: a longitudinal study. J Genet Couns 2016 Jun;25(3):572-582 [FREE Full text] [doi: 10.1007/s10897-015-9911-z] [Medline: 26578231]
22. Lee SS. Obligations of the "gift": reciprocity and responsibility in precision medicine. Am J Bioeth 2021 Apr;21(4):57-66 [FREE Full text] [doi: 10.1080/15265161.2020.1851813] [Medline: 33325811]

Abbreviations

C: clinician
MiOtoSeq: Michigan Otolaryngology and Translational Oncology Sequencing Center
P: patient

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Original Paper

The Cancer Research Database (CRDB): Integrated Platform to Gain Statistical Insight Into the Correlation Between Cancer and COVID-19

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Abstract

Background: The advancement of cancer research has been facilitated through freely available cancer literature, databases, and tools. The age of genomics and big data has given rise to the need for cooperation and data sharing in order to make efficient use of this new information in the COVID-19 pandemic. Although there are many databases for cancer research, their access is not easy owing to different ways of processing and managing the data. There is an absence of a unified platform to manage all of them in a transparent and more comprehensible way.

Objective: In this study, an improved integrated cancer research database and platform is provided to facilitate a deeper statistical insight into the correlation between cancer and the COVID-19 pandemic, unifying the collection of almost all previous published cancer databases and defining a model web database for cancer research, and scoring databases on the basis of the variety types of cancer, sample size, completeness of omics results, and user interface.

Methods: Databases examined and integrated include the Data Portal database, Genomic database, Proteomic database, Expression database, Gene database, and Mutation database; and it is expected that this launch will sort, save, advance the understanding and encourage the use of these resources in the cancer research environment.

Results: To make it easy to search valuable information, 85 cancer databases are provided in the form of a table, and a database of databases named the Cancer Research Database (CRDB) has been built and presented herein. Furthermore, the CRDB has been herein equipped with unique navigation tools in order to be explored by three methods; that is, any single database can be browsed by typing the name in the given search bar, while all categories can be browsed by clicking on the name of the category or image expression icon, thus serving as a facility that could provide all the category databases on a single click.

Conclusions: The computational platform (PHP, HTML, CSS, and MySQL) used to build CRDB for the cancer scientific community can be freely investigated and browsed on the internet and is planned to be updated in a timely manner. In addition, based on the proposed platform, the status and diagnoses statistics of cancer during the COVID-19 pandemic have been thoroughly investigated herein using CRDB, thus providing an easy-to-manage, understandable framework that mines knowledge for future researchers.

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KEYWORDS

cancer database; COVID-19; CRDB; genomics; PHP; CRDB; cancer and COVID-19; cancer statistics; cancer research; health database; research platform

Introduction

Cancer is a category of diseases causing irregular cell growth with the ability to infiltrate or spread to other areas of the body. As of 2019, approximately 18 million new cases are reported per year [1], among which 22% of cancer deaths are caused by tobacco use and 10% are caused by obesity, an unhealthy diet, a lack of physical activities, or excessive alcohol use [2]. In the past 2 or 3 decades, recent data have shown that approximately 5%-10% of cancers are caused by genetic disorders [3]. Patients with cancer seem to exhibit exacerbated conditions and a higher mortality rate when exposed to the virus [4]. The COVID-19 pandemic has spread over the world. As in 18 October 2021, there have been 219 million confirmed cases and 4.55 million deaths worldwide, with the number of cases continuing to rise in 216 countries [5]. Patients with cancer are thought to be particularly prone to SARS-CoV-2 infection and the development of more severe COVID-19 symptoms, which could be related to a systemic immunosuppressive condition caused directly by tumor growth and indirectly by anticancer therapy's side effects [6]. Infection can affect people of various ages, but in most situations, disease severity is linked to age limit and pre-existing disorders that decrease immunity, such as cancer. COVID-19 has been linked to an increased risk of severe sickness and death among patients with cancer, according to several studies [7]. Brunello et al [8] suggested that people with cancer are faced with two challenges that potentially lead to death: one is from getting cancer and the other is COVID-19—the latter resulting from undertreatment or overtreatment conditions. Initial investigations revealed that patients with cancer were more likely to contract the virus and become infected with COVID-19.

Because of the effects of antineoplastic therapy, supportive drugs including steroids, and the immunosuppressive qualities of cancer, people with cancer could be immunocompromised [5]. The advancement of modern genomic technology—such as microarrays, proteomics, transcriptomics, and gene sequencing—and the serious situation resulting from the COVID-19 pandemic have resulted in the generation of a huge amount of data [9,10]; therefore, the first challenge of these multi-omics cancer and COVID-19 data was the design and usage of electronic databases to store and manage the large amount of knowledge [11]. A number of databases have been published in this research area, which have explained the wide-ranging information about cancer research and COVID-19 [10,12-16], such as The Cancer Genome Atlas (TCGA), RespCanDB, cBioPortal, Co-19PDB, and ICGC, these databases have been exploring, analyzing, and visualizing multidisciplinary genomics data. Further, we have presented a comparison table with previously published work, in which we have noticed a considerable growth in the number of databases, and we have provided the list of all the cancer databases and have built a database of the databases named the Cancer Research Database (CRDB), with the improvement highlighted in Table 1. To make it easier for researchers and the scientific community, a well-organized and easily accessible platform is required, where all cancer research data can be accessed with a single click. To that end, we have gathered almost all cancer databases and classified them into six categories based on data types: Data Portal database, Genomic database, Proteomic database, Expression database, Gene database, and Mutation database; this would provide an easy way to search data, and users can directly type the name of the needed databases in the search bar or can click the required category, which will lead them to all the databases with a single click. In addition, we have obtained deep insight into the link between cancer and the COVID-19 pandemic, having explained up and down of cancer, new cases, death ratios, etc, before and during the COVID-19 pandemic.

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Table 1. Comparison of the Cancer Research Database with other published work.

Database	Databases, n	Type	Year	Component	Journal	Reference
Cancer research database	98	Database+list	2022	Cancer	N/A[a]	N/A
Munich Information Center for Protein Sequences	22	List	2011	Different categories	*Nucleic Acids Research*	[17]
No name	6	Database	2018	Aging	*Nucleic Acids Research*	[18]
COVID-19 pandemic database	59	Database+list	2021	COVID-19	*Computer Methods and Programs in Biomedicine Update*	[10]
Swiss Institute of Bioinformatics	12	Database	2016	Different categories	*Nucleic Acids Research*	[19]
Human cancer databases	58	List	2015	Cancer	*Oncology Reports*	[20]
No name	38	List	2014	Hepatology	*Journal of Hepatology*	[21]
LiverAtlas	53	Databases	2013	Liver	*Liver International*	[22]
No name	16	List	2015	Cancer	*Genomics, Proteomics & Bioinformatics*	[3]

[a]N/A: not applicable.

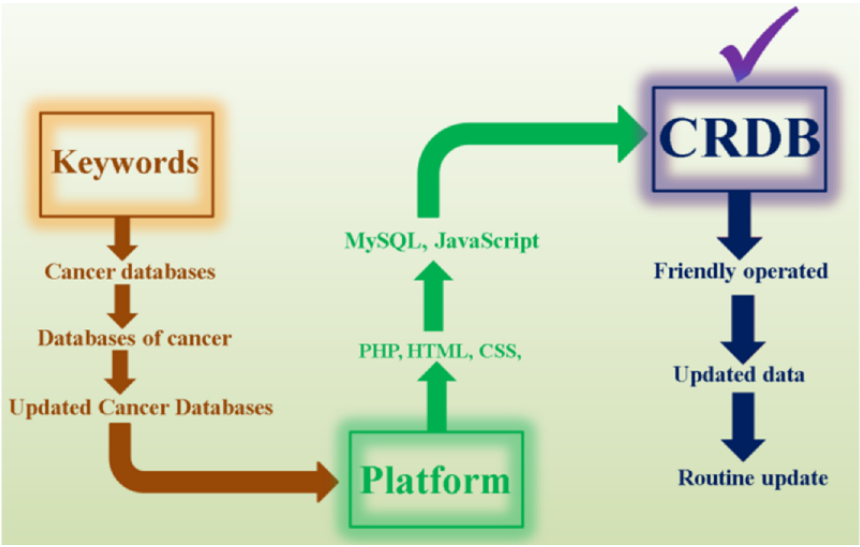
Previously, we have published several articles in well-known journals, such as the database of Phospho-sites in Animals and Fungi [23] in *Scientific Reports*, the Circadian Gene Database [24] in *Nucleic Acids Research*, Co-19PDB [10] in *Computer Methods and Programs in Biomedicine Update*, DataBases relevant to Human Research [25] in *Future Science* and DataBase of Plant Research [26]; we have provided 15 databases to the scientific community during the COVID-19 pandemic, which can be accessed on the internet [27].

Methods

Construction of the CRDB and Content

We integrated the data from multiple different sources including PubMed, Google, Google Scholar, etc. We used various keywords such as "Cancer database," "cancer database list," and "database of cancer" as search terms to retrieve published cancer-related databases with the help of PubMed. To circumvent missing data, we have manually collected the latest cancer databases from *Nucleic Acids Research*, and *Genomics, Proteomics & Bioinformatics*, which are the leading journals on the database issue. We only collected all cancer databases and have removed all nonfunctional links and programming platforms such as PHP, MySQL, HTML, CSS, and JavaScript have been used to construct the CRDB. Figure 1 shows all the procedures of our database. Finally, we provided a compressive cancer research database to the scientific community, which is easy to operate and will be updated over time.

Figure 1. Flowchart and procedure for the collection and integration of cancer databases and the construction of the Cancer Research Database (CRDB).



Database Classification

Several articles have been published in this research area [28-30], each has its their own classification of databases based on its function, application, technological feature, and organism, such as human and mouse [29], Plant [26], Drosophila [31], fungi, COVID-19, etc. According to such published works, we have also classified the cancer databases into six categories:

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Data Portal database, Genomic database, Proteomic database, Expression database, Gene database, and Mutation database—their details are given bellow.

Expression Databases

In cancer expression databases, the expression levels of thousands of genes can be continuously measured under particular experimental environments and conditions resulting from marked advancements in DNA microarray technology. This technology made it possible to understand life at the molecular level, and enables us to generate large-scale gene expression data. It has also been applied in a wide range of applications such as cancer prediction, diagnosis, and drug discovery, which are very important issues for cancer treatment [32]. Some well-known expression databases including BioXpress [33], miRCancer [34], and Gene Expression Database [35] are shown in Figure 2A.

Figure 2. Main pages of some commonly using cancer databases. (A) A screenshot of the Expression Database named GXD, (B) a screenshot of the Data Portal category named CNVs (copy number variations), (C) "IARCTP53": a database of the Gene category, (D, E, and F) main pages of Proteomic database, Mutation database, and Genomic database respectively.

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Data Portal Databases

Data Portal is a type of database that provides comprehensive genomic, epigenomic, transcriptomic, and proteomic data. a large number of data are publicly available for anyone in the research community and are used to diagnose, treat, and prevent cancer [12]. There are different published databases such as The European Genome-phenome Archive (EGA), which is a data center for all types of sequencing and genotyping experiments. Almost 58% of all studies in the EGA are related to cancer [36]. The "CanEvolve" database fulfills the need for data integration and interpretation. It contains data from 90 studies involving more than 10,000 patients. Data analysis can be performed at different levels: primary analysis including mRNA, microRNA (miRNA), and protein expression, genome variations, and protein–protein interactions; integrative analysis of gene and miRNA expression, gene expression, and copy number variations, and gene set enrichment analysis; network analysis; and survival analysis [37]; the main page of this database is shown in Figure 2B.

Gene Databases

Gene databases collect various types of gene data and information related to cancer [38] and also provide help to researchers in understanding the genetic architecture of complex diseases and improve the accuracy of diagnosis and the effectiveness of therapy [39]. Various databases have been published such as the "IARCTP53" shown in Figure 2C; this database compiles various types of data and information on human *TP53* variations related to cancer [38]. The "TGDBs" gene database includes mechanisms of oncogenic activation, regulation, frequency of involvement in various tumor types, and chromosomal location. Data about the encoded proteins includes the cell type in which they are found, subcellular location, DNA-, protein-, and ligand-binding, role in development, and normal biochemical function [40].

Proteomic Databases

Cancer proteome databases encompass tumor tissues, cells, and biological fluids to interpret signaling pathways, identify signatures related to tumor initiation, invasion, and metastasis, and determine analytical, predictive, and prognostic markers [41], and also help determine the molecular details of proteome differentiation in various human tissues and organs, thus greatly improving our understanding of disease and human biology [23,42]. A number of databases have been published in this research area such as those shown in Figure 2D: "CanProVar" is designed to store and display single amino acid alterations including both germline and somatic variations in the human proteome, particularly those related to the genesis or development of human cancer based on the published studies and sources [43].

Mutation Databases

Mutation databases play an important role in science, diagnostics, and genetic health care and can play a vital role in life and death decisions. These databases are extensively used, but only gene- or locus-specific databases have been previously reviewed for their utility, accuracy, completeness, and currency [44]. Mutations in the tumor suppressor gene *TP53* are associated with a variety of cancers [45]. More than 50% of the human tumors harbor *TP53* mutations, resulting in a collection of over 45,000 somatic and germline mutations in the UMDTP53 database, as shown in Figure 2E. Analyses of these mutations have been helpful for improving our knowledge on the structure-function relations within the TP53 protein [46]. A number of databases have been published in this research area, which are of marked utility in the scientific community.

Genomic Databases

The Cancer Genome Database represents one of numerous international groups dedicated to performing wide-ranging genomic and epigenomic studies of selected cancer types to develop our understanding of disease and provide an open-access resource for international cancer research [47]. This database is aimed at improving the understanding of the molecular basis of cancer development [48]. Several databases have been published in this research area; for example, the MethCNA comprehensive database for genomic data in human cancer (Figure 2F). Per a most recent publication, this database contains approximately 10,000 tumor samples covering 37 cancer types. All the data were collected from the TCGA and the National Center for Biotechnology Information and were evaluated using a pipeline that combined multiple computational resources and tools [49]. BioMuta is a single-nucleotide variation and disease association database where variations are mapped to genomes and RefSeq nucleotide entries and are incorporated through UniProtKB/Swiss-Prot positional coordinates. The recent version of BioMuta contains only nonsynonymous single-nucleotide variations associated with cancer [50].

Results and Discussion

Database Statistics

In this work, we have provided almost all cancer databases (Table S1 in Multimedia Appendix 1) and shown the year-wise growth of the CRDB. Figure 3 shows the magnitude of category-wise growth of the databases. Table 2 shows the year-wise growth distribution of cancer databases, which marks tremendous growth and is an achievement for the cancer scientific community. Further, we have modified or deleted all the nonfunctional and inaccessible database links and have provided a new, updated cancer database in the form of a database named CRDB and a table (Table S1 in Multimedia Appendix 1).

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Figure 3. The statistics data of the Cancer Research Database (DB)—distribution of the database category.

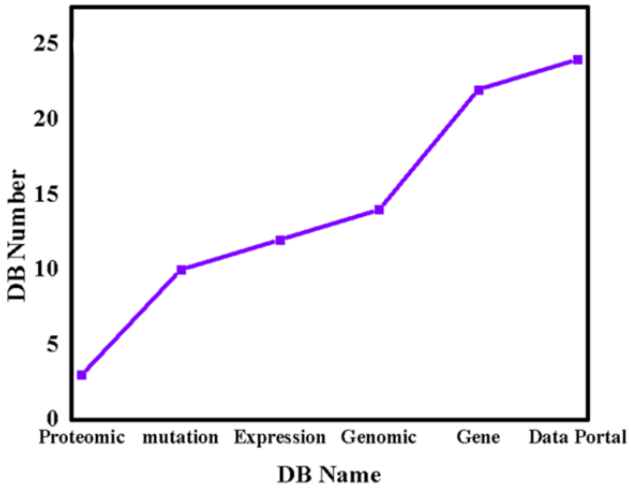

Table 2. Year-wise growth of the Cancer Research Database.

Year	Database growth, %
1999	1
2004	1
2005	1
2006	2
2007	2
2008	2
2009	2
2010	5
2011	6
2012	2
2013	7
2014	5
2015	6
2016	6
2017	11
2018	7
2019	7
2020	14
2021	12

Usage of the CRDB

The CRDB has been developed to provide an easy and user-friendly search experience; for easier and faster search, three options are provided for finding cancer databases. First, browsing can be carried out by typing the name of the database in the search bar, which is highlighted in Figure 4A, or by clicking on the name of the category or image expression, which is shown in Figure 4B. with CRDB statistics as well, which will lead to the category list page (Figure 4C), and a brief overview with the original link of the required search will be accessed by clicking the needed database. Further, for a specific database search, the “CT Database” is used as an example from the expression Databases to make it more user-friendly.

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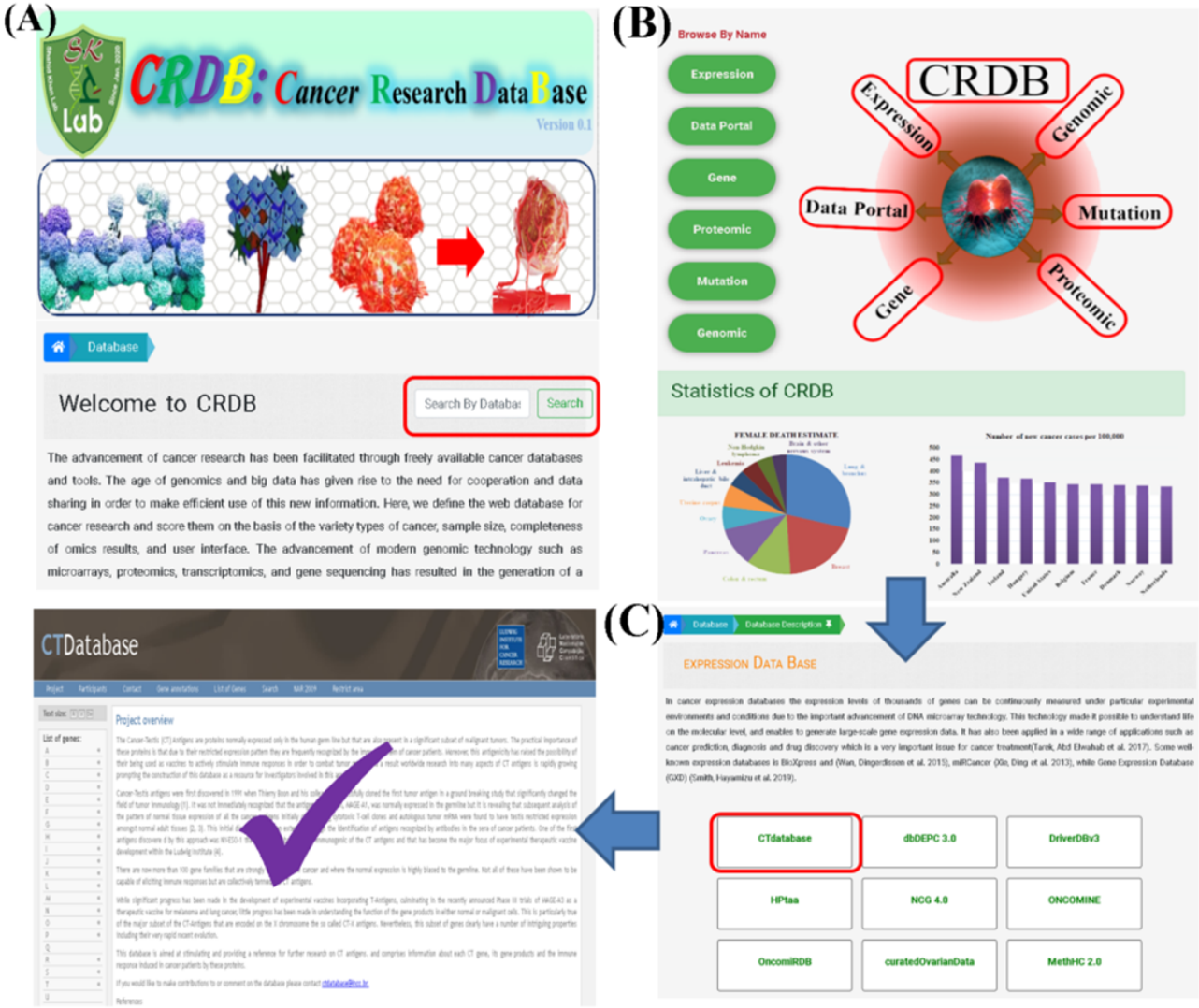
Figure 4. Browse options of the Cancer Research Database (CRDB). (A) Can be browsed by typing the name. (B) Can be browsed by category name or image expression. (C) An example and the final result.



Example of Cancer Diagnosis During the COVID-19 Pandemic

As of the previously reported reductions in cancer screening and other preventive care visits during the COVID-19 pandemic, the number of new cancer cases in 2020 is likely to be smaller than anticipated. According to one survey of diagnostic results, there was a 46% decrease in diagnosis of six different cancers (colorectal, pancreatic breast, lung, esophageal, and stomach cancer) from March 1 to April 18, 2020, relative to the period between January 6, 2019, and February 29, 2020, varying from a 25% decrease in the detection rate of pancreatic cancer to a 52% decrease in that of breast cancer [51,52]. Another study found that new CRC diagnoses were 30% lower from January to mid-April 2020 relative to the same timeframe in 2019 [53]. Across the world, similar losses have been noted, including those in the United Kingdom [54], the United States [54], and the Netherlands [55]. While these preliminary observations may provide insight into the pandemic's effect on cancer diagnosis, population-based cancer registry evidence and the degree to which these delays may lead to more advanced-stage disease will not be available for some time.

COVID-19 and Cancer

People with active cancer are more vulnerable to infectious pathogens as a result of a compromised immune system due to the malignancy and its treatment (eg, surgery and chemotherapy). This has raised fears that COVID-19–related problems and mortality may be more common among patients with cancer [56]. According to a 2020 study, patients with cancer may be at a higher risk of COVID-19 than those without cancer [57]. COVID-19 infection can impact persons with a wide range of hematologic diseases; however, the risk of infection is lower in patients with chronic myeloid proliferative neoplasms such as chronic myeloid leukemia and greater in persons on immunosuppressive medication [57,58]. A study at a tertiary care hospital in Wuhan, China, reported that patients with lung cancer above the age 60 years are at a high risk of COVID-19 locally [14,58,59] and worldwide [59,60]. It was also revealed that of the many cancer types, people with lung cancer who are over 60 years old are especially susceptible to COVID-19. Although it may seem intuitive that people with a defective respiratory epithelium are more susceptible to rapid virus entry into the lungs [61]. Another study shows a decrease in 6 types of cancer, with the total number of detected cancers

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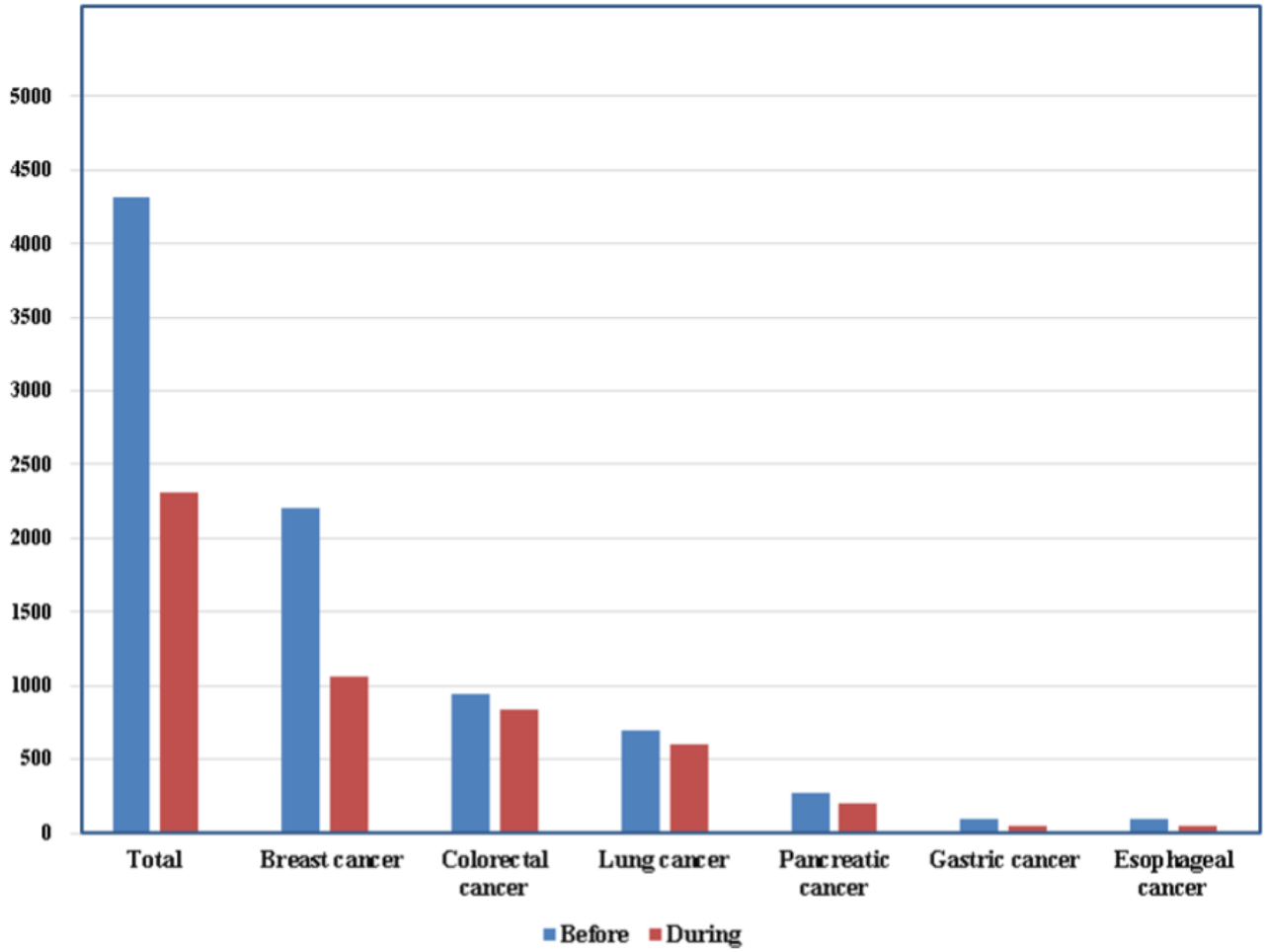
being 4310 before and 2310 during the COVID-19 pandemic, with breast cancer ranking the highest with 2208 cases before and 2310 cases during the COVID-19 pandemic, followed by colorectal cancer at 946 cases before and 840 cases during the pandemic, and Figure 5 shows details regarding all 6 cancer databases before and during the COVID-19 pandemic [52].

Figure 5. The number of cancers detected before and during the COVID-19 pandemic.



Global Cancer Rate

According to American institute for cancer research [62], the rates of all cancers have increased in almost in all countries, the privation of which is the major task for public health in 2021. Decreasing the cancer rate involves coordinated and comprehensive intervention from all facets of society, particularly the public sphere, civil society, and health and other occupations. Figure 6 shows the top 10 country-wise cancer rate from Oceania, Europe, and North America, in which the highest rate of cancer was reported in Australia (468.0 people per 100,000 population). For these 10 countries, the age-standardized average was at least 320 people per 100,000 population. With 579.9 men per 100,000 population, the age-standardized average was at least 360 people per 100,000 population, and with 363.0 women per 100,000 population, the age-standardized average was at least 300 people per 100,000 population.

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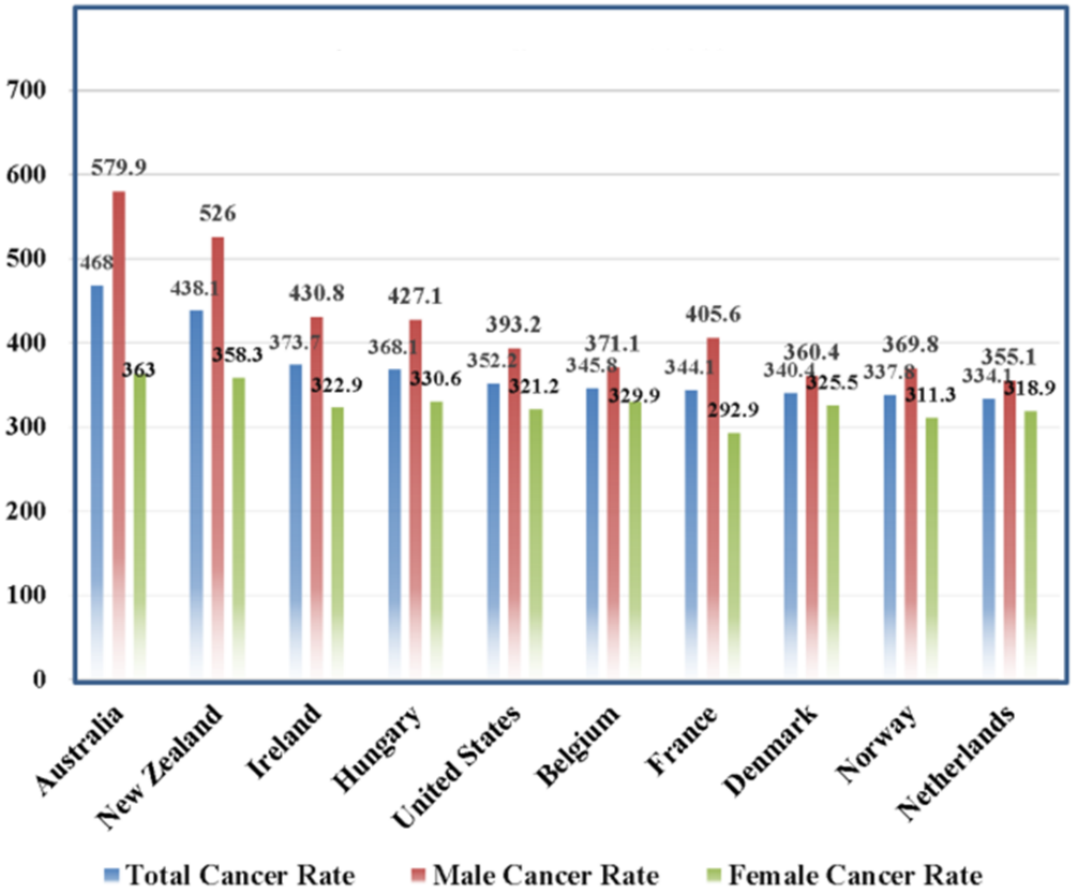
Figure 6. Country-wise cancer rate with an age-standardized average (per 100,000 population).



New Cases and Deaths

The American Cancer Society Cancer Action NetworkSM works worldwide to increase the quality of care for patients with and survivors of cancer. With time and the emergence of new cases worldwide, we have compiled a list of the top 10 cancers diagnosed in the United States in 2021. Table 3 shows the number of new cancer cases, with breast cancer in women and prostate cancer in men ranking first (30% cases) and second (26%), respectively. Although mortality estimates are shown in Table 3, lung and bronchial cancer showed the same rates in both male and female patients and ranked the highest, followed by breast and prostate cancer.

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Table 3. Rates of new cancers and mortality between male and female patients.

Cancer type	New cancers, %		Mortality, %	
	Male	Female	Male	Female
Prostate	26	N/A[a]	11	N/A
Breast	N/A	30	N/A	15
Lung and bronchial	12	13	22	22
Colorectal	8	8	9	8
Urinary bladder	7	__[b]	4	—
Skin melanoma	6	5	—	—
Kidney and renal pelvis	5	3	—	—
Non-Hodgkin lymphoma	5	4	4	3
Oral cavity and pharynx	4	—	—	—
Leukemia	4	3	4	3
Pancreatic	3	3	8	8
Uterine corpus	N/A	7	N/A	4
Brain and other nervous system regions	—	—	3	3
Liver and intrahepatic bile duct	—	—	6	3
Esophageal	—	—	4	—
Ovarian	N/A	—	N/A	5

[a]N/A: not applicable.
[b]—: not determined.

Conclusions

A biological database provides facilities for storing, organizing, and retrieving biological data such as DNA, RNA, carbohydrates, proteins, and cancers. It can be easily viewed, managed, and modified. A number of papers have been published in this research field, which have their own classification of cancer databases based on their function, use, certain technical aspects, and on species such as human, mouse, plant, and fungi. According to such published studies, we have classified the cancer databases into six categories: Data Portal database, Genomic database, Proteomic database, Expression database, Gene database, and Mutation database. Further, we have collected almost all cancer databases with a short introduction and have updated or removed all nonfunctional links. Furthermore, we have understood the current situation of cancer and its correlation with COVID-19; for example, the up-down, mortality, and new case count based on continent and countries, etc. Our database can be searched through an easy-to-use, user-friendly method, can be searched by clicking on category name of image expression, or users can type the name of needed databases in the given search bar and they will be updated with time. In addition, we have examined the status and diagnoses of cancer during the COVID-19 pandemic and have provided easy and understandable information for future researchers.

Acknowledgments

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Availability of Data and Material

These data will be available under the journal rule and regulation. To avoid future conflict and plagiarism issue, CRDB database is uploaded on the internet [63] so that we have provided some content in this article.

Authors' Contributions

SU supervised the study with TG, DAK, WR, GA, FU, MI, AU and collected and verified the data carefully. SU drafted the manuscript. All authors reviewed the manuscript and agreed to submit it. Both TG and SU are the corresponding authors for this manuscript.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Cancer databases.
[DOCX File , 22 KB - cancer_v8i2e35020_app1.docx]

References

1. Sciacovelli M, Schmidt C, Maher ER, Frezza C. Metabolic Drivers in Hereditary Cancer Syndromes. Annu Rev Cancer Biol 2020 Mar 09;4(1):77-97. [doi: 10.1146/annurev-cancerbio-030419-033612]
2. Jayasekara H, MacInnis RJ, Room R, English DR. Long-Term Alcohol Consumption and Breast, Upper Aero-Digestive Tract and Colorectal Cancer Risk: A Systematic Review and Meta-Analysis. Alcohol Alcohol 2016 May;51(3):315-330. [doi: 10.1093/alcalc/agv110] [Medline: 26400678]
3. Yang Y, Dong X, Xie B, Ding N, Chen J, Li Y, et al. Databases and web tools for cancer genomics study. Genomics Proteomics Bioinformatics 2015 Feb;13(1):46-50 [FREE Full text] [doi: 10.1016/j.gpb.2015.01.005] [Medline: 25707591]
4. Han HJ, Nwagwu C, Anyim O, Ekweremadu C, Kim S. COVID-19 and cancer: From basic mechanisms to vaccine development using nanotechnology. Int Immunopharmacol 2021 Jan;90:107247 [FREE Full text] [doi: 10.1016/j.intimp.2020.107247] [Medline: 33307513]
5. Tian J, Miao X. Challenges and recommendations for cancer care in the COVID-19 pandemic. Cancer Biol Med 2020 Aug 15;17(3):515-518 [FREE Full text] [doi: 10.20892/j.issn.2095-3941.2020.0300] [Medline: 32944386]
6. Liu C, Zhao Y, Okwan-Duodu D, Basho R, Cui X. COVID-19 in cancer patients: risk, clinical features, and management. Cancer Biol Med 2020 Aug 15;17(3):519-527 [FREE Full text] [doi: 10.20892/j.issn.2095-3941.2020.0289] [Medline: 32944387]
7. Pathania AS, Prathipati P, Abdul BA, Chava S, Katta SS, Gupta SC, et al. COVID-19 and Cancer Comorbidity: Therapeutic Opportunities and Challenges. Theranostics 2021;11(2):731-753 [FREE Full text] [doi: 10.7150/thno.51471] [Medline: 33391502]
8. Brunello A, Galiano A, Finotto S, Monfardini S, Colloca G, Balducci L, et al. Older cancer patients and COVID-19 outbreak: Practical considerations and recommendations. Cancer Med 2020 Dec;9(24):9193-9204 [FREE Full text] [doi: 10.1002/cam4.3517] [Medline: 33219746]
9. Sarode GS, Sarode SC, Maniyar N, Anand R, Patil S. Oral cancer databases: A comprehensive review. J Oral Pathol Med 2018 Jul;47(6):547-556. [doi: 10.1111/jop.12667] [Medline: 29193424]
10. Ullah S, Ullah A, Rahman W, Ullah F, Khan SB, Ahmad G, et al. An innovative user-friendly platform for Covid-19 pandemic databases and resources. Comput Methods Programs Biomed Update 2021;1:100031 [FREE Full text] [doi: 10.1016/j.cmpbup.2021.100031] [Medline: 34604832]
11. Percudani R, Carnevali D, Puggioni V. Ureidoglycolate hydrolase, amidohydrolase, lyase: how errors in biological databases are incorporated in scientific papers and vice versa. Database (Oxford) 2013;2013:bat071 [FREE Full text] [doi: 10.1093/database/bat071] [Medline: 24107613]
12. Cancer Genome Atlas Research Network, Weinstein JN, Collisson EA, Mills GB, Shaw KRM, Ozenberger BA, et al. The Cancer Genome Atlas Pan-Cancer analysis project. Nat Genet 2013 Oct;45(10):1113-1120 [FREE Full text] [doi: 10.1038/ng.2764] [Medline: 24071849]
13. Zhang J, Baran J, Cros A, Guberman JM, Haider S, Hsu J, et al. International Cancer Genome Consortium Data Portal--a one-stop shop for cancer genomics data. Database (Oxford) 2011;2011:bar026 [FREE Full text] [doi: 10.1093/database/bar026] [Medline: 21930502]
14. Ullah S. EDBCO-19: Emergency Data Base of COVID-19. J Clin Med Res 2020 Aug 1. [doi: 10.37191/mapsci-2582-4333-2(5)-047]
15. Bakouny Z, Hawley J, Choueiri T, Peters S, Rini B, Warner J, et al. COVID-19 and Cancer: Current Challenges and Perspectives. Cancer Cell 2020 Nov 09;38(5):629-646 [FREE Full text] [doi: 10.1016/j.ccell.2020.09.018] [Medline: 33049215]
16. International Cancer Genome Consortium T, Hudson TJ, Anderson W, Artez A, Barker AD, Bell C, et al. International network of cancer genome projects. Nature 2010 Apr 15;464(7291):993-998 [FREE Full text] [doi: 10.1038/nature08987] [Medline: 20393554]
17. Mewes HW, Ruepp A, Theis F, Rattei T, Walter M, Frishman D, et al. MIPS: curated databases and comprehensive secondary data resources in 2010. Nucleic Acids Res 2011 Jan;39(Database issue):D220-D224 [FREE Full text] [doi: 10.1093/nar/gkq1157] [Medline: 21109531]
18. Tacutu R, Thornton D, Johnson E, Budovsky A, Barardo D, Craig T, et al. Human Ageing Genomic Resources: new and updated databases. Nucleic Acids Res 2018 Jan 04;46(D1):D1083-D1090 [FREE Full text] [doi: 10.1093/nar/gkx1042] [Medline: 29121237]

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19. SIB Swiss Institute of Bioinformatics Members. The SIB Swiss Institute of Bioinformatics' resources: focus on curated databases. Nucleic Acids Res 2016 Jan 04;44(D1):D27-D37 [FREE Full text] [doi: 10.1093/nar/gkv1310] [Medline: 26615188]
20. Pavlopoulou A, Spandidos D, Michalopoulos I. Human cancer databases (review). Oncol Rep 2015 Jan;33(1):3-18 [FREE Full text] [doi: 10.3892/or.2014.3579] [Medline: 25369839]
21. Teufel A. Bioinformatics and database resources in hepatology. J Hepatol 2015 Mar;62(3):712-719 [FREE Full text] [doi: 10.1016/j.jhep.2014.10.036] [Medline: 25450718]
22. Zhang Y, Yang C, Wang S, Chen T, Li M, Wang X, et al. LiverAtlas: a unique integrated knowledge database for systems-level research of liver and hepatic disease. Liver Int 2013 Sep;33(8):1239-1248. [doi: 10.1111/liv.12173] [Medline: 23601370]
23. Ullah S, Lin S, Xu Y, Deng W, Ma L, Zhang Y, et al. dbPAF: an integrative database of protein phosphorylation in animals and fungi. Sci Rep 2016 Mar 24;6:23534 [FREE Full text] [doi: 10.1038/srep23534] [Medline: 27010073]
24. Li S, Shui K, Zhang Y, Lv Y, Deng W, Ullah S, et al. CGDB: a database of circadian genes in eukaryotes. Nucleic Acids Res 2017 Jan 04;45(D1):D397-D403 [FREE Full text] [doi: 10.1093/nar/gkw1028] [Medline: 27789706]
25. Ullah S, Rahman W, Ullah F, Ahmad G, Ijaz M, Gao T. DBHR: a collection of databases relevant to human research. Future Sci OA 2022 Mar;8(3):FSO780 [FREE Full text] [doi: 10.2144/fsoa-2021-0101] [Medline: 35251694]
26. Ullah S, Rahman W, Ullah F, Ahmad G, Ijaz M, Gao T. DBPR: DataBase of Plant Research. Research Square. URL: https://www.researchsquare.com/article/rs-153167/v1 [accessed 2022-04-22]
27. Khan SA. Tremendous Contribution of Dr. Shahid Ullah to Scientific Community during COVID-19 Pandemic in the Form of Scientific Research. J Clin Med Res 2020 Aug 1. [doi: 10.37191/mapsci-2582-4333-2(5)-049]
28. Xu D. Protein databases on the internet. Curr Protoc Protein Sci 2012 Nov;Chapter 2:Unit2.6. [doi: 10.1002/0471140864.ps0206s70] [Medline: 23151744]
29. Celis J, Ostergaard M, Jensen N, Gromova I, Rasmussen H, Gromov P. Human and mouse proteomic databases: novel resources in the protein universe. FEBS Lett 1998 Jun 23;430(1-2):64-72 [FREE Full text] [doi: 10.1016/s0014-5793(98)00527-4] [Medline: 9678596]
30. Harper R. Access to DNA and protein databases on the Internet. Curr Opin Biotechnol 1994 Feb;5(1):4-18. [doi: 10.1016/s0958-1669(05)80063-1] [Medline: 7764641]
31. Sanchez C, Lachaize C, Janody F, Bellon B, Röder L, Euzenat J, et al. Grasping at molecular interactions and genetic networks in Drosophila melanogaster using FlyNets, an Internet database. Nucleic Acids Res 1999 Jan 01;27(1):89-94 [FREE Full text] [doi: 10.1093/nar/27.1.89] [Medline: 9847149]
32. Tarek S, Abd Elwahab R, Shoman M. Gene expression based cancer classification. Egypt Inform J 2017 Nov;18(3):151-159. [doi: 10.1016/j.eij.2016.12.001]
33. Wan Q, Dingerdissen H, Fan Y, Gulzar N, Pan Y, Wu T, et al. BioXpress: an integrated RNA-seq-derived gene expression database for pan-cancer analysis. Database (Oxford) 2015;2015 [FREE Full text] [doi: 10.1093/database/bav019] [Medline: 25819073]
34. Xie B, Ding Q, Han H, Wu D. miRCancer: a microRNA-cancer association database constructed by text mining on literature. Bioinformatics 2013 Mar 01;29(5):638-644. [doi: 10.1093/bioinformatics/btt014] [Medline: 23325619]
35. Smith C, Hayamizu T, Finger J, Bello S, McCright IJ, Xu J, et al. The mouse Gene Expression Database (GXD): 2019 update. Nucleic Acids Res 2019 Jan 08;47(D1):D774-D779 [FREE Full text] [doi: 10.1093/nar/gky922] [Medline: 30335138]
36. Lappalainen I, Almeida-King J, Kumanduri V, Senf A, Spalding JD, Ur-Rehman S, et al. The European Genome-phenome Archive of human data consented for biomedical research. Nat Genet 2015 Jul;47(7):692-695 [FREE Full text] [doi: 10.1038/ng.3312] [Medline: 26111507]
37. Samur MK, Yan Z, Wang X, Cao Q, Munshi NC, Li C, et al. canEvolve: a web portal for integrative oncogenomics. PLoS One 2013;8(2):e56228 [FREE Full text] [doi: 10.1371/journal.pone.0056228] [Medline: 23418540]
38. Olivier M, Eeles R, Hollstein M, Khan MA, Harris CC, Hainaut P. The IARC TP53 database: new online mutation analysis and recommendations to users. Hum Mutat 2002 Jun;19(6):607-614. [doi: 10.1002/humu.10081] [Medline: 12007217]
39. Su L, Liu G, Bai T, Meng X, Ma Q. MGOGP: a gene module-based heuristic algorithm for cancer-related gene prioritization. BMC Bioinformatics 2018 Jun 05;19(1):215 [FREE Full text] [doi: 10.1186/s12859-018-2216-0] [Medline: 29871590]
40. Gong X, Wu R, Zhang Y, Zhao W, Cheng L, Gu Y, et al. Extracting consistent knowledge from highly inconsistent cancer gene data sources. BMC Bioinformatics 2010 Feb 05;11:76 [FREE Full text] [doi: 10.1186/1471-2105-11-76] [Medline: 20137077]
41. Arntzen M, Boddie P, Frick R, Koehler CJ, Thiede B. Consolidation of proteomics data in the Cancer Proteomics database. Proteomics 2015 Nov;15(22):3765-3771. [doi: 10.1002/pmic.201500144] [Medline: 26316313]
42. Uhlén M, Fagerberg L, Hallström BM, Lindskog C, Oksvold P, Mardinoglu A, et al. Proteomics. Tissue-based map of the human proteome. Science 2015 Jan 23;347(6220):1260419. [doi: 10.1126/science.1260419] [Medline: 25613900]
43. Li J, Duncan DT, Zhang B. CanProVar: a human cancer proteome variation database. Hum Mutat 2010 Mar;31(3):219-228 [FREE Full text] [doi: 10.1002/humu.21176] [Medline: 20052754]
44. George RA, Smith TD, Callaghan S, Hardman L, Pierides C, Horaitis O, et al. General mutation databases: analysis and review. J Med Genet 2008 Feb;45(2):65-70 [FREE Full text] [doi: 10.1136/jmg.2007.052639] [Medline: 17893115]

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45. Li VD, Li KH, Li JT. TP53 mutations as potential prognostic markers for specific cancers: analysis of data from The Cancer Genome Atlas and the International Agency for Research on Cancer TP53 Database. J Cancer Res Clin Oncol 2019 Mar;145(3):625-636. [doi: 10.1007/s00432-018-2817-z] [Medline: 30542790]
46. Leroy B, Anderson M, Soussi T. TP53 mutations in human cancer: database reassessment and prospects for the next decade. Hum Mutat 2014 Jun;35(6):672-688. [doi: 10.1002/humu.22552] [Medline: 24665023]
47. Cooper LA, Demicco EG, Saltz JH, Powell RT, Rao A, Lazar AJ. PanCancer insights from The Cancer Genome Atlas: the pathologist's perspective. J Pathol 2018 Apr;244(5):512-524 [FREE Full text] [doi: 10.1002/path.5028] [Medline: 29288495]
48. Lee J. Exploring cancer genomic data from the cancer genome atlas project. BMB Rep 2016 Nov;49(11):607-611 [FREE Full text] [doi: 10.5483/bmbrep.2016.49.11.145] [Medline: 27530686]
49. Deng G, Yang J, Zhang Q, Xiao Z, Cai H. MethCNA: a database for integrating genomic and epigenomic data in human cancer. BMC Genomics 2018 Feb 13;19(1):138 [FREE Full text] [doi: 10.1186/s12864-018-4525-0] [Medline: 29433427]
50. Dingerdissen H, Torcivia-Rodriguez J, Hu Y, Chang T, Mazumder R, Kahsay R. BioMuta and BioXpress: mutation and expression knowledgebases for cancer biomarker discovery. Nucleic Acids Res 2018 Jan 04;46(D1):D1128-D1136 [FREE Full text] [doi: 10.1093/nar/gkx907] [Medline: 30053270]
51. Biondi‐Zoccai G, Sciarretta S, Bullen C, Nocella C, Violi F, Loffredo L, et al. Acute Effects of Heat‐Not‐Burn, Electronic Vaping, and Traditional Tobacco Combustion Cigarettes: The Sapienza University of Rome‐Vascular Assessment of Proatherosclerotic Effects of Smoking (SUR‐VAPES) 2 Randomized Trial. JAHA 2019 Mar 19;8(6). [doi: 10.1161/jaha.118.010455]
52. Kaufman HW, Chen Z, Niles J, Fesko Y. Changes in the Number of US Patients With Newly Identified Cancer Before and During the Coronavirus Disease 2019 (COVID-19) Pandemic. JAMA Netw Open 2020 Aug 03;3(8):e2017267 [FREE Full text] [doi: 10.1001/jamanetworkopen.2020.17267] [Medline: 32749465]
53. Antoniewicz L, Brynedal A, Hedman L, Lundbäck M, Bosson JA. Acute Effects of Electronic Cigarette Inhalation on the Vasculature and the Conducting Airways. Cardiovasc Toxicol 2019 Oct;19(5):441-450 [FREE Full text] [doi: 10.1007/s12012-019-09516-x] [Medline: 30963443]
54. Waziry R, Jawad M, Ballout RA, Al Akel M, Akl EA. The effects of waterpipe tobacco smoking on health outcomes: an updated systematic review and meta-analysis. Int J Epidemiol 2017 Feb 01;46(1):32-43. [doi: 10.1093/ije/dyw021] [Medline: 27075769]
55. Leventhal AM, Strong DR, Kirkpatrick MG, Unger JB, Sussman S, Riggs NR, et al. Association of Electronic Cigarette Use With Initiation of Combustible Tobacco Product Smoking in Early Adolescence. JAMA 2015 Aug 18;314(7):700-707 [FREE Full text] [doi: 10.1001/jama.2015.8950] [Medline: 26284721]
56. Siegel R, Miller K, Fuchs H, Jemal A. Cancer Statistics, 2021. CA Cancer J Clin 2021 Jan;71(1):7-33 [FREE Full text] [doi: 10.3322/caac.21654] [Medline: 33433946]
57. Cattaneo C, Daffini R, Pagani C, Salvetti M, Mancini V, Borlenghi E, et al. Clinical characteristics and risk factors for mortality in hematologic patients affected by COVID-19. Cancer 2020 Dec 01;126(23):5069-5076 [FREE Full text] [doi: 10.1002/cncr.33160] [Medline: 32910456]
58. Yu J, Ouyang W, Chua MLK, Xie C. SARS-CoV-2 Transmission in Patients With Cancer at a Tertiary Care Hospital in Wuhan, China. JAMA Oncol 2020 Jul 01;6(7):1108-1110 [FREE Full text] [doi: 10.1001/jamaoncol.2020.0980] [Medline: 32211820]
59. UK Coronavirus Cancer Monitoring Project team. The UK Coronavirus Cancer Monitoring Project: protecting patients with cancer in the era of COVID-19. Lancet Oncol 2020 May;21(5):622-624 [FREE Full text] [doi: 10.1016/S1470-2045(20)30230-8] [Medline: 32304634]
60. Li H, Liu SM, Yu XH, Tang SL, Tang CK. Coronavirus disease 2019 (COVID-19): current status and future perspectives. Int J Antimicrob Agents 2020 May;55(5):105951 [FREE Full text] [doi: 10.1016/j.ijantimicag.2020.105951] [Medline: 32234466]
61. Zhang H, Wang L, Chen Y, Wu Q, Chen G, Shen X, et al. Outcomes of novel coronavirus disease 2019 (COVID-19) infection in 107 patients with cancer from Wuhan, China. Cancer 2020 Sep 01;126(17):4023-4031 [FREE Full text] [doi: 10.1002/cncr.33042] [Medline: 32573776]
62. Global cancer data by country. World Cancer Research Fund International. URL: https://www.wcrf.org/cancer-trends/global-cancer-data-by-country/ [accessed 2022-04-25]
63. Welcome to CRDB. CRDB: Cancer Research Database. URL: https://habdsk.org/crdb.php [accessed 2022-04-25]

Abbreviations

CNV: copy number variation
CRDB: cancer research database
EGA: European Genome-phenome Archive
miRNA: microRNA
TCGA: The Cancer Genome Atlas

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Original Paper

A Cancer Exercise Toolkit Developed Using Co-Design: Mixed Methods Study

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Abstract

Background: Access to exercise therapy for cancer survivors is poor. Professional development to support exercise professionals in delivering these interventions is needed. Few online resources exist for exercise professionals to address this issue.

Objective: To develop and evaluate a freely available online toolkit to support exercise professionals working with cancer survivors.

Methods: A 2-phase, experience-based co-design approach was used to develop and evaluate the online toolkit. The two phases were as follows: 1) needs identification and co-design of resources and platform and 2) pilot evaluation. Four co-design workshops were conducted, transcribed, and thematically analyzed to identify key elements for the toolkit. For the pilot evaluation, a customized survey (the Determinants of Implementation Behavior Questionnaire) was distributed to exercise professionals at baseline and 3 months after launch of the online toolkit to determine its usability, utility, and effectiveness in improving their knowledge, confidence, and behavior. Results were reported as the median and interquartile range and changes were calculated using non-parametric tests. Website analytics described site usage after the initial evaluation.

Results: Twenty-five exercise professionals participated in co-designing 8 key elements of the online Cancer Exercise Toolkit: the homepage and pages for getting started, screening and safety, assessment, exercise prescription, education, locations, and resources. For the pilot evaluation, 277/320 respondents (87% of whom were physiotherapists) from 26 countries completed the survey at baseline, with 58 exercise professionals completing follow-up surveys at 3 months. Exercise professionals' knowledge, skills, and confidence in delivering exercise therapy to cancer survivors increased 3 months after baseline (items 1, 6, and 8: median score 5, IQR 3 to 6) to follow-up (items 1 and 6: median score 6, IQR 5 to 6; item 8: median score 5, IQR 5 to 7; $P<.001$) on a 1 to 7 Likert scale. Most participants (35/44, 80%) agreed or strongly agreed they would recommend the toolkit to colleagues. In the 6 months following the pilot evaluation, the toolkit received an average of 866 views per month.

Conclusions: The co-designed online Cancer Exercise Toolkit was a useful resource for exercise professionals that may increase their knowledge, skills, and confidence in providing exercise therapy to cancer survivors.

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KEYWORDS

cancer; website; online learning; professional development; physiotherapy; exercise; cancer survivorship; cancer survivor; digital health; online health; online toolkit

Introduction

International guidelines support the integration of exercise into cancer care to improve cancer outcomes [1,2]. Well-established evidence shows exercise therapy can reduce cancer-related impairments such as fatigue and improve the health-related quality of life of cancer survivors [1]. Exercise may prevent development of chronic disease, prolong survival, and prevent cancer recurrence in some cancer cohorts, such as breast, colorectal, and prostate cancer [3,4]. Despite compelling evidence that exercise is important for cancer survivors, access to specialized exercise therapy programs for people with cancer is poor, with just 1 in 200 cancer survivors able to participate in an exercise-based rehabilitation program in Australia [5,6].

Skilled exercise professionals are critical for the implementation and delivery of exercise therapy to cancer survivors [7]. Exercise professionals, including physiotherapists and exercise physiologists, are well placed to provide exercise therapy given their expertise in prescribing exercise and behavior change for people with chronic health conditions [8,9]. In Australia alone, there are over 40,000 registered exercise professionals who could provide services to people with cancer [10,11]. Despite their professional training, recent surveys of Australian and Irish physiotherapists found they lack confidence in providing care, including exercise therapy, to cancer survivors [12,13]. Education and practical support are required for exercise professionals to safely and effectively prescribe exercise and monitor progress according to current cancer guidelines [1].

Exercise professionals may be able to develop and consolidate their knowledge through attendance of in-person courses and lectures and passive text-based resources. However, these knowledge sources may be less effective at improving knowledge and skills than active approaches such as e-learning, which provide greater flexibility to cater for individual learning needs [14]. Online material has been shown to be feasible for educating clinicians about exercise, with multimedia innovations, such as video, infographics, quizzes, and podcasts, enhancing clinician engagement [15]. For example, the online Pulmonary Rehabilitation Toolkit [16], developed in Australia over 10 years ago, is now considered an essential reference for physiotherapists and students working in pulmonary rehabilitation [17]. Currently, few similar resources exist to facilitate professional development for exercise professionals working in cancer rehabilitation. With a rapid rise in exercise and cancer research [18,19], it can be challenging for clinicians to keep up with best practices. Online resources may overcome time and cost barriers to professional development and offer convenience for time-poor clinicians [20].

The primary aim of this study is to develop an online toolkit, based on experience-based co-design [21] methods, to provide support to exercise professionals by delivering evidence-based exercise interventions to cancer survivors. A secondary aim is to evaluate the initial use of the online toolkit and explore its effect on exercise professionals' knowledge, confidence, and behavior.

Methods

Study Design

An online toolkit called the Cancer Exercise Toolkit was developed with an experience-based co-design approach [21] using mixed methods between May 2020 and October 2021. Qualitative interviews, workshops, and online surveys informed the toolkit development. The study procedure (Multimedia Appendix 1) was based on the experience-based co-design (EBCD) toolkit [21] and a published study using EBCD to develop a cancer prehabilitation program [22]. EBCD is a collaborative approach to service improvement completed in partnership with end users [21]. Co-design helps researchers build meaningful relationships with research participants [23], whereby users are recognized as experts in their own experiences [24]. The study was completed in two phases: (1) needs identification and co-design of resources for the online platform and (2) pilot evaluation (Figure 1).

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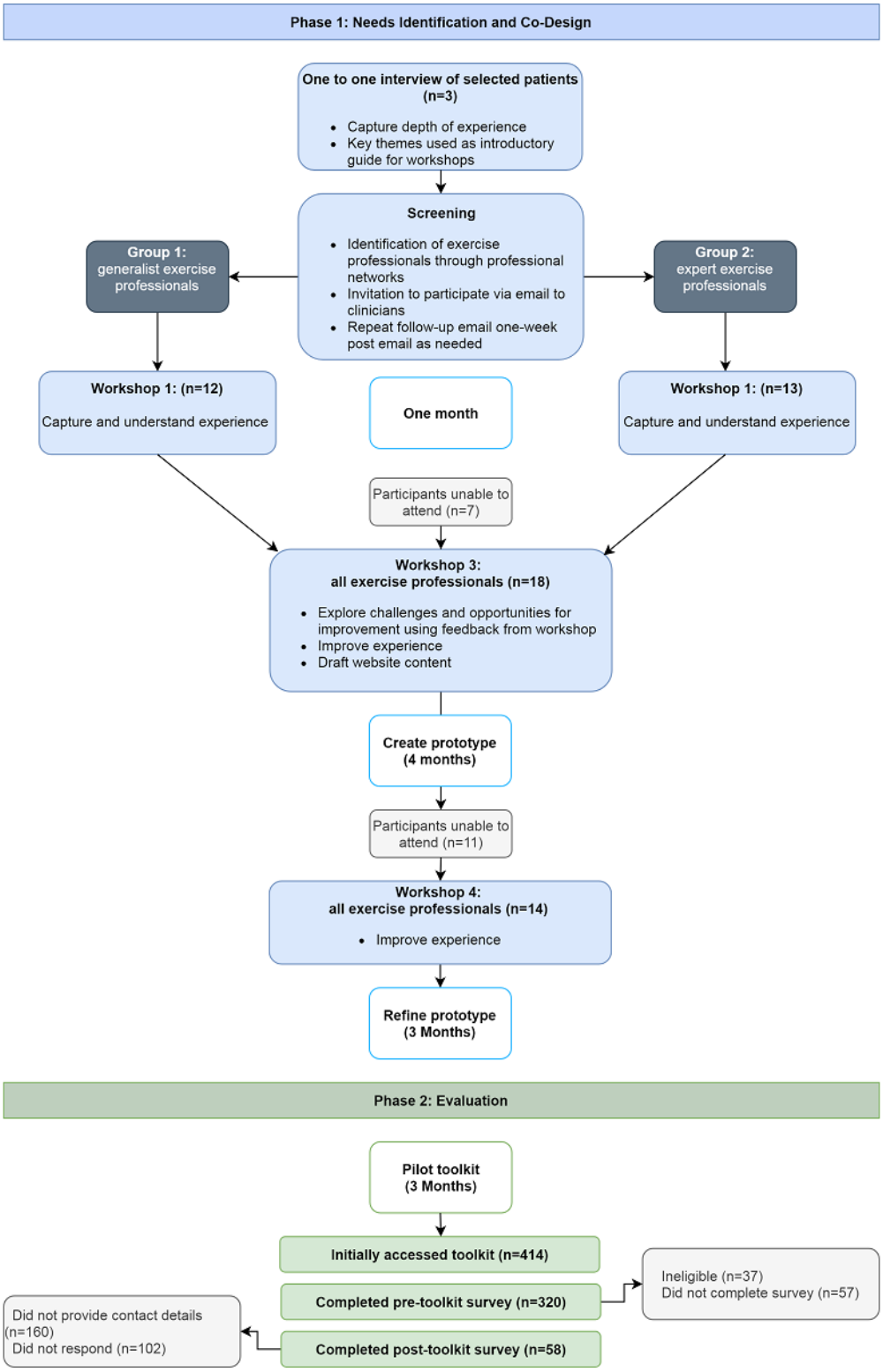
Figure 1. Participant recruitment procedure for the creation and evaluation of the Cancer Exercise Toolkit.



Participants

Two groups of participants were included in the co-design workshops for toolkit development. Group 1 included "generalist" exercise professionals, defined as physiotherapists and exercise physiologists working in other areas who may have occasional contact with cancer survivors. Group 2 included "expert" or experienced cancer exercise professionals, defined as physiotherapists and exercise physiologists who had worked specifically in cancer for at least 2 years. The workshops did not include patients, as exercise professionals were intended to be the end users of this resource. However, patients who had been diagnosed with cancer and participated in exercise-based cancer rehabilitation were invited to participate in a brief video shown to clinicians in the co-design workshops, setting the scene and direction for the session. Snowball sampling was undertaken to recruit participants over a 2-week period. Exercise professionals were invited to participate in the study through

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an invitation email distributed by a health service and through local professional networks (eg, the Australian Physiotherapy Association). For workshops 1 and 2, it was estimated that 8 to 10 participants in each group would be sufficient to provide varied experiences and contribute to new knowledge [21].

For the pilot evaluation phase of the toolkit, a third group of exercise professionals was recruited. We aimed to recruit a convenience sample of at least 100 exercise professionals over a 3-month period. This sample size assumed that 50% of participants would be confident enough to prescribe exercise therapy to cancer survivors and that this would be sufficient for estimating the expected proportion of sufficiently confident participants with 10% absolute precision and 95% CI [25]. Recruitment was not capped, as participants received recognition for continuing professional development as part of participation.

Procedure

Phase 1: Needs Identification and Co-Design

One-hour semi-structured interviews (Multimedia Appendix 2) were completed via teleconference (Zoom Video Communications) with 3 patients who had participated in cancer rehabilitation in a public subacute hospital in Australia. Interviews were conducted by a member of the research team who had previous experience in conducting qualitative interviews and did not have any prior involvement in the treatment of these patients. The interviews included questions exploring the patients' journey in participating in an exercise-based cancer rehabilitation program. The videos were independently analyzed by 2 research team members (AD and CT) using an inductive approach to identify key touchpoints of the overall cancer rehabilitation experience [21]. The videos were edited into a short video clip and used at the start of workshops 1 and 2 to set the scene for the sessions.

Separate workshops (workshops 1 and 2, each 1 hour long) with the generalist and expert exercise professionals were conducted to explore areas for health care improvement and identify therapist learning needs. Learning needs identified from the workshop formed the content outline of the new online toolkit. A combined workshop (workshop 3; 1.5-2 hours long) was then held with all the participating exercise professionals to design key content elements and the overall layout of the online toolkit. A prototype online toolkit was developed based on findings from the combined workshop and key cancer rehabilitation literature [1,26,27]. A weblink was sent to exercise professionals attending the workshops to trial the toolkit for 1 month.

Following 1 month of access to the prototype, a second joint workshop (workshop 4; 1.5 hours long) was conducted to facilitate feedback. In this workshop, participant perceptions regarding the strengths and limitations of the new resource were explored. Further refinements to the toolkit were made by the research team following this workshop before it was formally evaluated by the broader exercise community (Phase 2).

Workshops were facilitated by a researcher with experience in EBCD (CT). Two members of the study team (AC and AD) generated field notes to assist in triangulation and data trustworthiness. Project team members acted as observers and additional facilitators for the larger joint workshops. Immediately after each workshop, project team members debriefed with the workshop facilitator and discussed their reflections.

Recordings from all workshops were transcribed, stored, and managed using Microsoft Word and NVivo (version 12). Transcripts were coded independently by 2 reviewers (AD and CT), who used an inductive thematic analysis approach to identify touchpoints from the workshops [28]. The team then came together to discuss and reach consensus on the key touchpoints, which informed the structure and design of the online toolkit. All but 1 team member had experience in conducting qualitative research (Multimedia Appendix 3).

Phase 2: Pilot Evaluation

The online toolkit was formally piloted and evaluated with a broader, international sample of exercise professionals, including co-design participants (February 2021 to April 2021). An open online survey, Research Electronic Data Capture (RedCap) [29], was distributed to a large health service and via local professional networks (eg, the Australian Physiotherapy Association and Exercise and Sports Science Australia), as well as international ones (eg, the Canadian Physiotherapy Association and the University of British Columbia Clinical Exercise Physiology Lab) through email and social media pages. Participants gained access to the website after completion of the survey. The survey was completed twice: (1) prior to accessing the website (T0) and (2) 3 months after initially gaining access to the website (T1). The T1 surveys were sent only to participants who provided contact details at the end of the T0 survey. Reminder emails were sent at 7 and 14 days after distribution of the T1 survey. A free professional development event held via webinar was also conducted at follow-up to promote survey completion.

This anonymous online survey (Multimedia Appendix 4) aimed to explore the website's effectiveness in addressing knowledge gaps, confidence, and behavior in prescribing exercise according to guidelines [1] along with the usability and utility of the toolkit [16]. It comprised 3 sections and took approximately 10 minutes to complete. Section 1 included demographic data. Section 2 included questions derived from the Determinants of Implementation Behavior Questionnaire (DIBQ), which is based on the theoretical domains framework [30]. Domains in the DIBQ show high discriminant validity, reliability, and internal consistency [30]. The 45-item instrument assessed the impact of continuing professional development activities on health professionals' knowledge, confidence, and implementation behaviors. Each item was measured on a 7-point Likert scale (ranging from 1, "strongly disagree" to 7, "strongly agree"). Item 45 was reverse scaled. Section 3 related to the usability and utility of the website [31] and was included in the follow-up survey only. This survey was tested by members of the research team (AD, CB, and CO) for readability and functionality prior to its distribution. A short quiz created by the researchers was also embedded as a learning tool within the toolkit to test user knowledge related to published recommendations on exercise and cancer [1,26]. Website views at the end of the 3-month trial period (May to October 2021) were reported to identify engagement with the website.

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Data analysis

Survey and website metadata were described using proportions, medians, and interquartile ranges. Content analysis was conducted on open-ended survey questions by 2 researchers (AC and CO) independently. Following recommendations for the analysis of anonymous survey data that cannot be paired [32], differences in DIBQ scores between baseline and follow-up were analyzed using the Mann Whitney *U* test with Bonferroni adjustment for multiple comparisons. A sensitivity analysis was applied to account for dependence in the follow-up survey. This involved using the same sample size at baseline and follow up in a random sample of data from the baseline survey [32]. Data were analyzed using SPSS version 27 (IBM Corp).

Ethics Approval

This study was reported in accordance with the Consolidated Criteria for Reporting Qualitative Studies [33] and Good Reporting of A Mixed Methods Study [34] checklists and approved by the hospital and university ethics committees (LR 20-020). Workshop participants provided written informed consent. Consent for the online surveys was implied by survey completion.

Results

Phase 1: Needs Identification and Co-Design

Twenty-five exercise professionals (13 experts and 12 generalists) participated in the co-design workshops. The co-design group included 21 physiotherapists and 4 exercise physiologists. Thirteen co-design participants worked in hospital settings in Australia. On average, the exercise professionals had 15 years of total experience (Table 1).

Table 1. Characteristics of co-design participants.

Characteristics, n (%)	All (N=25)	Expert (n=13)	Generalist (n=12)
Profession			
Physiotherapist	21 (84)	11 (85)	10 (83)
Exercise physiologist	4 (16)	2 (15)	2 (17)
Setting			
Hospital	12 (48)	10 (77)	3 (25)
Community	9 (36)	1 (8)	8 (67)
Both	1 (4)	1 (8)	0 (0)
Funding			
Public	14 (56)	8 (62)	7 (58)
Private	2 (8)	0 (0)	2 (17)
Both public and private	6 (25)	3 (23)	3 (23)
Years of total experience, mean (SD)	14.8 (8.6)	17.2 (8.0)	12.3 (8.6)

Workshops 1 and 2 identified 5 key touchpoints describing successful cancer rehabilitation programs (Table 2). These touchpoints highlighted the knowledge exercise professionals required to be included in the toolkit for implementation in cancer rehabilitation programs. Overall, touchpoints were similar between the expert and generalist exercise professionals.

> *Need easy access to latest guidelines for general knowledge...often difficult to keep up to date...* [Expert group participant]
>
> *[Need] access [to] article(s), training... [to be] more confident to safely advocate...to other health professionals.* [Generalist group participant]

When compared to the generalist group, the experts identified more nuanced, disease-specific knowledge, such as the need for strict infection control procedures and cancer-specific assessments. The importance of practical considerations, understanding the impact of cancer treatment and side effects, and education provision and access were common themes forming the foundational content of the toolkit prototype. These touchpoints informed 8 key sections of the toolkit: the homepage; getting started; screening and safety; assessment; exercise prescription; education; locations; and resources (Multimedia Appendix 5).

In the joint workshop (workshop 3), the exercise professionals agreed the toolkit needed to be simple, practical, and not duplicate existing resources. Participants provided suggestions for existing resources that could be linked or embedded in the toolkit and described a need for templates that could be used in their clinical practice. Website monitoring and updating were identified as critical for the website's sustained success. At the conclusion of this workshop, the research team drafted the toolkit content. Freely available multimedia resources (videos, infographics, patient handouts, and podcasts) were sourced to supplement information provided on the website rather than creating new multimedia content.

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Table 2. Key touchpoints from workshops 1 and 2.

Elements of cancer rehabilitation	Common themes	Expert only	Generalist only
Getting started	Setting up the environment, including social support, space, equipment, and group dynamics; communicating with patients how to get started with cancer rehabilitation	Importance of infection control due to work with immunocompromised patients	Whether to deliver therapy one-to-one or in groups; uncertainty as to how to integrate cancer patients with other disease populations; standardized templates and letters
Screening and safety; assessment	Understanding impact of cancer treatment; precautions and contraindications	Discussion of impairment, performance, and quality of life measures used for assessment, including cancer-specific measures	Emphasis on importance and challenges of goal setting
Exercise prescription	Individualization; modification and progression/regression; monitoring fatigue	More emphasis on guidelines and optimal dosage	Patient-centered approach to tailor exercise based on needs and symptoms
Education	Requirement for multidisciplinary input, including psychological and nutritional support and fatigue management; need for resources for both patients and clinicians; inclusion of patient testimonials	N/A[a]	N/A
Access	Poor access to cancer rehabilitation	Acknowledgement of lack of sufficient suitable programs	Difficulty of generating and managing referrals; low confidence of other health professionals to refer patients to cancer rehabilitation

[a]N/A: Not applicable. There were no differences in the themes related to education between the 2 groups.

At the second joint workshop (workshop 4), further refinements were made (Multimedia Appendix 6) including changing the website name to the Cancer Exercise Toolkit [35] and creating a logo. The main feedback was related to navigation and the addition of content. More content was added on special cancer populations, including exercise modifications for specific cancers and side-effects of treatment. The final website was, and still is, a freely available web-based resource that can be self-navigated by users. At the time of evaluation, it comprised 8 sections including relevant information related to implementing exercise-based rehabilitation for cancer survivors (Multimedia Appendix 5 and Multimedia Appendix 7).

Phase 2: Pilot Evaluation

The website [31] was launched on World Cancer Day (February 4, 2021) and the baseline survey was accessed by 414 people, 37 of whom did not identify as exercise professionals; the survey was terminated. An additional 57 participants did not complete the survey. Respondents who were exercise professionals included 320 clinicians from 26 countries, with most having 5 years or less of cancer-specific experience (Table 3). The majority were physiotherapists (277/320, 87%). Just 120 of the 320 clinicians (38%) worked exclusively in cancer, palliative care, or lymphedema care. The main motivations for accessing the website were for professional development (142/320, 44%) and to improve patient care (17/320, 22%) (Figure 2).

Contact details for follow-up surveys were provided by 160 respondents, of whom 58 completed the follow-up survey (for a response rate of 36%). There were no differences in demographics between those who completed the baseline and follow-up surveys (Table 3).

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Table 3. Participant characteristics at baseline and in a 3-month follow-up survey.

Characteristics	Baseline (N=320)	3-month follow-up (n=58)
Discipline, n (%)		
Physiotherapy	277 (87)	51 (88)
Exercise physiology	43 (13)	7 (12)
Country or region, n (%)		
Australia	249 (78)	50 (86)
Europe/United Kingdom	38 (12)	3 (5)
Americas	15 (5)	3 (5)
Asia/Pacific	8 (3)	0 (0)
Africa	7 (2)	2 (3)
Middle East	1 (0.3)	0 (0)
City-based, n (%)	228 (71)	41 (71)
Setting, n (%)		
Public	159 (50)	29 (50)
Private	116 (36)	21 (36)
Both public and private	36 (11)	7 (12)
Other	9 (3)	0 (0)
Years of experience, mean (SD)	14 (10)	15 (10)
Years of cancer-specific experience (if applicable), n (%)		
<1	82 (26)	9 (16)
1-2	60 (19)	12 (21)
3-5	60 (19)	12 (21)
6-10	29 (9)	9 (15)
>10	25 (8)	7 (12)
Primary area of clinical practice, n (%)		
Cancer/palliative care/lymphedema	118 (37)	23 (40)
Other	200 (63)	35 (60)
Proportion of caseload cancer, n (%)		
76-100%	61 (19)	14 (24)
51-75%	26 (8)	5 (9)
26-50%	55 (17)	14 (24)
≤25%	174 (54)	25 (43)
Highest level of qualification, n (%)		
Undergraduate degree	138 (43)	24 (41)
Post-graduate certificate	71 (22)	12 (21)
Masters by coursework	73 (23)	17 (29)
Masters by research	13 (4)	1 (2)
PhD	20 (6)	4 (7)
Cancer-specific professional development completed[a]		
Informal training	175 (55)	0 (0)
External courses	173 (54)	0 (0)
Post-graduate education	42 (13)	0 (0)
Other	23 (7)	0 (0)

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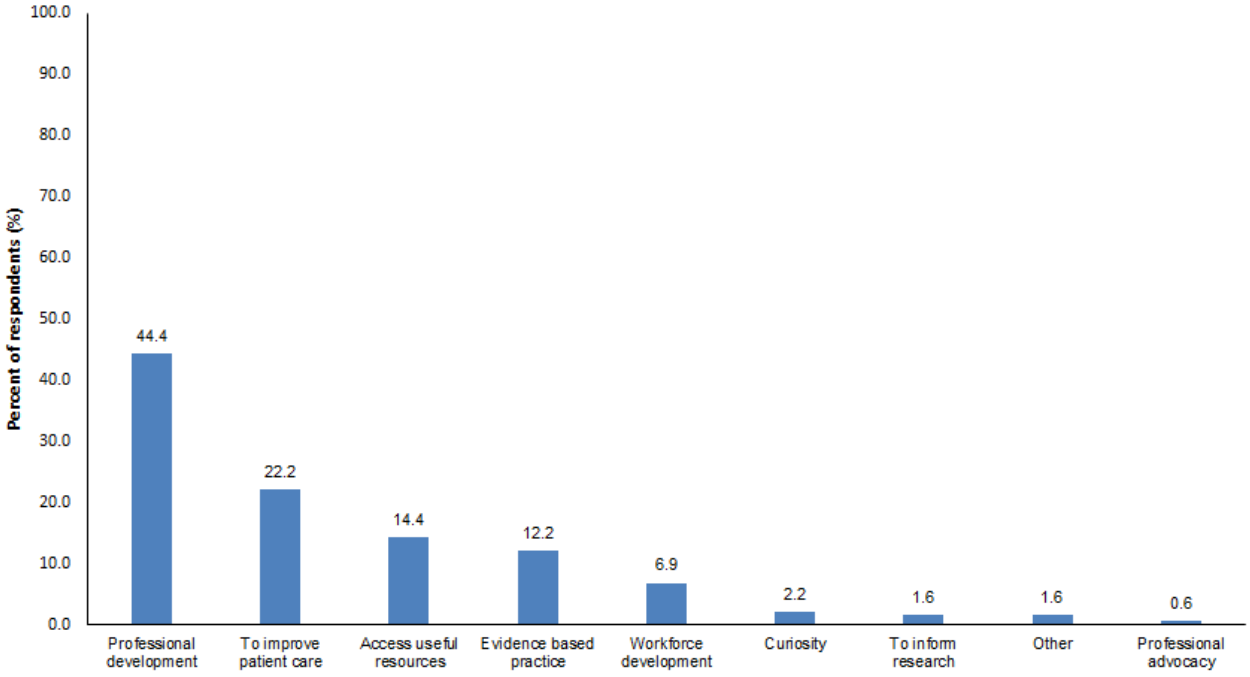
Characteristics	Baseline (N=320)	3-month follow-up (n=58)
None	45 (14)	0 (0)

[a]No responses were gained at follow-up as this question was not asked at follow-up.

Figure 2. Self-reported motivations for accessing the Cancer Exercise Toolkit website (multiple answers possible).



Usage, Usability, and Utility

After the 3-month pilot period, the toolkit received on average 866 views per month. Toolkit usage peaked in June 2021 at 1205 views and declined to 731 views in October 2021.

The most viewed pages were "Locations," "Patient Education," and "Precautions and Contraindications" (Multimedia Appendix 8).

Participants found the website useful, easy to understand, and easy to use (items 1 to 4: median score 6, IQR 5-7) (Table 4). Most participants (35/44, 80%) agreed or strongly agreed that they would recommend the Cancer Exercise Toolkit to colleagues. Open-ended feedback received from 11 participants was positive; the following are representative quotes:

> *Great source, filling a gap; like the pulmonary rehab toolkit.*
>
> *I had difficulties accessing the toolkit and never got around to sorting out the issue.*

Participants suggested some minor improvements to the website relating to accessibility (n=3), website function (n=2), increasing website scope (n=2), and dissemination (n=2).

Table 4. Website usability and utility.

Question	Median rating, IQR[a]	Rating 6 or 7 ("strongly agree"), n (%)
Overall, the Oncology Rehabilitation Toolkit website was easy to use (n=44)	6, 5-7	30 (68)
The content of the Oncology Rehabilitation Toolkit website met my expectations (n=44)	6, 5-7	31 (70)
Overall, it was easy to understand the organization of the Oncology Rehabilitation Toolkit website screens, especially the menu levels and the flow of the screens (n=42)	6, 5-7	28 (67)
How useful do you find the Oncology Rehabilitation Toolkit website to be? (n=44)	6, 5-7	29 (66)
I would recommend the Oncology Rehabilitation Toolkit website to my colleagues (n=44)	7, 6-7	35 (80)

[a]Numbers are Likert scales ranging from 1 ("strongly disagree") to 7 ("strongly agree")

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Determinants of Implementation Behavior Questionnaire

At baseline, participants rated themselves highest on items relating to their capability to deliver exercise rehabilitation according to guidelines and lowest on items relating to their training and ability to practice delivering exercise rehabilitation (Table 5, Multimedia Appendix 9).

At the 3-month follow-up, participants self-reported significantly higher scores on items related to knowledge and skills (items 1-7, $P<.001$) and confidence to deliver exercise therapy according to guidelines (items 8 and 9, $P<.001$) (Figure 3, Table 5).

Table 5. Determinants of Implementation Behavior Questionnaire. The significance level was set at $P<.001$ (Bonferroni adjustment). Italics indicate significance after the sensitivity analysis was applied. A total of 47 subjects did not complete this section of the survey at baseline. At follow-up, an additional 3 responses were excluded as participants indicated they never accessed the website.

Question	Baseline (N=273)	Follow-up (n=55)	Between-group difference (*P* value)
Knowledge, median (IQR)			
I know how to deliver Exercise Oncology Rehabilitation following the guidelines.	5 (3-6)	6 (5-6)	*<.001*
Objectives of Exercise Oncology Rehabilitation and my role in this are clearly defined for me.	4 (3-6)	5 (5-6)	*<.001*
With regard to Exercise Oncology Rehabilitation, I know what my responsibilities are.	5 (3-6)	6 (5-6)	*<.001*
In my work with Exercise Oncology Rehabilitation, I know exactly what is expected from me.	4 (3-5)	6 (5-6)	*<.001*
Skills, median (IQR)			
I have been trained in delivering Exercise Oncology Rehabilitation following the guidelines.	4 (1-5)	6 (4-6)	*<.001*
I have the skills to deliver Exercise Oncology Rehabilitation following the guidelines.	5 (3-6)	6 (5-6)	*<.001*
I am practiced to deliver Exercise Oncology Rehabilitation following the guidelines.	4 (2-5)	6 (4-6)	*<.001*
Confidence, median (IQR)			
I am confident that I can deliver Exercise Oncology Rehabilitation following the guidelines.	5 (3-6)	5 (5-7)	*<.001*
I am confident that I can deliver Exercise Oncology Rehabilitation following the guidelines even when other professionals with whom I deliver Exercise Oncology Rehabilitation do not do this.	4 (3-6)	5 (5-6)	*<.001*
I am confident that I can deliver Exercise Oncology Rehabilitation following the guidelines even when there is little time.	4 (3-5)	5 (4-6)	<.001
I am confident that I can deliver Exercise Oncology Rehabilitation following the guidelines even when participants are not motivated.	4 (3-5)	5 (4-6)	*<.001*

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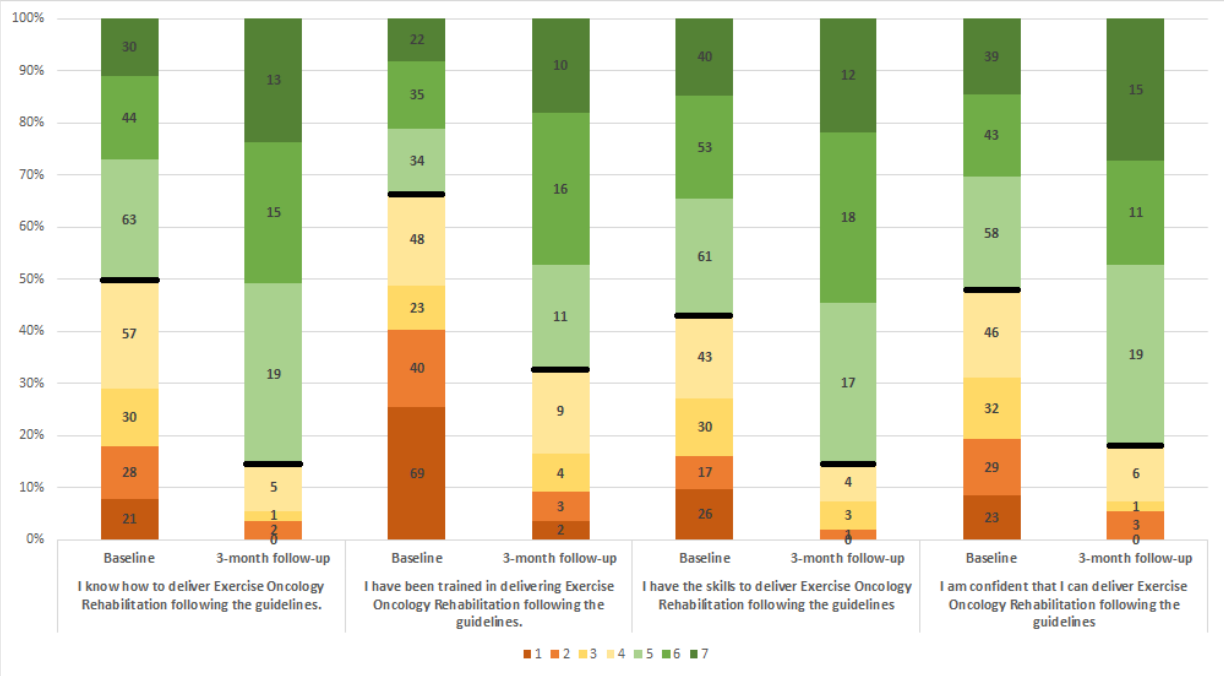
Figure 3. Differences in Determinants of Implementation Behavior (DIBQ) scores between baseline and 3-month follow-up. Figure legend: Shaded data refer to Likert scales ranging from 1 ("strongly disagree") to 7 ("strongly agree"), numbers refer to absolute number of participants who answered survey question.



Triangulation of Data

Qualitative data obtained from clinician workshops converged with quantitative survey data. Participants expressed a need to access information related to published exercise guidelines and described information related to exercise screening and safety as a priority. Areas of traffic on the toolkit were highest for pages related to safety and education (Multimedia Appendix 8). This aligned with survey item scores related to guidelines ("I know how to deliver Exercise Oncology Rehabilitation following the guidelines"; "I have been trained in delivering Exercise Oncology Rehabilitation following the guidelines"; "I have the skills to deliver Exercise Oncology Rehabilitation following the guidelines"; "I am confident that I can deliver Exercise Oncology Rehabilitation following the guidelines") improving at follow-up.

Discussion

Principal Findings

This study identified key learning needs of exercise professionals related to cancer care and facilitated development of the co-designed online Cancer Exercise Toolkit. Learning needs included knowledge of practical considerations for starting a cancer rehabilitation program; how to perform assessment, screening, and safety; and how to prescribe exercise, including tailoring and monitoring. Other important elements described by participants were facilitating access to care, clinician and patient education, and inclusion of templates and forms to support practice. The toolkit had international reach and was described as useful and easy to navigate. The pilot evaluation suggests the Cancer Exercise Toolkit may also improve exercise professionals' knowledge, skills, and confidence to deliver exercise therapy to cancer survivors.

Knowledge, skills, and confidence of exercise professionals to provide exercise therapy according to guidelines were rated higher after access to the Cancer Exercise Toolkit. This finding indicates that online toolkits such as this could be a useful knowledge translation strategy, supporting previous research showing that online platforms can support delivery of evidence-based practice [36]. The areas of highest traffic on the website after initial piloting included sections related to education, safety, and access. This aligns with the learning needs identified in the co-design workshops and with previous research indicating that these are the areas exercise professionals most lack confidence when managing people with cancer [12]. Building workforce capacity through development of high-quality education and broad dissemination is high on the agenda for the "Moving Through Cancer" movement to embed exercise as part of standard care by 2029 [37]. By improving the knowledge and skills of exercise professionals, it is likely to lead to better quality of care for cancer survivors and improve access to specialized cancer rehabilitation programs.

Most toolkit users were exercise professionals who did not specialize in cancer but were motivated to obtain professional development and improve patient care. Initial survey respondents and users indicated that we achieved a global reach, with more than 400 health professionals from 26 countries accessing the toolkit. This reach is important considering that recent national [38] and international guidelines [1] call for increased access and uptake of exercise services for cancer survivors. Highlighting the need for resources like the Cancer Exercise Toolkit, very few exercise professionals registered in Australia have specialist qualifications or training in cancer care. Moreover, many exercise professionals feel underprepared to practice in cancer care after their entry-level training [12]. Many professional bodies have only started developing post-graduate career pathways in cancer care in the past 5 years

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[39]. This study found that most clinicians receive their professional development through informal training, which may reflect the scarcity of professional development opportunities traditionally available in this area [12]. The Cancer Exercise Toolkit developed in this study provides generalist and specialist clinicians new opportunities to improve their cancer-specific knowledge and skills to meet increasing demand.

The toolkit appeared to meet clinician needs, being described as easy and useful, with most survey respondents agreeing they would recommend it to their colleagues. Characteristics of the toolkit informed by the co-design process reflected effective web design, such as easy navigation; inclusion of images, logos, and multimedia content; optimal organization, including a hierarchical structure; and content utility, determined by sufficiency, relevancy, quality, and motivational power of the information [40]. While there was a high initial uptake of the website, usage decreased over time. It is possible that participants obtained what they needed from the website when they initially accessed it, and that they therefore did not need to continue visiting it. Planning for ongoing promotion of the toolkit and updates with new content may also be required to improve user engagement. Planned strategies for ongoing sustainability include sharing and promotion via social media and seeking endorsement by key professional bodies. Maintenance of the toolkit will be imperative to ensure its ability to disseminate up-to-date exercise and cancer knowledge and meet clinicians' professional development needs in the future.

Strengths and Limitations

This is the first study to describe the development of a freely available toolkit to support exercise professionals working with cancer survivors. The co-design approach ensured end user learning needs were met through tailoring the toolkit based on clinician experience [23]. The effectiveness of co-design in health is not well established. However, qualitative reports indicate that participants in the co-design process have a positive experience, and materials derived from co-design projects are more applicable and acceptable to end users [23]. Co-design methods have commonly been used in curriculum design for secondary and tertiary education [41,42], but not for developing professional development toolkits in a health setting. Applicability of the toolkit was optimized by involving exercise professionals from a variety of clinical settings with a broad range of experience. Our broad dissemination approach, including engaging exercise professionals worldwide, also enhanced the generalizability of the end product.

There were limitations to this study. In the evaluation, only one-third of the original exercise professional participants completed the follow-up survey. Despite multiple attempts to improve engagement with the follow-up survey, including reminder emails and hosting a webinar where survey completion was promoted, the follow-up response rate remained low. This low response rate is consistent with other clinician surveys designed to evaluate physiotherapy professional development initiatives [43] and may be due to lack of time or motivation. To improve response rate, clinicians could be provided with further incentives to complete follow-up surveys, such as prizes, accredited professional development points, or certificates of completion. We were also unable to match participant responses due to the anonymous nature of the survey. It is also possible that the follow-up responses we did receive were from participants who were more interested and invested in cancer rehabilitation; these participants may have reported higher scores. However, the demographics of the participants who completed the follow-up survey were similar to the overall cohort. Additionally, a sensitivity analysis to account for the issue of dependence was conducted to increase the confidence in our results. Our inclusion of exercise professionals involved in the co-design of the toolkit during the evaluation phase also could have biased the outcome. However, we included this group to optimize the sample size available for evaluation, and to ensure that the changes made following the workshops were appropriate. Other health professionals, such as occupational therapists, dietitians, nurses, and doctors, were excluded, as they are not traditionally involved with specialist exercise prescription for cancer survivors. The website was developed for the Australian context. Health systems in other parts of the world may differ, and the content may need to be adapted to meet their needs. Despite this, positive feedback was received from participants from other countries, indicating that cross-cultural adaptation would likely be acceptable. Lastly, online resources may not be as effective at improving clinician behavior as more active learning strategies, such as workshops and mentoring [44].

Conclusion

This study described the development of the co-designed Cancer Exercise Toolkit. The toolkit was accessed by physiotherapists and exercise physiologists who described the website as valuable and easy to use. Exercise professionals rated their knowledge, skills, and confidence higher after accessing the website, indicating that it may be an effective alternative or complement to traditional professional development. The Cancer Exercise Toolkit may help improve access to exercise therapy and improve the effectiveness of care for cancer survivors through greater capability of the exercise professional workforce.

Acknowledgments

We would like to thank our steering committee, the co-design participants, and the consumers who helped with the development of the Cancer Exercise Toolkit. Thank you to Joshua Stopper for his contribution to web design. This project was funded by a grant from the Pat Cosh Trust.

Conflicts of Interest

None declared.

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Multimedia Appendix 1
Experience-based co-design (EBCD) steps.
[DOCX File , 22 KB - cancer_v8i2e34903_app1.docx]

Multimedia Appendix 2
Patient interview schedule.
[DOCX File , 24 KB - cancer_v8i2e34903_app2.docx]

Multimedia Appendix 3
Backgrounds of the research team.
[DOCX File , 12 KB - cancer_v8i2e34903_app3.docx]

Multimedia Appendix 4
Evaluation survey.
[DOCX File , 338 KB - cancer_v8i2e34903_app4.docx]

Multimedia Appendix 5
Description of website content.
[DOCX File , 12 KB - cancer_v8i2e34903_app5.docx]

Multimedia Appendix 6
Website changes.
[DOCX File , 13 KB - cancer_v8i2e34903_app6.docx]

Multimedia Appendix 7
Screenshot example of Cancer Exercise Toolkit.
[DOCX File , 2993 KB - cancer_v8i2e34903_app7.docx]

Multimedia Appendix 8
Cancer Exercise Toolkit Visits.
[DOCX File , 13 KB - cancer_v8i2e34903_app8.docx]

Multimedia Appendix 9
Full Determinants of Implementation Behavior Questionnaire (DIBQ) outcomes.
[DOCX File , 46 KB - cancer_v8i2e34903_app9.docx]

References

1. Campbell KL, Winters-Stone KM, Wiskemann J, May AM, Schwartz AL, Courneya KS, et al. Exercise guidelines for cancer survivors: consensus statement from International Multidisciplinary Roundtable. Med Sci Sports Exerc 2019 Nov;51(11):2375-2390. [doi: 10.1249/MSS.0000000000002116] [Medline: 31626055]
2. Schmitz KH, Campbell AM, Stuiver MM, Pinto BM, Schwartz AL, Morris GS, et al. Exercise is medicine in oncology: Engaging clinicians to help patients move through cancer. CA Cancer J Clin 2019 Nov;69(6):468-484 [FREE Full text] [doi: 10.3322/caac.21579] [Medline: 31617590]
3. Friedenreich CM, Stone CR, Cheung WY, Hayes SC. Physical activity and mortality in cancer survivors: a systematic review and meta-analysis. JNCI Cancer Spectr 2020 Feb;4(1):pkz080 [FREE Full text] [doi: 10.1093/jncics/pkz080] [Medline: 32337494]
4. Patel AV, Friedenreich CM, Moore SC, Hayes SC, Silver JK, Campbell KL, et al. American College of Sports Medicine Roundtable Report on Physical Activity, Sedentary Behavior, and Cancer Prevention and Control. Med Sci Sports Exerc 2019 Nov;51(11):2391-2402 [FREE Full text] [doi: 10.1249/MSS.0000000000002117] [Medline: 31626056]
5. Canestraro A, Nakhle A, Stack M, Strong K, Wright A, Beauchamp M, et al. Oncology rehabilitation provision and practice patterns across Canada. Physiotherapy Canada 2013 Jan;65(1):94-102. [doi: 10.3138/ptc.2011-53]
6. Dennett AM, Peiris CL, Shields N, Morgan D, Taylor NF. Exercise therapy in oncology rehabilitation in Australia: A mixed-methods study. Asia Pac J Clin Oncol 2017 Oct;13(5):e515-e527. [doi: 10.1111/ajco.12642] [Medline: 28004526]
7. Committee on Improving the Quality of Care Cancer. Addressing the challenges of an aging population, Board on Health Care Services, Institute of Medicine, an Aging Population BoHCS, Institute of Medicine. In: Levit L, Balogh E, Nass S, Ganz PA, editors. Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis. Levit L BE, Nass S. Ganz PA editors. Washington, DC: National Academies Press (US); Dec 27, 2013:-309.

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8. Allied Health Professionals Australia. Physiotherapy. 2021. URL: https://ahpa.com.au/allied-health-professions/physiotherapy/ [accessed 2021-11-04]
9. Allied Health Professionals Australia. Exercise Physiology. 2021. URL: https://ahpa.com.au/allied-health-professions/exercise-physiology/ [accessed 2021-11-04]
10. Australian Health Practitioner Regulation Agency (AHPRA). AHPRA and National Boards annual report 2019/20. URL: https://www.physiotherapyboard.gov.au/News/Annual-report.aspx [accessed 2022-01-18]
11. Exercise and Sport Science Association Australia. Annual Report '20. 2020. URL: https://www.essa.org.au/Public/About/Annual_Report/Public/ABOUT_ESSA/Annual_Reports.aspx?hkey=d2479c18-64d0-4f7a-ad7e-c1fb6be71898 [accessed 2020-09-20]
12. Dennett A, Rowe A, Mortimer J, Gordon C, Glagovski S, Osadnik C. Perceptions and work-readiness of Australian physiotherapists in cancer care: a national evaluation. Physiotherapy 2021;113:1-7. [doi: 10.1016/j.physio.2021.06.003]
13. Sheill G, Guinan E, O Neill L, Hevey D, Hussey J. Physical activity and advanced cancer: The views of chartered physiotherapists in Ireland. Physiother Theory Pract 2018 Jul;34(7):534-541. [doi: 10.1080/09593985.2017.1422821] [Medline: 29297722]
14. Scott SD, Albrecht L, O'Leary K, Ball GDC, Hartling L, Hofmeyer A, et al. Systematic review of knowledge translation strategies in the allied health professions. Implement Sci 2012 Jul 25;7:70 [FREE Full text] [doi: 10.1186/1748-5908-7-70] [Medline: 22831550]
15. Barton CJ, Merolli MA. It is time to replace publish or perish with get visible or vanish: opportunities where digital and social media can reshape knowledge translation. Br J Sports Med 2017 Nov 16;53(10):594-598. [doi: 10.1136/bjsports-2017-098367]
16. Lung Foundation Australia. Pulmonary Rehabilitation Toolkit. 2016. URL: https://pulmonaryrehab.com.au/ [accessed 2021-11-04]
17. Dale M. Media: Review - Pulmonary Rehabilitation Toolkit: a physiotherapist's perspective. J Physiother 2018 Oct;64(4):275-276 [FREE Full text] [doi: 10.1016/j.jphys.2018.07.002] [Medline: 30190215]
18. Stout NL, Baima J, Swisher AK, Winters-Stone KM, Welsh J. A systematic review of exercise systematic reviews in the cancer literature (2005-2017). PM R 2017 Sep;9(9S2):S347-S384 [FREE Full text] [doi: 10.1016/j.pmrj.2017.07.074] [Medline: 28942909]
19. Dennett AM, Elkins MR. Cancer rehabilitation. J Physiother 2020 Apr;66(2):70-72 [FREE Full text] [doi: 10.1016/j.jphys.2020.03.004] [Medline: 32291229]
20. Barton CJ, Ezzat AM, Bell EC, Rathleff MS, Kemp JL, Crossley KM. Knowledge, confidence and learning needs of physiotherapists treating persistent knee pain in Australia and Canada: a mixed-methods study. Physiotherapy Theory and Practice 2021 Apr 19:1-13. [doi: 10.1080/09593985.2021.1906805]
21. EBCD Experience-based co-design toolkit. The Point of Care Foundation. 2016. URL: https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/ [accessed 2021-09-17]
22. Tang CY, Turczyniak M, Sayner A, Haines K, Butzkueven S, O'Connell HE. Adopting a collaborative approach in developing a prehabilitation program for patients with prostate cancer utilising experience-based co-design methodology. Support Care Cancer 2020 Feb 18;28(11):5195-5202. [doi: 10.1007/s00520-020-05341-z]
23. Slattery P, Saeri AK, Bragge P. Research co-design in health: a rapid overview of reviews. Health Res Policy Sys 2020 Feb 11;18(1):17. [doi: 10.1186/s12961-020-0528-9]
24. Visser FS, Stappers PJ, van der Lugt R, Sanders EB. Context mapping: experiences from practice. CoDesign 2005 Apr;1(2):119-149. [doi: 10.1080/15710880500135987]
25. Dhand N, Khatkar M. Statulator: An online statistical calculator. 2014. URL: http://statulator.com/SampleSize/ss1P.html [accessed 2021-10-05]
26. Santa Mina D, Langelier D, Adams SC, Alibhai SMH, Chasen M, Campbell KL, et al. Exercise as part of routine cancer care. Lancet Oncol 2018 Sep;19(9):e433-e436. [doi: 10.1016/S1470-2045(18)30599-0] [Medline: 30191843]
27. Stout NL, Brown JC, Schwartz AL, Marshall TF, Campbell AM, Nekhlyudov L, et al. An exercise oncology clinical pathway: Screening and referral for personalized interventions. Cancer 2020 Jun 15;126(12):2750-2758 [FREE Full text] [doi: 10.1002/cncr.32860] [Medline: 32212338]
28. Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development. International Journal of Qualitative Methods 2016 Nov 29;5(1):80-92. [doi: 10.1177/160940690600500107]
29. Harris P, Taylor R, Minor B, Elliott V, Fernandez M, O'Neal L. The REDCap consortium: Building an international community of software platform partners. J Biomed Inform 2019:103208 [FREE Full text] [doi: 10.1016/j.jbi.2019.103208]
30. Huijg JM, Gebhardt WA, Dusseldorp E, Verheijden MW, van der Zouwe N, Middelkoop BJ, et al. Measuring determinants of implementation behavior: psychometric properties of a questionnaire based on the theoretical domains framework. Implementation Sci 2014 Mar 19;9(1):33. [doi: 10.1186/1748-5908-9-33]
31. Coursaris CS, Whitten P. Chapter 12 usability and accessibility of e-Health websites enabling nutrition and physical activity education for blind and low vision internet users. In: Evaluating Websites and Web Services: Interdisciplinary Perspectives on User Satisfaction 2014. Hershey, PA: IGI Global; 2014:E-23.

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32. Wang H. Using different methods to analyze the pre-post no-matching survey data in medical practical research. J Appl Computat Math 2015;4(5):55. [doi: 10.4172/2168-9679.C1.002]
33. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care 2007 Dec;19(6):349-357 [FREE Full text] [doi: 10.1093/intqhc/mzm042] [Medline: 17872937]
34. O'Cathain A, Murphy E, Nicholl J. The quality of mixed methods studies in health services research. J Health Serv Res Policy 2008 Apr;13(2):92-98. [doi: 10.1258/jhsrp.2007.007074] [Medline: 18416914]
35. Cancer Exercise Toolkit. 2021. URL: https://cancerexercisetoolkit.trekeducation.org [accessed 2021-10-20]
36. Camden C, Rivard LM, Hurtubise K, Héguy L, Berbari J. Can a community of practice improve physical therapists' self-perceived practice in developmental coordination disorder? Phys Ther 2017 Jul 01;97(7):746-755. [doi: 10.1093/ptj/pzx041] [Medline: 28444245]
37. Schmitz KH, Stout NL, Maitin-Shepard M, Campbell A, Schwartz AL, Grimmett C, et al. Moving through cancer: Setting the agenda to make exercise standard in oncology practice. Cancer 2021 Feb 01;127(3):476-484. [doi: 10.1002/cncr.33245] [Medline: 33090477]
38. Cormie P, Atkinson M, Bucci L, Cust A, Eakin E, Hayes S, et al. Clinical Oncology Society of Australia position statement on exercise in cancer care. Med J Aust 2018 Aug 20;209(4):184-187. [Medline: 29719196]
39. Stuiver MM, Stout NL, Dennett AM, Speksnijder CM, Campbell KL. An international perspective on integrating physiotherapists in oncology care. Journal of Physiotherapy 2019 Oct;65(4):186-188. [doi: 10.1016/j.jphys.2019.07.004]
40. Garett R, Chiu J, Zhang L, Young SD. A literature review: website design and user engagement. Online J Commun Media Technol 2016 Jul;6(3):1-14 [FREE Full text] [Medline: 27499833]
41. Wu J, Atit K, Ramey KE, Flanagan-Hall GA, Vondracek M, Jona K, et al. Investigating students' learning through co-designing with technology. J Sci Educ Technol 2021 Jan 25;30(4):529-538. [doi: 10.1007/s10956-020-09897-7]
42. Tissenbaum M, Lui M, Slotta J. Co-Designing collaborative smart classroom curriculum for secondary school science. J Univers Comput Sci 2012;18:327-352. [doi: 10.3217/jucs-018-03-0327]
43. Barton C, Kemp J, Roos E, Skou S, Dundules K, Pazzinatto M. Program evaluation of GLA:D® Australia: Physiotherapist training outcomes and effectiveness of implementation for people with knee osteoarthritis. Osteoarthritis Cartilage Open 2021:100175 [FREE Full text] [doi: 10.1016/j.ocarto.2021.100175]
44. Leahy E, Chipchase L, Calo M, Blackstock F. Which learning activities enhance physical therapist practice? part 1ystematic review and meta-analysis of quantitative studies. Phys Ther 2020;100(9):1469-1483. [doi: 10.1093/ptj/pzaa107]

Abbreviations

DIBQ: Determinants of Implementation Behavior Questionnaire
EBCD: experience-based co-design

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Original Paper

Mobile-Based Self-management Application Requirements for Patients With Gastric Cancer: Quantitative Descriptive Study of Specialist and Patient Perspectives

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Abstract

Background: Gastric cancer is one of the most common gastrointestinal cancers. Patients with gastric cancer experience disabilities and complications that lead to reduced quality of life. Empowering these patients by providing them with information and self-management skills can help reduce side effects and improve their quality of life.

Objective: The aim of this study was to identify the user requirements for developing a mobile-based self-management app to support patients with gastric cancer.

Methods: Data were analyzed using descriptive statistics and frequency distribution reports using IBM SPSS Statistics software.

Results: All of the data elements and functional requirements except “data recording times” and “weight changes in graphs” were identified as essential by clinical experts and patients. Among the functional requirements required in a gastric cancer self-management app, the capabilities related to informing, announcing warnings, and reminders are included. In the demographic data section, most patients (14/26, 53%) did not comment on the importance of recording data such as name, surname, and place of residence, and the demographic data section was met with less agreement from patients than clinicians.

Conclusions: Applying the requirements mentioned in this study can improve the self-management of patients with gastric cancer. Such apps can play an important role in empowering patients and improving their quality of life. However, the apps need to be designed and implemented to see how they can meet users’ requirements.

(JMIR Cancer 2022;8(2):e36788) doi:10.2196/36788

KEYWORDS

digital health, eHealth; telehealth; mHealth; mobile app; self-management; patient education; needs assessment, requirements analysis, stomach neoplasm, gastric cancer

Introduction

Cancer is one of the leading causes of death and disability worldwide, especially in developing countries. According to a report (GLOBOCAN), in 2020, 1 in 5 people were diagnosed with cancer during their lifetime, and 1 in 8 men and 1 in 11 women died due to the disease [1]. In some cases, cancer is caused not by a person's physical and genetic characteristics but by the person’s living environment [2-4]. Stomach cancer is now the fifth most common malignancy worldwide, after

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cancers of the lung, breast, colorectal, and prostate, with 1,033,701 new cases (5.7% of the total) estimated in 2018. It is the third most common cause of cancer-related death, with 782,685 deaths (8.2% of the total) in 2018 [5]. According to the National Cancer Institute, gastric cancer is very common in Japan, Central Latin America, South America, Eastern Europe, and parts of the Middle East [6]. In Iran, gastric cancer has been reported as the deadliest cancer. The statistics of disease incidence rates show the high incidence of gastrointestinal cancer in the northern provinces of the country, especially Mazandaran and Golestan [5,7].

Treatment for gastric cancer includes surgery, chemotherapy, and radiation therapy, which are used based on the stage of the disease. Surgery is a major and effective treatment in the early and advanced stages of the disease [8]. After gastrectomy surgery, there are many complications related to nutrition and gastrointestinal function. The most common of these complications are premature dumping syndrome, late dumping syndrome, and fat malabsorption, which can lead to gradual weight loss, premature satiety, abdominal pain, postprandial pain, and chronic diarrhea. Other nutritional problems that occur gradually include anemia, hypoxemia, vitamin C deficiency, and calorie and protein malnutrition, which have a significant impact on all aspects of the quality of life of these patients [9]. Self-management refers to the ability and autonomy of the individual to accept responsibility for self-care and to manage the physical, mental, and social consequences of having a chronic condition [10,11]. Today, self-management is performed by health care professionals through training booklets, audio and videotapes, and group meetings.

Currently, in the clinical environment, the most common types of patient education are using educational pamphlets, audiotapes, videos, and also oral presentations in personal or group sessions. These methods have low efficiency because they provide a large amount of information and rely on the individual's ability to recall information, which may lead to patient confusion. For example, about 40%-80% of oral information was immediately forgotten, and half of this information was not recalled correctly by patients [12]. Therefore, to solve these problems and limitations, new tools and approaches are needed, and smartphones are one of these suitable and well-known tools [13]. The advantages of using mobile health (mHealth) intervention include managing the improvement of the patient's condition during treatment and afterward, improving patient knowledge, self-management, drug management, and receiving social support from patients with similar conditions [14].

Therefore, due to the importance of self-management by patients with gastric cancer, the ineffectiveness of educational pamphlets and oral information, the role of smartphones in facilitating education and management [12,15,16], and the high prevalence of this cancer [1,5], the purpose of this study was to identify the requirements of mobile-based self-management app for patients with gastric cancer and help them to improve disease management.

Methods

Overview

This research was conducted using the quantitative descriptive method in 2021. The data collection tool in this study was a questionnaire designed by the research group (Multimedia Appendix 1). It was used to assess information needs and determine the data elements and capabilities required for a self-management app for patients with gastric cancer based on library studies, global guidelines for gastric cancer management and treatment, and searches of valid databases and scientific articles. This questionnaire was considered equal for the two groups of clinical staff and patients. The questionnaire consisted of 41 closed questions in 5 sections that included patient data (1 item), patient clinical data (8 items), disease management (6 items) and educational information (12 items), and app capabilities and functions in 3 areas of notices, program alerts, and reminders and screen capabilities of the program (14 items). At the end of the questionnaire, an open-ended question was asked to receive the participants' opinions on their issues. This questionnaire was designed based on a 5-point Likert scale. To determine the questionnaire content validity, the opinions of 5 experts in the field of cancer and information management were obtained, and the relevant corrections were made.

To determine questionnaire reliability, we used Cronbach alpha and invited 5 physicians and 10 patients with gastric cancer to participate. Cronbach alpha was 83% for the patient's individual data, 80% for the patient's clinical data section, 87% for the disease management section, 97% for the educational information section, and 92% for the app capabilities and functions section. Data analysis was performed based on the calculation of frequency distribution (number and percentage), mean, and quarter deviation index of each questionnaire question in IBM SPSS Statistics software (version 22; IBM Corp). Thus, if a total of 75% of the participants in the study or more chose the first two options (very important and important) in the questionnaire, that data element was considered in the final model, the data elements that a total of 50%-75% of the study population chose the first two options or the last two options in the questionnaire, were questioned again in the second stage of Delphi and comments below 50% of the model were removed. Thus, if a total of 75% of the participants in the study or more chose the first two options (very important and important) in the questionnaire, that data element was considered in the final model. The data elements for which 50%-75% of the study population chose the first two options or the last two options were included in the second stage of the Delphi process. Ultimately, comments below 50% of the model were removed. This study involved two rounds of the Delphi method. The scores of the questionnaire options were as follows: 5=very important, 4=important, 3=I have no opinion, 2=insignificant, and 1=very insignificant. In addition, if a new data element was suggested by at least 40% of the participants in the open question section of the questionnaire, the desired data element was used in the design of the program. Questionnaires were available to all medical specialists in the fields of cancer radiotherapy, blood and oncology, pathology, pharmacy, and head nurses of the chemotherapy department working in the hospitals of

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Mazandaran University of Medical Sciences, which had an oncology department (Bouali Sina and Imam Sari) and by available sampling to 30 patients with gastric cancer who were admitted to the oncology department and met the criteria for inclusion in the study. Inclusion criteria were technological skills, gastric cancer, smartphones, and a minimum age of 30 years and maximum age of 65 years. Finally, the obtained data were analyzed using descriptive statistics and frequency distribution reports and using IBM SPSS Statistics software.

Ethical Considerations

This study was reviewed by Mazandaran University of Medical Sciences and provided with ethics code IR.MAZUMS.REC.1399.7855.

Results

In the first round, 50 questionnaires (20 for clinical experts and 30 for patients) were distributed, and 42 questionnaires (16 by clinical experts and 26 by patients) were completed. In the second round, 50 questionnaires (20 for clinical experts and 30 for patients) were distributed, and 35 questionnaires (15 by clinical experts and 20 by patients) were completed. Most participants in the clinical group were male (n=10, 62%) and in the age range of 40-49 years (Table 1). Most of them had medical subspecialists degrees (n=9, 56%), and most of them (n=8, 50%) specialized in radiotherapy. In addition, most participants in this round (n=9, 56%) had work experience between 6 and 10 years. Most of the patient participants in the study were male (n=15, 57%) with a range of 50-59 years (Table 2). Most of them had a diploma (n=20, 77%), and most of them had a freelance job (n=8, 31%). Tables 1 and 2 show participants' characteristics in the first and second rounds of the Delphi study.

Table 1. Clinical experts' characteristics in the first and second rounds of the Delphi study.

Delphi study variables	Round 1, n (%)	Round 2, n (%)
Gender		
Male	10 (62)	9 (60)
Female	6 (38)	6 (40)
Age (years)		
30-39	0 (0)	0 (0)
40-49	12 (75)	11 (73)
50-59	2 (12)	2 (13)
60-69	2 (12)	2 (13)
Level of education		
BSc	2 (12)	2 (13)
MSc	0 (0)	0 (0)
Medical specialty	5 (31)	5 (33)
Medical subspecialty	9 (56)	8 (33)
Occupation		
Oncologist	2 (12)	2 (13)
Radiotherapist	8 (50)	7 (47)
Pathologist	3 (19)	3 (20)
Pharmacist	1 (6)	1 (7)
Nurse	2 (12)	2 (13)
Work experience in cancer (years)		
1-5	2 (12)	2 (13)
6-10	9 (56)	8 (53)
11-15	2 (12)	2 (13)
≥16	3 (19)	3 (20)

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Table 2. Patients characteristics in the first and second rounds of the Delphi study.

Delphi study variables	Round 1, frequency (%)	Round 2, frequency (%)
Gender		
Male	15 (57)	12 (60)
Female	11 (43)	8 (40)
Age (years)		
30-39	0 (0)	0 (0)
40-49	8 (31)	4 (20)
50-59	10 (38)	10 (50)
60-65	8 (31)	6 (30)
Level of education		
Diploma	20 (77)	16 (80)
Associate degree	3 (12)	1 (50)
BSc	3 (12)	3 (15)
MSc	0 (0)	0 (0)
PhD or above	0 (0)	0 (0)
Occupation		
Clerk	3 (12)	3 (12)
Farmer	4 (15)	0 (0)
Freelance job	8 (31)	12 (60)
Retired	7 (27)	5 (25)
Unemployed	4 (15)	0 (25)

Table 3 and Table 4 show participants' response distribution regarding data elements and functional requirements. Most of the data elements were identified as very important or significant by the majority of participants (Table 3).

Among the data elements required in the patient's clinical data part, the highest mean was the treatment types used (mean 4.3, SD 0.91), and appointment time with doctor had the lowest mean (3.3, SD 1.66). Among the data elements required in the disease management part, the treatment protocols (ie, surgery, radiotherapy, and chemotherapy) had the highest mean (4.6, SD 0.95), and complementary therapies had the lowest mean (3.8, SD 1.17). Among the data elements required by the educational information, the highest mean belonged to physical activity (mean 4.4, SD 0.91), and the lowest mean belonged to excretory substances (mean 3.6, SD 1.18). Moreover, medication reminders had the highest mean (4.2, SD 0.95), and the nutrition reminders had the lowest average of the functional requirements for mobile-based self-management apps (mean 3.3, SD 0.48). However, some data elements led to the second round of Delphi, such as medication, other diseases and medications, appointment time with a doctor, excretory substances, list of cancer treatment centers, hopeful quotes notification, nutrition reminder, the ability to display the date entry time and date, and weight changes graph (Table 4).

In the second round, 15 specialists and 20 patients participated. Most of the participants in the study were male (n=9, 60%) and in the age range of 40-49 years (n=11, 73%). Most of them had a subspecialty degree (n=8, 53%), and most of them specialized in radiotherapy (n=7, 47%). In addition, most participants in this round (n=8, 53%) had work experience between 6 and 10 years. In addition, most of the patient participants in the study were male (n=12, 60%) and in the age range of 50-59 years (n=10, 50%). Most of them had a diploma (n=16, 80%), and most of them had a free job (n=12, 60%).

These results show that in the demographic data section, most patients did not comment on the importance of recording data such as name, surname, and place of residence and were met with less agreement from patients compared to clinicians. Furthermore, the group of clinical specialists emphasized the importance of recording the type of treatments, paraclinical measures (eg, laboratory tests, sonography, mammography, radiography, endoscopy, and cytology), and their results as well as introducing the side effects of chemotherapy and their medication interactions. Patients emphasized the importance of educational information such as nutrition management, emotional support, health advice during chemotherapy, and wound care after surgery. In terms of functional requirements, the patient group paid more attention to the necessary reminders for medication, visiting a doctor, and performing paraclinical procedures in the app, while experts emphasized the need for reminders to screen the patient's first-degree family. Moreover, the experts stated as the main treatment for gastric cancer is related to chemotherapy and surgery, so the list of surgeons and medical subspecialists in hematology and oncology should be considered in the field of informing capabilities of the app.

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Table 3. Participants' response distribution regarding required data elements for mobile-based self-management app (round 1).

Data elements	Patients, mean (SD)	Clinical specialists, mean (SD)	Total, mean (SD)	Agreement
Demographic data	3.7 (0.82)	4.2 (0.93)	3.8 (1.15)	✓
Clinical patients data				
Occurrence of early symptoms (day/month/year)	3.92 (1)	4.4 (0.72)	4.1 (1.07)	✓
Diagnosis time (day/month/year)	3.9 (0.88)	3.8 (1.14)	3.8 (1.02)	✓
Paraclinical test history	3.9 (1.19)	4.36 (0.76)	4.1 (1.02)	✓
Treatments type (surgery, chemotherapy, radiotherapy)	4.1 (0.98)	4.46 (0.74)	4.3 (0.91)	✓
Medication	3.1 (1.57)	3.6 (1.66)	3.4 (1.59)	__[a]
Other diseases and medications	3.1 (1.44)	3.7 (1.12)	3.4 (1.32)	—
Appointment time with a doctor	3.1 (1.55)	3.6 (1.66)	3.3 (1.66)	—
Time for paraclinical tests	3.85 (1.01)	4.6 (0.8)	4.2 (0.95)	✓
Disease management				
Gastric cancer causes	4.0 (1.14)	4.5 (0.51)	4.2 (0.99)	✓
Gastric cancer symptoms	4.1 (0.94)	4.7 (0.34)	4.3 (0.94)	✓
Diagnostic methods (test, ultrasound, imaging, pathology)	3.7 (1.11)	4.1 (0.99)	3.9 (1.1)	✓
Treatment protocols (surgery, radiation therapy, chemotherapy, etc)	4.2 (1.06)	4.8 (0.34)	4.6 (0.95)	✓
Side effects and Medication interactions	4.1 (0.98)	4.4 (0.82)	4.3 (0.91)	✓
Complementary therapies	3.7 (1.21)	4.0 (0.96)	3.8 (1.17)	✓
Educational information				
Nutrition management	4.5 (0.51)	4.1 (0.96)	4.3 (0.8)	✓
Risk factors	4.2 (1.04)	4.1 (1.32)	4.1 (1.10)	✓
Excretory substances	3.4 (1.09)	3.8 (1.36)	3.6 (1.18)	—
Rest	4.1 (0.99)	3.7 (1.11)	3.9 (1.13)	✓
Stress management	4.2 (0.98)	4.1 (1.2)	4.1 (1.1)	✓
Emotional support for patient and family	4.4 (0.82)	4.1 (1.02)	4.3 (0.91)	✓
Physical activity management	4.6 (0.82)	4.3 (1.02)	4.4 (0.91)	✓
Health advice during chemotherapy	4.1 (1.31)	3.7 (1.26)	3.9 (1.28)	✓
Warning/danger symptoms during treatment (jaundice, bloody stools, bloody vomit)	4.1 (0.99)	3.7 (1.17)	3.8 (1.13)	✓
Family education	4.0 (0.96)	3.9 (1.21)	3.9 (1.17)	✓
Wound care after surgery	4.4 (0.82)	4.1 (0.98)	4.3 (0.91)	✓
Frequently asked questions	3.9 (1.13)	4.4 (0.72)	4.0 (1.07)	✓

[a]No agreement reached.

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Table 4. Distribution of the participants' responses regarding functional requirements for mobile-based self-management app (round 1).

App functional requirements	Patients, mean (SD)	Clinical specialists, mean (SD)	Total, mean (SD)	Agreement
Notices				
List of cancer treatment centers	3.6 (1.19)	3.3 (1.45)	3.5 (1.28)	__[a]
List of cancer radiotherapists and hematologist-oncologist	4.3 (0.76)	3.9 (1.19)	4.1 (1.05)	✓
Alerts and reminders				
Medication reminder	4.4 (0.81)	4.1 (1.09)	4.2 (0.95)	✓
Appointment reminder	4.0 (0.92)	3.9 (1.13)	3.9 (1.03)	✓
paraclinical test reminder	4.1 (0.99)	3.7 (1.17)	3.8 (1.09)	✓
Screening reminder	3.6 (1.26)	4.1 (0.96)	3.9 (1.12)	✓
Physical activity reminder	3.6 (1.26)	4.0 (0.92)	3.8 (1.15)	✓
Hopeful quotes notification	3.6 (1.19)	3.2 (1.45)	3.4 (1.23)	—
Nutrition reminder	3.0 (1.50)	3.6 (1.46)	3.3 (1.48)	—
Display capabilities				
Ability to display data entry date	3.4 (1.36)	3.7 (1.39)	3.6 (1.38)	—
Ability to display data recording time	3.3 (1.45)	3.7 (1.11)	3.5 (1.32)	—
Show weight changes graphically	3.1 (1.50)	3.7 (0.98)	3.5 (1.23)	—
Ability to record ultrasound images, test results, etc	3.9 (1.16)	3.8 (1.05)	3.8 (1.13)	✓
Reports	4.1 (0.99)	3.7 (1.11)	3.9 (1.05)	✓

[a]No agreement reached.

Discussion

Principal Findings

The findings of this study showed that from the perspective of clinicians and patients, most components related to personal data, patient clinical data, disease management, and educational information, as well as app capabilities such as notices, alerts, and reminders, and screen-related capabilities other than "ability to display data recording hours and display weight changes in charts" were required. The findings of this study showed that most patients did not comment on the importance of recording data such as name, surname, and location, and personal data were met with less agreement from patients compared to clinicians. This may be due to concerns about privacy and confidentiality. Therefore, the results of this study are in line with the results of Neobek et al [17], who expressed users' concerns about privacy as the main obstacle in using health-related self-management programs. In addition, the study of Malmi et al [18] also mentioned the importance of security and access to identity information in the design of apps. Therefore, due to the possibility of data transfer and communication with clinical specialists in apps, the existence of demographic information in self-management apps is essential.

In similar studies, the importance of recording patient clinical data was reported. In this regard, Sicotte et al [19] has shown that recording patient data and using electronic medical records led to improved flow of information, increased quality of care, and reduced the average waiting time in cancer outpatient centers. In addition, Yazdanian et al [20] stated it is possible to record patients' clinical data electronically and manage the course of cancer from screening and prevention to treatment and beyond, despite the breadth of data elements related to cancer patient care. Levy et al [21] also created a form to collect data related to the chemotherapy protocol, assess pretreatment symptoms and provide chemotherapy training in the electronic health record. This form included data elements such as name, dose, and method of injection, as well as the expiration date of the medication. Mukai et al [22] also designed the Advanced Medical Information Database System (AMIDAS) to record clinical data and archive radiotherapy information. The data required by the AMIDAS system included patient demographic information, tumor data, radiotherapy treatment plan, follow-up (tumor complications, disease progression reactions, mortality, etc), laboratory results, and treatment delivery. Therefore, it seems that designing an app with a mobile phone will provide a complete view of patients with cancer by considering the types of data required by the oncology, chemotherapy, and radiotherapy departments, resulting in the integration of the data of patients with cancer, improving the quality of care, making more informed decisions, and reducing the time required to search for patient information.

The findings showed, due to the need for disease management, the presence of information on gastric cancer and its causes, symptoms, types of diagnostic methods, and treatment regimens are necessary. In a study conducted to develop a tablet-based app for patients with gastric cancer, Wu et al [15] found that patients had much less weight loss than the control group by providing sufficient information on the symptoms of the disease.

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In addition, Wu et al [23] designed a smartphone-based app that reminded activities related to nutritional status, medical information management, drainage follow-up, and wound care in patients with gastric cancer after surgery. This app informed patients of severe weight loss or possible bleeding by including clinical decision support. Ultimately, it achieved the highest level of satisfaction in 93% of users. Therefore, it seems that patients with gastric cancer need sufficient information about the causes and symptoms of the disease, diagnostic methods, and types of treatment regimens to improve their knowledge about the pathology and the course of the disease and the role and importance of treatment regimens.

Educational information was another major topic that many patients and clinicians emphasized, including the importance of nutrition management, stress management, health advice during chemotherapy, and more. In a similar study, June and Park [24] conducted a self-management program with 22 items in 7 areas of management of dietary restrictions, avoidance of risk factors, attention deposits, stress management and psychological support, attention to rest, regular diet, and follow-up care for patients with gastric cancer after gastrectomy. In this regard, Davoodi et al [9] emphasized the important role of the effect of self-care program training on the quality of life of patients with gastric cancer after surgery, especially in the psychological dimension. Moreover, Xuan [25] emphasized the very positive effect of self-management training on weight changes and quality of life in patients with gastric cancer that undergoing chemotherapy. In a review study, Mehdizadeh et al [12] found that mobile apps can provide easy access to appropriate and reliable information for patients with cancer and their families. Therefore, it seems providing educational information for supporting self-management by using mHealth intervention and mobile app can help patients with gastric cancer. It could be useful for nutrition management, diet therapy, improved physical activity, psychological and social effects, and sharing patients' experiences with others.

Functional requirements related to informing, warnings, and reminders were functional requirements identified by participants as essential features for a gastric cancer self-management app. Some studies have reported that timely use of medications can lead to reduced disease recurrence and progression, reduced risk of mortality, and increased quality of life in patients with colorectal cancer. In this regard, Slatter et al [26] helped patients and their families by designing the ONCO FAMILY APP app, which had a reminder module for taking medication and seeing a doctor. In another study, Kock and colleagues [27] designed a LESS app with a calendar and reminder module for children with cancer. This module automatically reminds users of their appointments and periodic tests by specifying points on the calendar. Therefore, it seems mHealth interventions could be used as a promotional tool for encouraging people to participate in self-management activities and improving patient adherence to treatment protocols and communication between health care providers and patients.

Limitations

This research had some limitations. First of all, although most medical specialists in the fields of cancer radiotherapy, blood and oncology, pathology, pharmacy, and head nurses of the chemotherapy department working in the teaching hospitals of Mazandaran University of Medical Sciences, which had an oncology department (Bouali Sina and Imam Sari), took part in the study, the number of the participants in the first and second rounds of the Delphi study was limited. However, as there is no well-defined rule for selecting a specific number of participants in a Delphi study and representation is assessed by the quality of the expert panel rather than its number, we can conclude that the participants were well-experienced clinicians in cancer care and the results might be generalized to larger sample sizes. The second issue might be related to the level of details associated with each data element. Although we reached a large number of data elements necessary for designing a mobile-based self-management app for patients with gastric cancer, it was not possible to include all of them in the questionnaire. Therefore, more details about other data elements, which might not be mentioned in this study, should be investigated before or during designing a real system.

Conclusions

The goal of this study was to identify app requirements for the self-management of patients with gastric cancer. The features provided included personal data, patient clinical data, disease management, educational information, and functional requirements such as notifications and reminders that could be used for developing software or apps and made available for users. These apps can play an important role in empowering patients and also improving their quality of life. However, the apps need to be designed and implemented to see how they can meet users' requirements.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Data elements and functional requirements questionnaire.
[DOCX File , 23 KB - cancer_v8i2e36788_app1.docx]

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References

1. Sung H, Ferlay J, Siegel RL, Laversanne M, Soerjomataram I, Jemal A, et al. Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries. CA Cancer J Clin 2021 May 04;71(3):209-249. [doi: 10.3322/caac.21660] [Medline: 33538338]
2. Amereh F, Jahangiri-Rad M, Mazloomi S, Rafiee M. The role of environmental and lifestyle factors in the incidence and prevalence of cancer. J Environ Health Eng 2017 Jan 01;4(1):30-42. [doi: 10.18869/acadpub.jehe.4.1.30]
3. Jemal A, Bray F, Center MM, Ferlay J, Ward E, Forman D. Global cancer statistics. CA Cancer J Clin 2011 Feb 04;61(2):69-90 [FREE Full text] [doi: 10.3322/caac.20107] [Medline: 21296855]
4. Vineis P, Xun W. The emerging epidemic of environmental cancers in developing countries. Ann Oncol 2009 Feb;20(2):205-212 [FREE Full text] [doi: 10.1093/annonc/mdn596] [Medline: 18854551]
5. Ghasemi-Kebria F, Amiriani T, Fazel A, Naimi-Tabiei M, Norouzi A, Khoshnia M, et al. Trends in the Incidence of Stomach Cancer in Golestan Province, a High-risk Area in Northern Iran, 2004-2016. Arch Iran Med 2020 Jun 01;23(6):362-368. [doi: 10.34172/aim.2020.28] [Medline: 32536172]
6. Rastaghi S, Jafari-Koshki T, Mahaki B, Bashiri Y, Mehrabani K, Soleimani A. Trends and risk factors of gastric cancer in Iran (2005–2010). International journal of preventive medicine 2019 May 17;10(1):79. [doi: 10.4103/ijpvm.ijpvm_188_17]
7. Ghorbani Gholiabad S, Yazdani Cherati J, an Babai G, Shabankhani B. Survival of Patients with Gastric Cancer in Mazandaran Province, 2007-2012. J Mazandaran Univ Med Sci 2013 May;23(100):43-50 [FREE Full text]
8. Yazdani CJ, Zare S, Ghorbanpour E, Shabankhani B. Demographic and geographical pattern of mortality rate from stomach cancer and related factors in Mazandaran province from 2001 to 2005. J Maz Univ Med Sci 2010 Oct 05;20(79):2-7 [FREE Full text]
9. Davoodi A, Gholizadeh L, Rezazadeh H, Sheikalipour Z, Lakdizaji S, Mirinajad K, et al. Effects of a self-care education program on quality of life of patients with gastric cancer after gastrectomy. Journal of Community and Supportive Oncology 2015 Sep 01;13(9):330-336. [doi: 10.12788/jcso.0158]
10. Tung H, Lin C, Chen K, Chang C, Lin Y, Chou C. Self-management intervention to improve self-care and quality of life in heart failure patients. Congest Heart Fail 2013 Aug 01;19(4):E9-E16 [FREE Full text] [doi: 10.1111/chf.12014] [Medline: 23279120]
11. Omisakin F, Ncama B. Self, self-care and self-management concepts: implications for self-management education. Educational Research 2011 Dec 01;2(12):1733-1737 [FREE Full text]
12. Mehdizadeh H, Asadi F, Mehrvar A, Nazemi E, Emami H. Smartphone apps to help children and adolescents with cancer and their families: a scoping review. Acta Oncol 2019 Jul 01;58(7):1003-1014. [doi: 10.1080/0284186X.2019.1588474] [Medline: 30915872]
13. Williams PD, Schmideskamp J, Ridder EL, Williams AR. Symptom monitoring and dependent care during cancer treatment in children: pilot study. Cancer Nursing 2006 Jun 01;29(3):188-197. [doi: 10.1097/00002820-200605000-00004] [Medline: 16783117]
14. Nasi G, Cucciniello M, Guerrazzi C. The role of mobile technologies in health care processes: the case of cancer supportive care. J Med Internet Res 2015 Mar 12;17(2):e26 [FREE Full text] [doi: 10.2196/jmir.3757] [Medline: 25679446]
15. Wu J, Yu H, Ho T, Su X, Lin M, Lai F. Tablet PC-enabled application intervention for patients with gastric cancer undergoing gastrectomy. Comput Methods Programs Biomed 2015 May;119(2):101-109. [doi: 10.1016/j.cmpb.2015.03.004] [Medline: 25819034]
16. Wu J, Ho T, Chang Y, Hsu C, Tsai CJ, Lai F, et al. Wearable-Based Mobile Health App in Gastric Cancer Patients for Postoperative Physical Activity Monitoring: Focus Group Study. JMIR Mhealth Uhealth 2019 Apr 23;7(4):e11989 [FREE Full text] [doi: 10.2196/11989] [Medline: 31012858]
17. Neubeck L, Lowres N, Benjamin EJ, Freedman SB, Coorey G, Redfern J. The mobile revolution--using smartphone apps to prevent cardiovascular disease. Nat Rev Cardiol 2015 Jul;12(6):350-360. [doi: 10.1038/nrcardio.2015.34] [Medline: 25801714]
18. Malmi E, Weber I. Demographic prediction based on user's apps. 2016 Presented at: International AAAI Conference on Web and Social Media; 2016/05/20; Cologne-Germany.
19. Sicotte C, Lapointe J, Clavel S, Fortin M. Benefits of improving processes in cancer care with a care pathway-based electronic medical record. Pract Radiat Oncol 2016;6(1):26-33. [doi: 10.1016/j.prro.2015.08.011] [Medline: 26598908]
20. Yazdanian A, Ayatollahi H, Nahvijou A. A Conceptual Model of an Oncology Information System. Cancer Manag Res 2020;12:6341-6352 [FREE Full text] [doi: 10.2147/CMAR.S259013] [Medline: 32821154]
21. Levy MA, Giuse DA, Eck C, Holder G, Lippard G, Cartwright J, et al. Integrated information systems for electronic chemotherapy medication administration. J Oncol Pract 2011 Jul;7(4):226-230 [FREE Full text] [doi: 10.1200/JOP.2011.000259] [Medline: 22043185]
22. Mukai M, Ando Y, Yokooka Y, Okuda Y, Seki M, Kimura M, et al. Development of Clinical Database System Specialized for Heavy Particle Therapy. Stud Health Technol Inform 2015;216:933. [Medline: 26262235]
23. Wu J, Lin M, Ho T, Su X, Lai F. Smartphone Application for Post-operative Gastric Patients. 2014 Apr 20 Presented at: The Sixth International Conference on Bioinformatics, Biocomputational Systems and Biotechnologies; 2014/04/20; Chamonix, France.

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24. Jeon MK, Park GJ. Development of a Self-Care Performance Scale for Patients with Stomach Cancer after Gastrectomy. Asian Oncol Nurs 2016;16(2):67. [doi: 10.5388/aon.2016.16.2.67]
25. Zhuo-yan C. Application of self-management education to the dietary guidance in gastric cancer patients with chemotherapy. Journal of Qilu Nursing 2012:30.
26. Slater PJ, Fielden PE, Bradford NK. The Oncology Family App: Providing Information and Support for Families Caring for Their Child With Cancer. J Pediatr Oncol Nurs 2018;35(2):94-102. [doi: 10.1177/1043454217741874] [Medline: 29161974]
27. Kock AK, Kaya RS, Müller C, Andersen B, Langer T, Ingenerf J. Design, implementation, and evaluation of a mobile application for patient empowerment and management of long-term follow-up after childhood cancer. Klin Padiatr 2015 May;227(3):166-170. [doi: 10.1055/s-0035-1548840] [Medline: 25985450]

Abbreviations

AMIDAS: Advanced Medical Information Database System
mHealth: mobile health

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Original Paper

Evaluation of a Mobile Health App Offering Fertility Information to Male Patients With Cancer: Usability Study

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Abstract

Background: Cancer and its treatment can adversely affect male fertility. Although sperm banking is an effective fertility preservation method, there is an unmet need for information and support surrounding these issues.

Objective: This usability study evaluates a mobile health app providing male patients with cancer with credible information about the impact of cancer and its treatment on fertility and fertility preservation.

Methods: Participants were recruited by a market research firm. Eligibility criteria were men who were 18-45 years of age, identified as male, diagnosed with new or recurring cancer within 1 year, not in fertility treatment, able to read and write in English or French, and had internet access. App usage was tracked for 2 weeks. After app use, participants provided qualitative feedback about their experiences using the app as well as quantitative data regarding their sperm banking decisions, perceived change in fertility knowledge, evaluation of the app's information on the Information Assessment Method, and the app's quality on the user version of the Mobile App Rating Scale.

Results: The sample included 40 men aged 27-45 years. Approximately 68% (27/40) indicated that no one had previously spoken to them about the impact of cancer on fertility, and 85% (34/40) had not received information on fertility preservation. Approximately 83% (33/40) found the app's information relevant, and 85% (34/40) said that it increased their fertility knowledge. Approximately 23% (9/40) made a decision about sperm banking after using the app. Participants rated the app's quality highly, with mean scores (out of 5) of 4.14 for information, 4.06 for functionality, 3.84 for aesthetics, and 3.63 for engagement.

Conclusions: The app proved to be useful for male patients with cancer, suggesting that mobile health resources could be beneficial to incorporate into clinical care to enable shared decision-making about fertility.

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KEYWORDS

mobile app; eHealth; male; cancer; infertility; fertility preservation; psycho-oncology

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Introduction

About 8600 Canadian boys and men aged 15-39 years are diagnosed with cancer yearly [1]. Cancer can adversely affect male fertility by damaging the reproductive organs, disrupting hormone levels, or impairing sperm production/release [2]. Male fertility can also be affected by cancer treatment, including chemotherapy, radiation, and surgery [3-6]. As survival rates improve [7], patients face long-term consequences of cancer and its treatment [8]. Psychological distress is common among men with cancer who may fear disease recurrence or feel inadequate and for whom cancer might interfere with career goals and family planning [9]. Cancer treatment may result in decreased libido, sexual dissatisfaction, erectile dysfunction [9], and cause difficulties in cultivating intimate relationships [10].

The most established method to preserve male fertility before cancer treatment is semen cryopreservation, also known as sperm banking [4,11]. For most patients, the semen sample is collected via masturbation [12]. However, in patients with difficulties providing a semen sample via ejaculation, there are a variety of alternative sperm retrieval techniques that can be used (eg, electroejaculation, aspiration of sperm from the testicle or epididymis) [12,13]. Banked sperm can then be used to achieve a pregnancy with the use of assisted reproductive techniques such as in vitro fertilization and intracytoplasmic sperm injection [4]. There are also options for men who do not have viable sperm, such as the use of donor sperm in conjunction with in vitro fertilization and intracytoplasmic sperm injection, as well as adoption [11].

Although sperm banking is an effective fertility preservation method [14], there is an unmet need for information and support surrounding these issues [15-17]. Most male patients with cancer view receiving fertility information as very important but are often dissatisfied with the information obtained [16]. The urgency to begin treatment or fear of passing cancer to offspring may act as barriers to sperm banking [15,18,19]. Factors that often prevent fertility preservation conversations include the potential distress from discussing infertility risk, limited access to educational materials, and clinicians' lack of time and knowledge [20]. Additionally, men may not initiate these conversations since they are generally less likely than women to ask questions during medical appointments [21].

There is a need for fertility preservation resources to be better integrated into cancer care [4,15,18,22]. In a survey conducted by our team, 80% of male patients with cancer preferred receiving fertility information at the first oncology consult or at the time of diagnosis and treatment planning [15]. Loren et al [18] recommend that referrals to counselling services be incorporated into routine care for men with fertility concerns. Thus, it is imperative that clinicians discuss fertility preservation with patients as early as possible and refer them to reproductive specialists.

eHealth resources are viewed positively by cancer survivors [23] and are suitable for men who often value autonomy and anonymity when seeking information [24]. However, current web-based information for male patients with cancer is not comprehensive, less accessible than that for female patients [25], of inadequate readability and quality [26], and is not rigorously evaluated [27]. One study has assessed the feasibility of a web-based intervention targeting fertility distress after cancer, but their sample includes only 4 men [28,29]. Given the widespread use of smartphones [30], mobile health (mHealth) apps show promise as tools to improve the quality of life of patients with cancer [31].

To address the need for fertility information tailored to male patients with cancer, our team developed an mHealth app, *Infotility XY*, providing information on the impact of cancer and its treatment on male fertility and fertility preservation. In this study, we evaluate the app's quality and information, as well as its potential to improve fertility knowledge and help patients make fertility preservation decisions.

Methods

App Study Design

The study design for the *Infotility XY* app adhered to the Medical Research Council guidelines for the development and evaluation of complex interventions [32]. The guidelines include 4 phases: development, feasibility and piloting, evaluation, and implementation [32].

In the development phase of the study, our team designed 3 versions of the *Infotility/Infotilité XY* app for 3 populations in collaboration with an app development company: men in the general public, male patients with infertility, and male patients with cancer. In this paper, only data from the sample of patients with cancer are presented.

The app content was written by our team and informed by extensive literature reviews and a needs assessment survey of the fertility-related informational and support needs of male patients with cancer [15]. Key stakeholders, including male patients with cancer, were included throughout the app development process, informing the app's content and design elements. Content was vetted by health professionals and experts in patient-centered care. All content was available in English and French.

In addition to information about sperm banking, the app for male patients with cancer provided information on fertility treatment in general (eg, in vitro fertilization) as well as the use of donor sperm. The app also addressed common concerns among male patients with cancer such as the risk of passing their cancer onto future children, which was a concern that came up in the needs assessment survey among male patients with cancer. The app included 19 articles grouped into 4 categories: "Fertility and cancer," "Sperm banking 101," "After banking," and "Talking to my partner about sperm banking" (see Multimedia Appendix 1 for the list of the articles). Each article had the option to give a thumbs-up/down to indicate its usefulness. The app featured pop-up glossary definitions, infographics, animations, and a Canada-wide map of fertility clinics (see Multimedia Appendix 2 for screenshots of the app).

Our research team collaborated with an app company to transform the informational content into a user-friendly app.

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The app company helped develop the look and feel of the app (eg, color scheme, graphics), the different features in the app (eg, map of fertility clinics, pop-up glossary definitions), and the navigation. The app company did not have access to users' data.

In the feasibility/piloting phase of the study, an interactive prototype of the *Infotility XY* app was developed, which allowed the research team to make changes to the organization of the information before presenting the app to participants.

In the evaluation phase of the study, we assessed the uptake and usability of the app by using a pre-post study design. We determined our 2 main outcome measures (the user version of the Mobile App Rating Scale [uMARS] and the Information Assessment Method [IAM]) based on literature reviews of available tools to assess the quality and information of apps. The next phase of the study is implementation, which includes finding partners to disseminate the app and provide long-term follow-up and monitoring [32].

Ethics Approval and Recruitment

This study was approved by the Medical/Biomedical Research Ethics Committee of CIUSSS (Centre intégré universitaire de santé et de services sociaux) West-Central Montreal Research Ethics Board (MP-05-2016-344). Participants were recruited between August and October 2020 across Canada by a market research firm ("recruitment company"). The recruitment company was selected based on their experience in medical research, their ability to recruit a representative sample of participants from Canada, and their adherence to the highest standards in research methodology, ethical practices, respondent rights, and personal privacy. The recruitment company did not have access to participants' data. In the communications between our team and the recruitment company, participants were referred to by their unique code, which did not identify them, to protect participants' confidentiality. The recruitment company recruited patients with cancer via physicians and patient advocacy groups and contacted them via email and telephone. The recruitment company screened potential participants for the following criteria: identified as male, had internet access, able to read and write in English/French, aged 18-45 years, diagnosed with new/recurrent cancer within the past year, and not in fertility treatment. Individuals who met the eligibility criteria and provided written informed consent were enrolled in the study. Once the target sample of 40 participants was reached, recruitment was terminated.

Participants

Guidelines for this phase of the evaluation of web-based interventions suggest that a sample of at least 20 users is required for statistical significance [33]. To account for possible attrition, we aimed to recruit 40 men. The recruitment company contacted 586 patients with cancer; 63 agreed to be screened, 43 were eligible and consented, and 40 completed the study. Of these 40 men, 24 were recruited via referrals from health care providers, 11 via patient referrals, and 5 via the recruitment company's database.

Procedures

After providing informed consent online, participants created an app account, completed pre–app usage questionnaires, and gained access to the app for 2 weeks. This period was selected based on our previous experience [34], where app usage tended to drop off after 2 weeks. After app use, participants were blocked from viewing the app and directed to post–app usage questionnaires. After completing the questionnaires, participants regained app access. To reduce attrition, participants were sent up to 3 reminder emails to complete questionnaires and use the app. Participants received CAD $150 from the recruitment company upon study completion. See Multimedia Appendix 3 for the study's procedures.

Measures

Background Questionnaire

Participants provided information about their sociodemographic characteristics, including relationship status, age, ethnicity, immigrant status, education, income, religion, and parity. Participants were also asked whether anyone had spoken to them about the impact of cancer on fertility, whether they received information about fertility preservation, and if so, whether they received all the information they needed, their most recent cancer diagnosis, and the age at which they received it, and their current cancer status.

Fertility Knowledge and Preservation

After app use, participants were asked (1) whether the app increased their knowledge of fertility in relation to cancer, using a scale from 0 ("No, not at all") to 3 ("Yes, quite a lot"); (2) whether they made a decision about sperm banking during the study (yes/no); and (3) if they selected "yes," they were asked what decision they made (eg, I banked my sperm), and what factors helped them make the decision.

IAM

The IAM was used to evaluate participants' ratings of the app's information. The measure was developed to assess the relevance, cognitive impact, use, and health benefits of web-based health information and has been validated with patients and consumers of web-based health information [35,36]. Our team adapted the 8-item measure from the 2019 IAM version for Fertility and the IAM4All. All items are considered individually. No total scores or cutoffs exist.

uMARS

The uMARS was used to measure participants' rating of the app's quality. This 20-item measure consists of 4 subscales. The Engagement subscale measures whether the app is interesting, customizable, and interactive; the Functionality subscale asks about the app's functionality and navigation; the Aesthetics subscale asks about the app's visual appeal; and the Information subscale asks whether the app contains credible, high quality information. Each subscale is measured on a scale from 1-5; higher scores represent higher ratings. The mean score is obtained by averaging the 4 subscales' scores. An additional 4 items measuring the app's subjective quality can be averaged to obtain a *subjective* quality score. The uMARS was developed by Stoyanov et al [37] and tested in a sample of Australians

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aged 16-25 years. The Flesch-Kincaid readability test indicated that the uMARS required a grade 8 reading level [37]. The total score demonstrated excellent internal consistency (α=.90) and interrater reliability (intraclass correlation=0.79) [38]. Each subscale demonstrated satisfactory consistency, with Cronbach alpha ranging from .70 to .80 [37].

Qualitative and Quantitative Data on App Usage

To capture participants' experiences using the app, our team developed open-ended questions.

1. Please describe any fertility topics or features that were not included in the app and that you would have liked to be included. Please tell us why you want those topics or features to be included.
2. Please tell us what you liked best about the app and why.
3. Please tell us what you liked least about the app and why.

We present quantitative data for the following app usage metrics: unique pageviews and thumbs-up/down assessments.

Quantitative Analyses

No questionnaire data were missing. Quantitative analyses were performed using SPSS (IBM Corp). Descriptive quantitative analyses were used to assess participants' sociodemographic characteristics and informational needs, the influence of the app on treatment decisions and fertility knowledge, and evaluation of the app's information and quality. Given the small sample size (N=40), we did not conduct multivariate analyses. However, descriptive statistics were sufficient in answering our overarching question regarding the usability of the app in conjunction with the qualitative feedback.

App Usage

The app company compiled the app usage metrics. For each participant, the numbers of unique pages viewed and thumbs-up/down assessments were extracted. These metrics were presented as totals and were also classified into categories: medical (11 articles), legal (3 articles), or psychosocial (5 articles; Multimedia Appendix 1). Developed for analytic purposes, these categories were not seen by participants. If a participant visited a page multiple times, it was only counted once. No app usage data were missing.

Qualitative Feedback

All participants responded to the open-ended questions assessed in the questionnaires delivered after using the app. Their feedback was analyzed by 2 researchers (KK and ENG) on a qualitative data analysis software (NVivo, QSR International) using directed content analysis with an iterative approach [39]. A directed content analysis approach allows researchers to use predetermined codes. The uMARS dimensions of aesthetics, functionality, engagement, and information guided analyses and were used as the pre-existing codes. These categories allowed researchers to understand participants' qualitative feedback in relation to the quantitative data, which also looked at users' perceptions of the app on these quality rating scales. After the first round of coding, discrepancies were discussed and resolved between 2 researchers.

Results

Sociodemographic Data

The sample consisted of 40 patients with cancer, all of whom accessed the app in English (see Multimedia Appendix 4 for sociodemographics). The age range was 27-45 years (mean 36.93 [SD 5.48] years). Most participants were in heterosexual relationships (27/40, 68%), followed by single (8/40, 20%), and in nonheterosexual relationships (5/40, 13%). More than half of the men had children (22/40, 55%), and most indicated that they would like to have children in the future (33/40, 83%). Most were White (25/40, 63%), born in Canada (35/40, 88%), had an income between CAD $50,000-CAD $89,999 (19/40, 48%), had a high school or CEGEP (Collège d'enseignement général et professionnel) education level (23/40, 58%), and were not religious (25/40, 63%). During the study, approximately 68% (27/40) of the participants were in cancer treatment, 25% (10/40) in partial remission, and 8% (3/40) in remission, with an average remission time of 1 year (SD 1.73, range 0-3). The most common diagnoses were prostate cancer (7/40, 18%), testicular cancer (7/40, 18%), skin cancer (5/40, 13%), and bladder cancer (4/40, 10%). The average age of diagnosis was 36.1 (SD 5.49) years (range 26-45 years).

Information Seeking

Of the 40 participants, 27 (68%) indicated that no one had ever spoken to them about the impact of cancer on fertility and 34 (85%) had not received information on fertility preservation. Of those who did receive this information, 67% (4/6) did not get all the information they needed.

App Usage

On average, participants viewed 99% (18.80/19) of the app's articles (SD 0.97, range 13-19), and specifically 99% of the medical articles (10.93/11, SD 0.27, range 10-11), and 98% of psychosocial articles (4.88/5, SD 0.79, range 0-5). All participants viewed each of the 3 lifestyle articles. Participants gave a thumbs-up to an average of 7.85 (SD 7.94, range 0-19) articles and specifically to an average of 4.53 (SD 4.59, range 0-11) medical articles, 1.40 (SD 1.39, range 0-3) lifestyle articles, and 1.93 (SD 2.24, range 0-5) psychosocial articles. No article received a thumbs-down.

Fertility Knowledge and Preservation

Of the 40 participants, 34 (85%) said the app increased their fertility knowledge. Prior to the study, 95% (38/40) of men had not banked their sperm. During the study, 23% (9/40) of the participants made a decision about sperm banking: 1 decided to bank his sperm, 7 are planning to do so in the future, and 1 decided not to. Of the 8 who decided to bank their sperm, 6 (75%) said the app helped them make the decision.

Evaluation of the App's Information

80% (32/40) of the participants viewed the app to satisfy their curiosity about a health matter (Table 1). Approximately 83% (33/40) found the information relevant, 95% (38/40) understood the information well, and 83% (33/40) learned something new. Of the 78% (31/40) who used the information for themselves, 90% (28/31) said the information helped them better understand

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a particular health issue. Of the 85% (34/40) who benefited (or expect to benefit) from the information, 79% (27/34) said the information helped them feel less worried about a health problem and 53% (18/34) said it facilitated their communication with health professionals.

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Table 1. Data on the app's information evaluated by the Information Assessment Method (IAM) (N=40).

Information Assessment Method question	Values, n (%)
Why did you look on this app for information?	
To answer a question about my health	27 (68)
To answer a question about the health of someone else	12 (30)
To satisfy my curiosity about a health matter	32 (80)
To help me decide if I should see a health professional	13 (33)
To prepare myself before talking to a health professional	8 (20)
To follow up on the information given by a health professional	5 (13)
To find choices different from those given by a health professional	6 (12)
Is the app's information relevant?	
Very little relevant	3 (8)
Somewhat relevant	4 (10)
Relevant	19 (48)
Very relevant	14 (35)
Did you understand the app's information?	
Very poorly	0
Poorly	2 (5)
Well	23 (58)
Very well	15 (38)
What do you think about the app's information?	
Now I know something new	33 (83)
This information says I did or I am doing the right thing	21 (53)
Now I am reassured	22 (55)
I am reminded of something I already knew	10 (25)
Now I want to learn more about this health matter	16 (40)
I am not satisfied with this information	3 (8)
I think there is a problem with this information	0
I think this information could be harmful	0
Did you or will you use the app's information for yourself?	
Yes	31 (78)
No, not for myself, but I used this information for someone else	6 (15)
No, I did not use this information for myself or for someone else	3 (8)
If yes, how did you or will you use it?	
This information helped (will help) me to better understand a particular issue about my health.	28 (90)
I did not know what to do, and this information helped (will help) me make a decision about my health.	16 (52)
I knew what to do, and I used (will use) this information to be more certain about my health care.	12 (39)
I was doing (going to do) something concerning my health, and I used (will use) this information to do it differently.	4 (13)
I used (will use) this information in a discussion with a health professional	2 (7)
Did you (do you expect to) benefit from the app's information?	
Yes	34 (85)

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Information Assessment Method question	Values, n (%)
No	6 (15)
If yes, how did you (do you expect to) benefit?	
This information helped (helps) me feel less worried about a health problem	27 (79)
This information made (makes) me more satisfied with health care I receive	16 (40)
This information allowed (will allow) me to better communicate with a health professional	18 (53)
Because of this information, I was (will be) more involved in decisions about my health	14 (41)
This information helped (will help) me to better handle a problem with my health	9 (27)
This information helped (will help) me prevent a health problem or the worsening of a health problem	2 (6)
This information helped (will help) to improve my health	1 (3)

Evaluation of the App's Quality

Participants rated the app's quality highly (Table 2). The average quality rating was the highest for information, followed by functionality. The lowest rated subscale was engagement, though it was still rated 3.63/5.00 on average. Most men would recommend the app.

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Table 2. App quality analysis using the user version of the Mobile App Rating Scale (uMARS) (N=40).

uMARS item	Value
Objective quality subscale, mean (SD)	
Engagement (range 2.20-4.80)	3.63 (0.75)
Functionality (range 2.25-5.00)	4.06 (0.74)
Aesthetics (range 2.67-5.00)	3.84 (0.65)
Information (range 3.00-5.00)	4.14 (0.61)
Objective quality total score (range 3.02-4.84)	3.92 (0.62)
What is your overall (star) rating of the app? (range 2.00-5.00), mean (SD)	3.75 (0.54)
App rating, n (%)	
1 (One of the worst apps I've used)	0
2	1 (3)
3 (Average)	9 (23)
4	29 (73)
5 (One of the best apps I've used)	1 (3)
Would you recommend this app to people who might benefit from it? n (%)	
Not at all	0
Very few people	3 (8)
Maybe	12 (30)
Many people	17 (43)
Definitely	8 (20)
How many times do you think you would use this app in the next 12 months? n (%)	
None	3 (8)
1-2	7 (18)
3-10	20 (50)
10-50	9 (23)
>50	1 (3)
Would you pay for this app? n (%)	
1 (Definitely not)	7 (18)
2	8 (20)
3	15 (38)
4	8 (20)
5 (Definitely yes)	2 (5)
Subjective quality total score (range 2.00-4.75), mean (SD)	3.30 (0.696)

Qualitative Feedback

Engagement

Participants liked the videos because they were "interesting" (participant #24) and "informative" (participant #14), and they suggested including more videos. Men would have also liked the ability to connect with others, for example, to obtain "…feedback from people who have banked sperm…" (participant #4).

Functionality

Participants liked the app's functionality, finding it "extremely easy to use and navigate" (participant #8) and that it had a "very intuitive design" (participant #9). Apart from being "neatly organized" (participant #29), men appreciated that the app allowed the user to "read at [his] own pace" (participant #29).

Information

Participants found the app "very educational and very useful" (participant #36) and appreciated that it was a "one stop shop for fertility info" (participant #23), which helped prevent information overload: "The link to detailed information is

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available on demand, it prevents from unnecessary information burden…" (participant #38). Participants liked that the information was "very comprehensive" (participant #26) and "… [was] applicable for different scenarios" (participant #39). However, some thought there was "too much information" (participant #22).

Participants appreciated that the app included "a lot of good links and honest information about [w]here to go for help" (participant #19). They particularly liked the sperm banking resources, saying that the app "help[ed] locat[e] sperm banks near me" (participant #5). Participants wanted "more cost-based information" (participant #16), including the "average cost of each procedure" (participant #27) and "if [each procedure is] covered by health care…" (participant #19). Participants also wanted more in-depth information about the effects of cancer on fertility, for example, about "… certain types of cancers and how it affects each one differently" (participant #10).

Participants valued that the app had a "wealth of useful info from very trustworthy sources" (participant #17). They also thought the information "was very easy to read" (participant #11), and "not too complicated or jargon heavy" (participant #7). However, 1 man would have liked if the information was "less wordy" (participant #30).

The app's information made participants feel "reassured" (participant #25): "This app really made me feel comfortable about how I was feeling about my diagnosis and how to go about my family's future" (participant #2). Men also mentioned that the information "ma[de] [him] feel safe and confident to look at donating sperm and how to do it" (participant #36). Though some found the information "depressing at times" (participant #6), overall men appreciated the "very supportive tone" of the app (participant #31).

Discussion

Principal Findings

Overall, participants valued *Infotility XY* as a source of comprehensive, relevant, and accessible information. Most participants had not received information about the impact of cancer on fertility or fertility preservation prior to the study. Those who did receive this information did not receive all the information they needed. After app use, most men felt that their fertility knowledge increased and that the information promoted better communication with clinicians, indicating that an mHealth app may be useful in clinical practice to address the fertility-related informational needs of male patients with cancer. Providing patients with written information may help initiate fertility discussions with medical staff, leading to a referral to a reproductive specialist [40].

The fact that most participants had not received fertility information prior to the study might have contributed to the high engagement level. Men seemed to be motivated to learn about fertility and sperm banking. Most participants found the information relevant, credible, and easy-to-read. Given the lack of oncofertility educational materials suitable for patients with varying health literacy levels [41], our study highlights the possibility of presenting scientific content in simple terms that is accessible to diverse patient groups.

Furthermore, although almost all men had never banked sperm prior to the intervention, 8 decided to bank during the study. Owing to lack of information, patients with cancer may not fully participate in decision-making regarding their future fertility, which can prevent them from banking sperm [42]. Our results indicate that an mHealth app can empower patients to feel more in control of their reproductive health and be proactive in preserving fertility. Furthermore, the information helped participants feel comforted and reassured that they were making the right decisions about their fertility. Thus, our study demonstrates the potential of an mHealth app to help address the fertility concerns of patients with cancer by providing evidence-based information in a supportive manner. Additionally, based on participants' feedback, future mHealth apps should present a significant proportion of content in video format to help users with different health literacy levels understand and retain the material. A chat option may also benefit patients by allowing them to seek social support [43].

Study Limitations and Strengths

This study has several limitations. First, there may have been selection bias since participants volunteered to enroll in the study. Thus, our sample may not fully reflect the broader population of male patients with cancer. As we remunerated participants in appreciation of their involvement in the research, they may have felt more inclined to complete the study or provide more positive feedback about the app, which may have introduced bias into our results. Second, since our sample was small and did not include Francophones, French content was not evaluated, potentially limiting the generalizability of results. Third, our sample did not include men aged 18-26 years. This subgroup might not be concerned with family building yet but should nevertheless be informed about the impact of cancer on fertility, and thus, it is an important group to include in future research.

Despite these limitations, our study has notable strengths. We used quantitative methods and content analysis, allowing for a nuanced understanding of participants' experiences using the app. Our sample was socioeconomically diverse with respect to income and education. There was also variation in participants' relationship and fatherhood statuses, suggesting generalizability of results to patients at different life stages. Recruiting people at the hospital bedside who were in active cancer treatment for a psychosocial research project may have been challenging, especially given that recruitment took place during the COVID-19 pandemic. Therefore, using a recruitment company who could recruit participants remotely allowed for us to successfully recruit our target sample size (N=40).

Conclusions

This usability study provides preliminary support that an mHealth app may be valuable in clinical practice by assisting in educating patients about the impact of cancer on fertility, thereby helping them make fertility preservation decisions and providing comfort. To our knowledge, this study is the first to evaluate an mHealth app providing male patients with cancer

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with evidence-based information about the impact of cancer on fertility and fertility preservation. We are in contact with professional organizations and patient advocacy groups to engage in knowledge transfer and to plan future studies. Randomized controlled trials with larger samples are warranted to assess the effectiveness of mHealth interventions in improving patients' fertility knowledge and influencing their sperm banking decisions. Further efforts are needed to increase the availability of evidence-based mHealth apps for patients with cancer.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Categories and articles of the Infotility XY app.
[DOCX File , 16 KB - cancer_v8i2e33594_app1.docx]

Multimedia Appendix 2
Design and features of the Infotility XY app.
[DOCX File , 1351 KB - cancer_v8i2e33594_app2.docx]

Multimedia Appendix 3
Study procedures.
[PNG File , 66 KB - cancer_v8i2e33594_app3.png]

Multimedia Appendix 4
Sociodemographic characteristics of our sample.
[DOCX File , 19 KB - cancer_v8i2e33594_app4.docx]

References

1. Canadian cancer statistics 2021. Canadian Cancer Society. URL: https://cancer.ca/en/research/cancer-statistics/canadian-cancer-statistics [accessed 2022-04-07]
2. How cancer and cancer treatment can affect fertility in males. American Cancer Society. 2020. URL: https://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects/fertility-and-men-with-cancer/how-cancer-treatments-affect-fertility.html [accessed 2021-05-02]
3. Bahadur G, Ozturk O, Muneer A, Wafa R, Ashraf A, Jaman N, et al. Semen quality before and after gonadotoxic treatment. Hum Reprod 2005 Mar;20(3):774-781. [doi: 10.1093/humrep/deh671] [Medline: 15689346]
4. Dohle GR. Male infertility in cancer patients: Review of the literature. Int J Urol 2010 Apr;17(4):327-331. [doi: 10.1111/j.1442-2042.2010.02484.x] [Medline: 20202000]
5. Fertility. Government of Canada. URL: https://www.canada.ca/en/public-health/services/fertility/fertility.html [accessed 2021-05-02]
6. Fertility issues in boys and men with cancer. National Cancer Institute. URL: https://www.cancer.gov/about-cancer/treatment/side-effects/fertility-men [accessed 2021-05-02]
7. Allemani C, Matsuda T, Di Carlo V, Harewood R, Matz M, Nikšić M, CONCORD Working Group. Global surveillance of trends in cancer survival 2000-14 (CONCORD-3): analysis of individual records for 37 513 025 patients diagnosed with one of 18 cancers from 322 population-based registries in 71 countries. Lancet 2018 Mar 17;391(10125):1023-1075 [FREE Full text] [doi: 10.1016/S0140-6736(17)33326-3] [Medline: 29395269]
8. Firkins J, Hansen L, Driessnack M, Dieckmann N. Quality of life in "chronic" cancer survivors: a meta-analysis. J Cancer Surviv 2020 Aug;14(4):504-517. [doi: 10.1007/s11764-020-00869-9] [Medline: 32162194]
9. Schepisi G, De Padova S, De Lisi D, Casadei C, Meggiolaro E, Ruffilli F, et al. Psychosocial Issues in Long-Term Survivors of Testicular Cancer. Front Endocrinol (Lausanne) 2019;10:113 [FREE Full text] [doi: 10.3389/fendo.2019.00113] [Medline: 30858829]
10. Alexis O, Adeleye AO, Worsley AJ. Men's experiences of surviving testicular cancer: an integrated literature review. J Cancer Surviv 2020 Jun;14(3):284-293. [doi: 10.1007/s11764-019-00841-2] [Medline: 31823122]
11. Nieman CL, Kazer R, Brannigan RE, Zoloth LS, Chase-Lansdale PL, Kinahan K, et al. Cancer survivors and infertility: a review of a new problem and novel answers. J Support Oncol 2006 Apr;4(4):171-178. [Medline: 16669459]

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12. Osterberg E, Ramasamy R, Masson P, Brannigan R. Current practices in fertility preservation in male cancer patients. Urol Ann 2014 Jan;6(1):13-17 [FREE Full text] [doi: 10.4103/0974-7796.127008] [Medline: 24669115]
13. Trost LW, Brannigan RE. Oncofertility and the male cancer patient. Curr Treat Options Oncol 2012 Jun;13(2):146-160. [doi: 10.1007/s11864-012-0191-7] [Medline: 22528369]
14. Chan P, Herrero M. ART success and long-term outcomes on offspring of cancer survivors. In: The Complete Guide to Male Fertility Preservation. Cham: Springer; 2018:67-76. [doi: 10.1007/978-3-319-42396-8_6]
15. Perez S, Lambert SD, Lee V, Loiselle CG, Chan P, Gupta A, et al. A fertility needs assessment survey of male cancer patients. Psychooncology 2018 Dec;27(12):2747-2753. [doi: 10.1002/pon.4874] [Medline: 30176700]
16. Ussher JM, Parton C, Perz J. Need for information, honesty and respect: patient perspectives on health care professionals communication about cancer and fertility. Reprod Health 2018 Jan 05;15(1):2 [FREE Full text] [doi: 10.1186/s12978-017-0441-z] [Medline: 29304873]
17. Wang Y, Anazodo A, Logan S. Systematic review of fertility preservation patient decision aids for cancer patients. Psychooncology 2019 Mar;28(3):459-467. [doi: 10.1002/pon.4961] [Medline: 30523651]
18. Loren AW, Mangu PB, Beck LN, Brennan L, Magdalinski AJ, Partridge AH, et al. Fertility Preservation for Patients With Cancer: American Society of Clinical Oncology Clinical Practice Guideline Update. JCO 2013 Jul 01;31(19):2500-2510. [doi: 10.1200/jco.2013.49.2678]
19. Peddie VL, Porter MA, Barbour R, Culligan D, MacDonald G, King D, et al. Factors affecting decision making about fertility preservation after cancer diagnosis: a qualitative study. BJOG 2012 Aug;119(9):1049-1057. [doi: 10.1111/j.1471-0528.2012.03368.x] [Medline: 22642563]
20. Nahata L, Cohen LE, Yu RN. Barriers to fertility preservation in male adolescents with cancer: it's time for a multidisciplinary approach that includes urologists. Urology 2012 Jun;79(6):1206-1209. [doi: 10.1016/j.urology.2012.02.035] [Medline: 22542423]
21. Wenger LM. Beyond ballistics: expanding our conceptualization of men's health-related help seeking. Am J Mens Health 2011 Nov;5(6):488-499 [FREE Full text] [doi: 10.1177/1557988311409022] [Medline: 21659353]
22. Kenney LB, Cohen LE, Shnorhavorian M, Metzger ML, Lockart B, Hijiya N, et al. Male Reproductive Health After Childhood, Adolescent, and Young Adult Cancers: A Report From the Children's Oncology Group. JCO 2012 Sep 20;30(27):3408-3416. [doi: 10.1200/jco.2011.38.6938]
23. Jansen F, van Uden-Kraan CF, van Zwieten V, Witte BI, Verdonck-de Leeuw IM. Cancer survivors' perceived need for supportive care and their attitude towards self-management and eHealth. Support Care Cancer 2015 Jun;23(6):1679-1688. [doi: 10.1007/s00520-014-2514-7] [Medline: 25424520]
24. Lohan M, Aventin, Oliffe JL, Han CS, Bottorff JL. Knowledge translation in men's health research: development and delivery of content for use online. J Med Internet Res 2015 Jan 29;17(1):e31 [FREE Full text] [doi: 10.2196/jmir.3881] [Medline: 25642787]
25. Shah T, Shin D. Availability of Male and Female Sexual Health and Fertility Information on National Cancer Institute-Designated Cancer Center Websites. Sex Med 2020 Jun;8(2):315-317 [FREE Full text] [doi: 10.1016/j.esxm.2020.02.007] [Medline: 32229105]
26. Robins S, Barr HJ, Idelson R, Lambert S, Zelkowitz P. Online Health Information Regarding Male Infertility: An Evaluation of Readability, Suitability, and Quality. Interact J Med Res 2016 Oct 21;5(4):e25 [FREE Full text] [doi: 10.2196/ijmr.6440] [Medline: 27769954]
27. McCann L, McMillan KA, Pugh G. Digital Interventions to Support Adolescents and Young Adults With Cancer: Systematic Review. JMIR Cancer 2019 Jul 31;5(2):e12071 [FREE Full text] [doi: 10.2196/12071] [Medline: 31368438]
28. Micaux Obol C, Lampic C, Wettergren L, Ljungman L, Eriksson LE. Experiences of a web-based psycho-educational intervention targeting sexual dysfunction and fertility distress in young adults with cancer-A self-determination theory perspective. PLoS One 2020;15(7):e0236180 [FREE Full text] [doi: 10.1371/journal.pone.0236180] [Medline: 32697801]
29. Wiklander M, Strandquist J, Obol CM, Eriksson LE, Winterling J, Rodriguez-Wallberg KA, et al. Feasibility of a self-help web-based intervention targeting young cancer patients with sexual problems and fertility distress. Support Care Cancer 2017 Dec;25(12):3675-3682 [FREE Full text] [doi: 10.1007/s00520-017-3793-6] [Medline: 28721554]
30. Silver L. Smartphone ownership is growing rapidly around the world, but not always equally. Pew Research Center. 2019. URL: https://www.pewresearch.org/global/2019/02/05/smartphone-ownership-is-growing-rapidly-around-the-world-but-not-always-equally/ [accessed 2021-06-03]
31. Buneviciene I, Mekary RA, Smith TR, Onnela J, Bunevicius A. Can mHealth interventions improve quality of life of cancer patients? A systematic review and meta-analysis. Crit Rev Oncol Hematol 2021 Jan;157:103123 [FREE Full text] [doi: 10.1016/j.critrevonc.2020.103123] [Medline: 33190065]
32. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. Int J Nurs Stud 2013 May;50(5):587-592. [doi: 10.1016/j.ijnurstu.2012.09.010] [Medline: 23159157]
33. US Department of Health and Human Services. 2006. URL: https://www.usability.gov/sites/default/files/documents/guidelines_book.pdf [accessed 2022-04-07]

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34. Kruglova K, O'Connell SBL, Dawadi S, Gelgoot EN, Miner SA, Robins S, et al. An mHealth App to Support Fertility Patients Navigating the World of Infertility (Infotility): Development and Usability Study. JMIR Form Res 2021 Oct 12;5(10):e28136 [FREE Full text] [doi: 10.2196/28136] [Medline: 34636741]
35. Bujold M, El Sherif R, Bush PL, Johnson-Lafleur J, Doray G, Pluye P. Ecological content validation of the Information Assessment Method for parents (IAM-parent): A mixed methods study. Eval Program Plann 2018 Feb;66:79-88 [FREE Full text] [doi: 10.1016/j.evalprogplan.2017.09.011] [Medline: 29053984]
36. Pluye P, Granikov V, Bartlett G, Grad RM, Tang DL, Johnson-Lafleur J, et al. Development and content validation of the information assessment method for patients and consumers. JMIR Res Protoc 2014 Mar 18;3(1):e7 [FREE Full text] [doi: 10.2196/resprot.2908] [Medline: 24550180]
37. Stoyanov SR, Hides L, Kavanagh DJ, Wilson H. Development and Validation of the User Version of the Mobile Application Rating Scale (uMARS). JMIR Mhealth Uhealth 2016 Jun 10;4(2):e72 [FREE Full text] [doi: 10.2196/mhealth.5849] [Medline: 27287964]
38. Stoyanov SR, Hides L, Kavanagh DJ, Zelenko O, Tjondronegoro D, Mani M. Mobile app rating scale: a new tool for assessing the quality of health mobile apps. JMIR Mhealth Uhealth 2015 Mar 11;3(1):e27 [FREE Full text] [doi: 10.2196/mhealth.3422] [Medline: 25760773]
39. Hsieh H, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res 2005 Nov;15(9):1277-1288. [doi: 10.1177/1049732305276687] [Medline: 16204405]
40. Flink DM, Sheeder J, Kondapalli LA. A Review of the Oncology Patient's Challenges for Utilizing Fertility Preservation Services. J Adolesc Young Adult Oncol 2017 Mar;6(1):31-44 [FREE Full text] [doi: 10.1089/jayao.2015.0065] [Medline: 27529573]
41. Nahata L, Anazodo A, Cherven B, Logan S, Meacham LR, Meade CD, et al. Optimizing health literacy to facilitate reproductive health decision-making in adolescent and young adults with cancer. Pediatr Blood Cancer 2020 Jul 06:e28476 [FREE Full text] [doi: 10.1002/pbc.28476] [Medline: 32633029]
42. Parton C, Ussher JM, Perz J. Hope, burden or risk: a discourse analytic study of the construction and experience of fertility preservation in the context of cancer. Psychol Health 2019 Apr;34(4):456-477. [doi: 10.1080/08870446.2018.1543764] [Medline: 30688090]
43. Patel D, Blandford A, Warner M, Shawe J, Stephenson J. "I feel like only half a man": Online Forums as a Resource for Finding a "New Normal" for Men Experiencing Fertility Issues. Proc ACM Hum-Comput Interact 2019 Nov 07;3(CSCW):1-20. [doi: 10.1145/3359184]

Abbreviations

IAM: Information Assessment Method
mHealth: mobile health
uMARS: user version of the Mobile App Rating Scale

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Original Paper

Extracting Multiple Worries From Breast Cancer Patient Blogs Using Multilabel Classification With the Natural Language Processing Model Bidirectional Encoder Representations From Transformers: Infodemiology Study of Blogs

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Abstract

Background: Patients with breast cancer have a variety of worries and need multifaceted information support. Their accumulated posts on social media contain rich descriptions of their daily worries concerning issues such as treatment, family, and finances. It is important to identify these issues to help patients with breast cancer to resolve their worries and obtain reliable information.

Objective: This study aimed to extract and classify multiple worries from text generated by patients with breast cancer using Bidirectional Encoder Representations From Transformers (BERT), a context-aware natural language processing model.

Methods: A total of 2272 blog posts by patients with breast cancer in Japan were collected. Five worry labels, “treatment,” “physical,” “psychological,” “work/financial,” and “family/friends,” were defined and assigned to each post. Multiple labels were allowed. To assess the label criteria, 50 blog posts were randomly selected and annotated by two researchers with medical knowledge. After the interannotator agreement had been assessed by means of Cohen kappa, one researcher annotated all the blogs. A multilabel classifier that simultaneously predicts five worries in a text was developed using BERT. This classifier was fine-tuned by using the posts as input and adding a classification layer to the pretrained BERT. The performance was evaluated for precision using the average of 5-fold cross-validation results.

Results: Among the blog posts, 477 included “treatment,” 1138 included “physical,” 673 included “psychological,” 312 included “work/financial,” and 283 included “family/friends.” The interannotator agreement values were 0.67 for “treatment,” 0.76 for “physical,” 0.56 for “psychological,” 0.73 for “work/financial,” and 0.73 for “family/friends,” indicating a high degree of agreement. Among all blog posts, 544 contained no label, 892 contained one label, and 836 contained multiple labels. It was found that the worries varied from user to user, and the worries posted by the same user changed over time. The model performed well, though prediction performance differed for each label. The values of precision were 0.59 for “treatment,” 0.82 for “physical,” 0.64 for “psychological,” 0.67 for “work/financial,” and 0.58 for “family/friends.” The higher the interannotator agreement and the greater the number of posts, the higher the precision tended to be.

Conclusions: This study showed that the BERT model can extract multiple worries from text generated from patients with breast cancer. This is the first application of a multilabel classifier using the BERT model to extract multiple worries from patient-generated text. The results will be helpful to identify breast cancer patients’ worries and give them timely social support.

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KEYWORDS

breast neoplasm; cancer; natural language processing; NLP; artificial intelligence; model; machine learning; content analysis; text mining; sentiment analysis; oncology; quality of life; social media; social support; breast cancer; BERT model; peer support; blog post; patient data

Introduction

Breast cancer is the most diagnosed female cancer worldwide, and treatment can last for 5 to 10 years, making this a familiar disease that women will live with for a long time [1-3]. Patients with breast cancer have multiple worries about treatment, family, finances, and so on, and these worries change over time. Although support for them is provided by medical professionals, patients' worries are sometimes overlooked in clinical settings [4].

Currently, many patients use social media as a source of medical information [5]. Patient-generated text such as posts and comments are accumulated on the internet and contain a wealth of information about patients' experiences and daily worries. It may be possible to use this information to help patients solve their problems and improve their quality of life. However, the substantial amount of text and the variable reliability of information on social media make it difficult for patients to get the accurate information they seek [6]. This large amount of social media data has become a new source of medical information and a target for natural language processing (NLP) [7,8].

Document classification by NLP can be used to extract information from text. This technique is useful for automatically identifying worries from patient-generated text and helping patients with breast cancer obtain appropriate information to resolve their worries. Although there are many NLP studies on portals for patients with breast cancer, most of them are content analyses that objectively analyze the contents of media. Although content analysis research can find multiple worries, the extracted worries cannot be defined. In contrast, document classification can set target worries and find them, but so far, there have been few document classification studies [9], and studies targeting worries are particularly rare. Therefore, it is necessary to create a document classification model that can automatically extract multiple worries from text generated from patients with breast cancer.

There has been much research on using NLP to extract topics and worries from patient-generated text automatically. Many studies used rule-based, bag-of-words, and topic models such as latent Dirichlet allocation (LDA) [10-12], and there remains room for improvement in extracting worries from the variously expressed patient descriptions in these models. These models have particular difficulty in dealing with context, but context can be used by deep-learning methods such as long short-term memory (LSTM) and Bidirectional Encoder Representations From Transformers (BERT), which has proved to be state of the art in several NLP tasks [13]. While there have been studies of patient-generated text using BERT to extract adverse drug effects [14,15], few studies have been conducted on text describing multiple worries that patients often have at the same time. There are some previous reports in which sentiment classification of patient-generated text was conducted using LSTM [16]. However, these only apply one label to one document and do not address multiple worries within a single document.

The purpose of this study was to develop a multilabel classification model using BERT to automatically extract multifaceted worries from text generated by patients with breast cancer.

Methods

Data Set

In this study, blog articles on Life Palette [17], one of the internet patient communities in Japan, were used. All the articles were written in Japanese. The data source consists of 13,570 posts written by 289 users from March 2008 to November 2014. A total of 2272 breast cancer posts were extracted as a data set, excluding drafts and duplicates (Figure 1).

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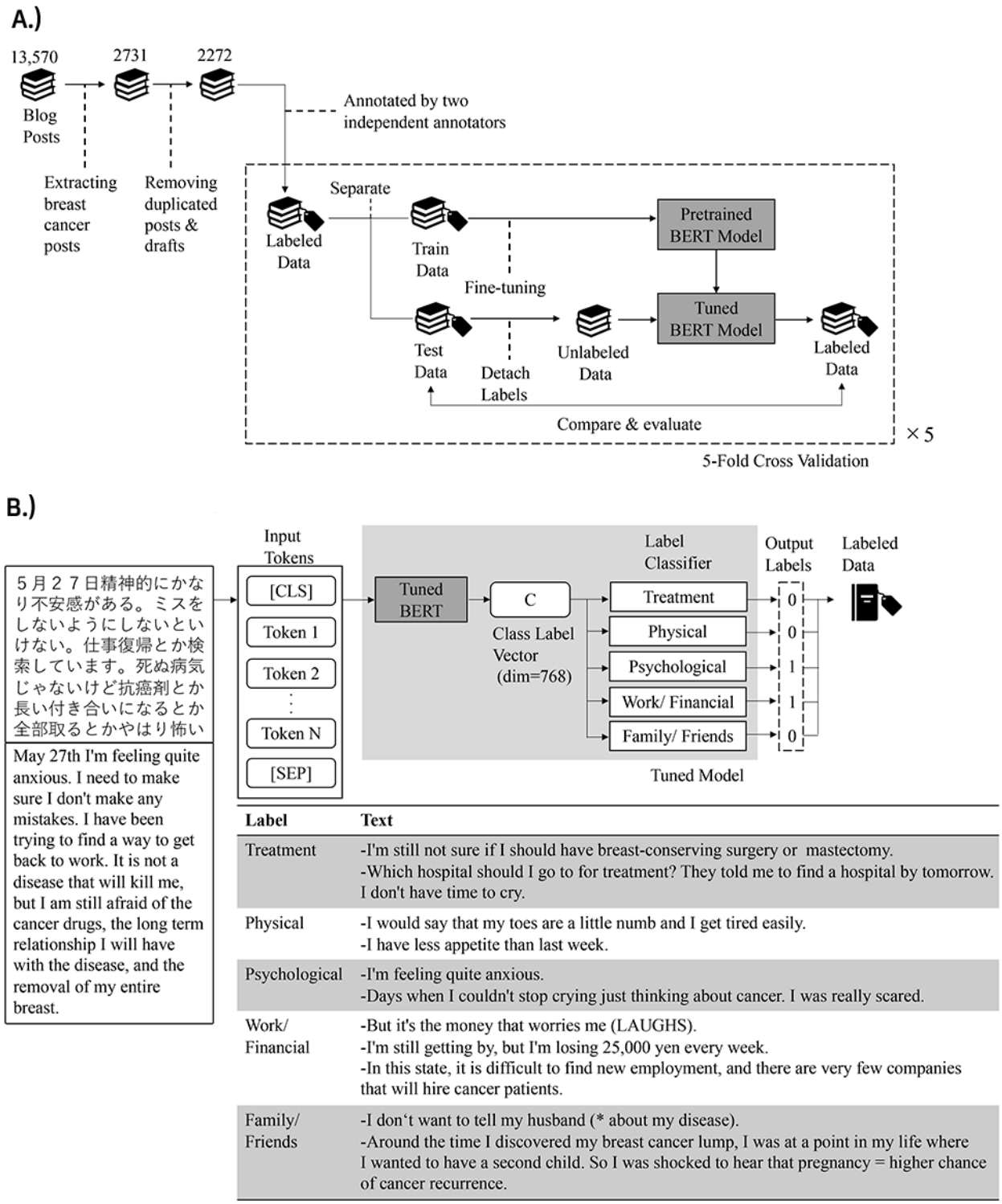
Figure 1. Overview of data processing and model function. (A) Data selection criteria and model training and testing process; (B) post label prediction model functions and outputs. *In Japanese sentences, the object is sometimes omitted, so the presumed object was judged from the context and added in parentheses. BERT: Bidirectional Encoder Representations From Transformers.



Label	Text
Treatment	-I'm still not sure if I should have breast-conserving surgery or mastectomy. -Which hospital should I go to for treatment? They told me to find a hospital by tomorrow. I don't have time to cry.
Physical	-I would say that my toes are a little numb and I get tired easily. -I have less appetite than last week.
Psychological	-I'm feeling quite anxious. -Days when I couldn't stop crying just thinking about cancer. I was really scared.
Work/ Financial	-But it's the money that worries me (LAUGHS). -I'm still getting by, but I'm losing 25,000 yen every week. -In this state, it is difficult to find new employment, and there are very few companies that will hire cancer patients.
Family/ Friends	-I don‘t want to tell my husband (* about my disease). -Around the time I discovered my breast cancer lump, I was at a point in my life where I wanted to have a second child. So I was shocked to hear that pregnancy = higher chance of cancer recurrence.

Ethical Approval

This study was approved by the ethics committee of the Keio University Faculty of Pharmacy (approval No 191218-2, 190301-1). All procedures were performed in accordance with the Ethical Guidelines for Medical and Health Research Involving Human Subjects (settled by the Ministry of Education, Culture, Sports, Science and Technology and the Ministry of Health, Labour and Welfare in Japan) and the Declaration of Helsinki and its later amendments. Consent to use the data from Life Palette for research purposes was obtained at the time of user registration. In this study, all data were analyzed anonymously and informed consent for this research was waived due to the retrospective observational design of the study.

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Annotation

The annotation criteria were defined based on previous studies [18]. To assess the reliability of the annotation criteria, 50 blog posts were randomly selected from the data set and annotated by two researchers with medical knowledge (authors TW and SH). After assessment of interannotator agreement (IAA) by means of Cohen kappa, one researcher (TW) annotated all the blogs. Cohen kappa takes a value close to 1 if the annotators are in perfect agreement; less than 0 is *poor*, 0-0.2 is *slight*, 0.21-0.4 is *fair*, 0.41-0.6 is *moderate*, 0.61-0.8 is *substantial*, 0.81-1 is *almost perfect* [19].

Based on the "Shizuoka Classification" [20], which is a method for classifying the worries of patients with cancer in Japan, the following five labels were established: "treatment," "physical," "psychological," "work/financial," and "family/friends" (Table S1 in Multimedia Appendix 1). If a single blog post contains descriptions of multiple worries, multiple labels were allowed.

Model Structure

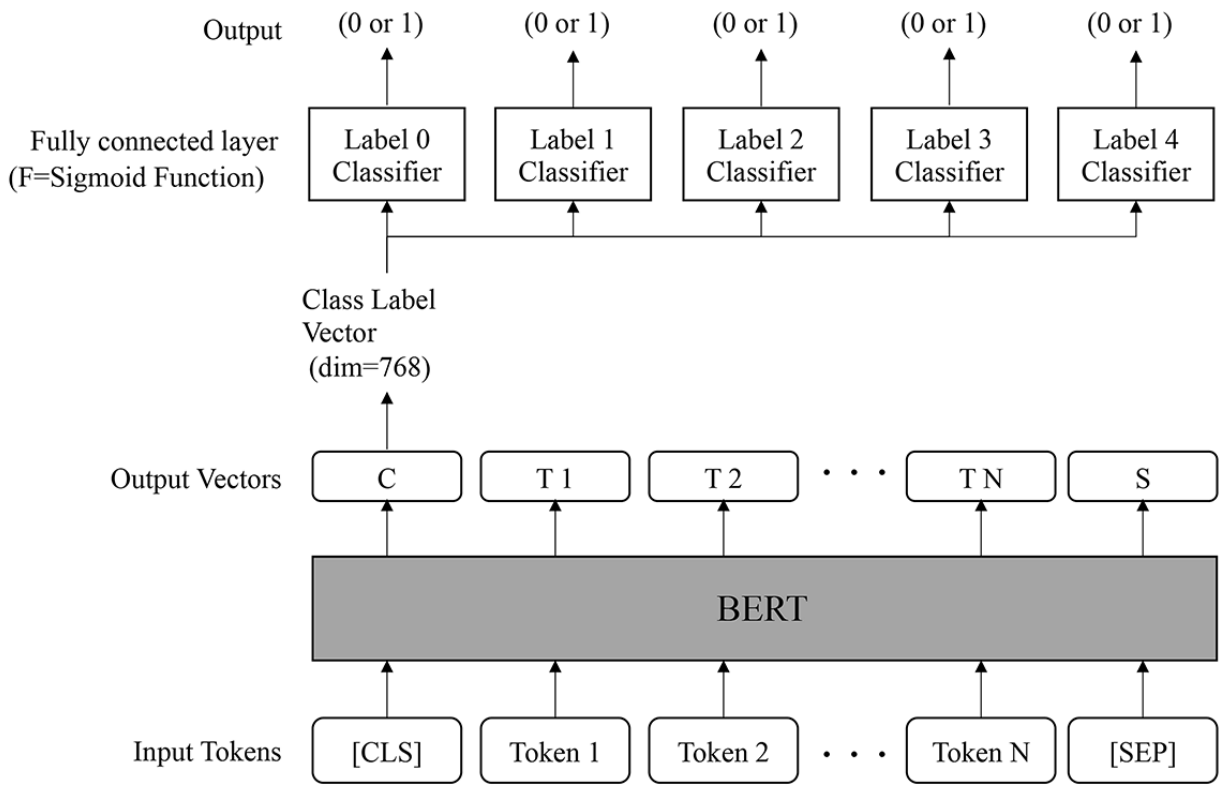
In this study, a multilabel classifier was built from the annotated multilabel data set to deal with multiple descriptions of worries. To develop the classifier, BERT, a state-of-the-art NLP model that can take context into account, was used. BERT is trained via a two-step learning process. The first step is pretraining using a large amount of text data and the second step is fine-tuning the model from new data.

The model was built by fine-tuning the pretrained Japanese BERT model of the Inui and Suzuki Laboratory, Tohoku University [21] (BERT-base model; 12 layers, 768 dimensions of hidden states, and 12 attention heads, tokenizer: MeCab [22], external dictionary: mecab-ipadic-NEologd [23]) from the annotated multilabel data set. Due to the capability of the pretrained model, the input was limited to 512 words, starting from the beginning of the sentence.

The [CLS] token and [SEP] token were added at the beginning of the sentence and at the end of the sentence, respectively. This was used as input to the BERT model. The model consists of a pretrained BERT and a fully connected layer, and the activation function was a sigmoid function that outputs five labeled positive/negative results. The model was built with reference to the previous study [24]. The input to the fully connected layer was the vector corresponding to the [CLS] token in the output vector of the pretrained BERT. The hyperparameters that could be adjusted prior to training were defined as follows. The loss function was cross-entropy, batch size was 16, five epochs were run, early stopping was not set, and all parameters were fine-tuned, including the pretrained BERT from Adam with a learning rate of 1e-5 (Figure 2).

In the BERT model, it is possible to incorporate a self-attention method that allows indicating which part of the output text has been paid attention to. Visualizing the attentions can be useful in interpreting the results of "black box" machine learning models. Therefore, in this study, the attention parts of each blog post were visualized and used as a reference for interpreting the labeling results.

Figure 2. Model structure developed in this study. The input is the post sentence with [CLS] token and [SEP] token added at the beginning and at the end, respectively. The output is 0/1, corresponding to negative/positive of each label. BERT: Bidirectional Encoder Representations From Transformers; dim: dimension.



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Task and Metrics

A multilabel task was performed to classify five labels simultaneously. The performance was evaluated in terms of precision, *F* score, and exact match accuracy, which indicates the percentage of correct predictions for all labels. As a way to use the research, we envision the construction of an information provision system tailored to each patient's problems. Therefore, we focused on precision so as not to provide unmatched information and inadvertently impose a burden on patients with breast cancer. The data set was divided into training data and test data in a ratio of 4:1, and the model was evaluated using the average of 5-fold cross-validation results to confirm its robustness.

Moreover, to examine the effect of the upper limit of the number of input words on the model performance, the performance for blog posts with over 512 words, that for all posts, and that for posts with 512 words or less were compared.

Results

Data Set Analysis

The mean number of words per blog post in the data set was 464.9, the median was 357, and the maximum was 6746. The number of documents with more than 512 words was 723 (31.8% of all blog posts; Figure S1 in Multimedia Appendix 1).

Annotation

The IAA values were the highest for "physical" and the lowest for "psychological" (Table 1). This time, the labels except for "psychological" showed a high degree of agreement with IAA values higher than 0.61, corresponding to "substantial" precision. The complete label agreement rate that indicates all the label-matched blog posts was 0.40.

The number of blog posts was highest for "physical" and lowest for "family/friends" (Table 1). The number of labels per blog post was the highest for single label posts and the lowest for posts with all five labels. Articles with no labels at all amounted to 544 (23.9%), and articles with a single label and multiple labels amounted to 892 (39.3%) and 836 (36.8%), respectively (Table 2). In addition, it was found that there were differences in worries among users, and the worries expressed by the same user changed over time (Figure S2 in Multimedia Appendix 1).

Table 1. The IAA[a] values and the number of posts for the five labels (N=2272).

Label	IAA[b]	Posts, n
Treatment	0.67	477
Physical	0.76	1138
Psychological	0.56	673
Work/financial	0.73	312
Family/friends	0.73	283

[a]IAA: interannotator agreement.

[b]Annotation agreement was evaluated using Cohen kappa.

Table 2. The number of labels per blog post (N=2272).

Number of labels	Posts, n (%)
0	544 (23.9)
1	892 (39.3)
2	578 (25.4)
3	199 (8.8)
4	57 (2.5)
5	2 (0.1)

Model

The precision was 0.59 for "treatment," 0.82 for "physical," 0.64 for "psychological," 0.67 for "work/financial," and 0.58 for "family/friends." Both the precision and the *F* score were highest for "physical" (Table 3). The exact match accuracy was 0.44.

The performances of posts with more than 512 words and posts with 512 words or less are presented in Multimedia Appendix 1.

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Table 3. Performance of the model.

Label	Accuracy (SD)	Precision (SD)	Recall (SD)	*F* score (SD)
Treatment	0.81 (0.01)	0.59 (0.09)	0.39 (0.15)	0.44 (0.09)
Physical	0.81 (0.01)	0.82 (0.02)	0.80 (0.02)	0.81 (0.01)
Psychological	0.77 (0.03)	0.64 (0.04)	0.54 (0.08)	0.58 (0.04)
Work/financial	0.88 (0.02)	0.67 (0.10)	0.28 (0.05)	0.38 (0.03)
Family/friends	0.88 (0.02)	0.58 (0.11)	0.33 (0.07)	0.41 (0.07)
Macro average	0.83 (0.01)	0.66 (0.04)	0.47 (0.05)	0.52 (0.03)

Discussion

Principal Findings

This is the first report of a multilabel classifier using the BERT model to extract multiple types of worries in patient-generated text, and our results indicate that BERT is effective for this purpose.

Comparison With Prior Work

Our model can extract multiple worries from a single post. There have been some NLP studies that have dealt with multiple worries in patient-generated text [18,25]. However, these studies used a multi-class classification that allows only one label per document and could not find multiple worries contained in a single document. Similar to this study, there was a previous study on classifying blog sentences with worry descriptions [18]. However, the previous study dealt with binary classification and short text, while our study dealt with multilabel classification and long text. Furthermore, our study outperformed the previous one in *F* score. Some studies have used a multilabel classifier of patient-generated messages based on the viewpoint of medical professionals [26,27]. In contrast, a noteworthy feature of this study was the classification of patient-generated text from the viewpoint of patients.

Strength of the Model

A multilabel classifier may be useful for patients with breast cancer because they may have multiple worries and the nature of their worries may change over time. This study has demonstrated that documents with multiple worries can be handled using BERT. As another approach, a lot of content analysis research has been done using topic models such as LDA for unsupervised learning [10]. LDA is a model that extracts multiple topics in a single document that would be suitable for handling a wide range of patient worries. However, this model is often used for content analysis rather than document classification, which ultimately requires manual interpretation of topics. An advantage of our model is that it automatically outputs the presence or absence of worries based on the input of sentences, so it does not require a final human judgment and can present the results quickly. Thus, our context-aware model is expected to be efficient for dealing with texts generated by patients with breast cancer that contain multiple worries and long descriptions because it extracts worries by paying attention to descriptions based on the human senses (Figure S3 in Multimedia Appendix 1).

Features of the Data Set

The reliability of the data set was inferred from the annotation results: the IAA was above 0.61, which was "substantial" for all labels except "psychological," indicating a high degree of agreement. The "psychological" label tended to be judged differently among researchers, compared with the other labels. However, it is considered that the data set was reliable enough as training data because the IAA values exceeded 0.41, which indicates "moderate" reliability. In the data set of posts written by patients with breast cancer, more than one worry was actually described in about 40% of the posts (Table 2), and it was confirmed that the worries described by the same user changed over time (Figure S1 in Multimedia Appendix 1), which was in agreement with previous studies. These results suggest that the data set was suitable for development of a multilabel classifier.

Error Analysis

To evaluate the reliability of the model, error analysis was conducted. Many of the false-positive cases were descriptions of changes in "physical," which had the highest precision, and dealt with conditions that were not covered by the annotation guidelines. They were similar to the "physical" descriptions, such as postoperative recovery, chest discomfort before diagnosis, and changes in physical condition that seemed unrelated to cancer (eg, "I was surprised that I could lift my arms more than before surgery!" "One day, I was surprised at the size of the difference between my left and right breasts," or "I drank a little wine and sake and felt dizzy"). Although there is still room for improvement in the performance of this model in discriminating between "presence of distress" and "presence of distress caused by breast cancer," this model will be useful in supporting patients with breast cancer because we were able to extract descriptions of "physical changes that cause distress" in patients with breast cancer.

Limitations

First, the BERT model used in this study has great strength in recognizing context, but the upper limit of the number of input words is 512. Although there was concern that the performance might deteriorate with posts having more than 512 input words, it was found that there was almost no difference between the performance only for posts with more than 512 input words and that for all posts. On the other hand, the performance for posts with 512 input words or less was slightly inferior to that for all posts. Based on these results, it was considered that truncation after 512 input words had little effect on the model performance,

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whereas the lack of information due to a small number of input words had a greater effect in this analysis. This suggests that blog posts containing a larger number of input words than the upper limit would not degrade model performance (Table 2 and Table S2 in Multimedia Appendix 1).

Second, the small number of blog posts for each label in our data set is also the limitation of this study. Our model was built from the data set containing descriptions of five worry types. The prediction performance of the model was different for each label, and the higher the IAA and the greater the number of posts, the higher the precision and the *F* score tended to be. This suggests that the IAA and the number of posts are important factors in constructing the classifier. This problem can be overcome by increasing the number of blog posts for each label.

Third, the patients' blogs used in this study were written in Japanese. It is important to develop a classification model in Japanese, but the lack of applicability to multiple languages may be a limitation.

Future Directions

Our findings could lead to the development of better patient support systems and methods that can respond to temporal and interindividual changes in worries. Our methodology also facilitates the identification of worries and may promote the sharing of problems among patients. Furthermore, in the future, by combining sentiment analysis with our model, it might be possible to enrich the interpretation of the findings and deepen the understanding of how breast cancer patients' worries influence their emotions. Although this study focused only on worries about breast cancer, there are many common worries that are not specific for breast cancer, and it is expected that the model could be extended to other disease areas.

Conclusion

In conclusion, this study showed that the BERT model can extract multiple worries, such as "treatment," "physical," "psychological," "work/financial," and "family/friends," from text generated by patients with breast cancer. This is the first study to deal with multiple patient worries using BERT and demonstrates the usefulness of NLP techniques in dealing with patient-generated text. The results will be helpful to identify breast cancer patients' worries and give them timely social support.

Acknowledgments

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Data Availability

The data consisting of blog articles in the study are available from Mediaid Corporation upon reasonable request.

Authors' Contributions

TW, SY, EA, HK, and SH designed the study. TW and SH conducted annotation. TW performed the data analysis, created the natural language processing (NLP) model, and conducted all experiments. HY owned and provided the data source of Life Palette. SY and EA supervised the study design from the NLP technical perspective. SH supervised the study. TW and SH drafted and completed the manuscript. All authors reviewed and approved the manuscript.

Conflicts of Interest

HY is the chief executive officer of Mediaid Corporation that operates Life Palette. The other authors declare no competing interests.

Multimedia Appendix 1
Supplementary material.
[DOCX File , 196 KB - cancer_v8i2e37840_app1.docx]

References

1. Sung H, Ferlay J, Siegel RL, Laversanne M, Soerjomataram I, Jemal A, et al. Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA Cancer J Clin 2021 May;71(3):209-249. [doi: 10.3322/caac.21660] [Medline: 33538338]
2. Burstein HJ, Lacchetti C, Griggs JJ. Adjuvant endocrine therapy for women with hormone receptor-positive breast cancer: ASCO clinical practice guideline focused update. J Oncol Pract 2019 Feb;15(2):106-107. [doi: 10.1200/JOP.18.00617] [Medline: 30523754]
3. Cancer Statistics in Japan-2019. Tokyo, Japan: Foundation for Promotion of Cancer Research; Mar 2020.
4. Montazeri A, Jarvandi S, Haghighat S, Vahdani M, Sajadian A, Ebrahimi M, et al. Anxiety and depression in breast cancer patients before and after participation in a cancer support group. Patient Educ Couns 2001 Dec 01;45(3):195-198. [doi: 10.1016/s0738-3991(01)00121-5] [Medline: 11722855]

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5. Aggarwal R, Hueniken K, Eng L, Kassirian S, Geist I, Balaratnam K, et al. Health-related social media use and preferences of adolescent and young adult cancer patients for virtual programming. Support Care Cancer 2020 Oct;28(10):4789-4801. [doi: 10.1007/s00520-019-05265-3] [Medline: 31974768]
6. Littlechild SA, Barr L. Using the Internet for information about breast cancer: a questionnaire-based study. Patient Educ Couns 2013 Sep;92(3):413-417. [doi: 10.1016/j.pec.2013.06.018] [Medline: 23891419]
7. Wang J, Deng H, Liu B, Hu A, Liang J, Fan L, et al. Systematic evaluation of research progress on natural language processing in medicine over the past 20 years: bibliometric study on PubMed. J Med Internet Res 2020 Jan 23;22(1):e16816 [FREE Full text] [doi: 10.2196/16816] [Medline: 32012074]
8. Mavragani A. Infodemiology and infoveillance: scoping review. J Med Internet Res 2020 Apr 28;22(4):e16206 [FREE Full text] [doi: 10.2196/16206] [Medline: 32310818]
9. Magge A, Klein A, Miranda-Escalada A, Al-Garadi MA, Alimova I, Miftahutdinov Z, et al. Overview of the Sixth Social Media Mining for Health Applications (#SMM4H) Shared Tasks at NAACL 2021. 2021 Presented at: Sixth Social Media Mining for Health (#SMM4H) Workshop and Shared Task; June 2021; Mexico City, Mexico p. 21-32. [doi: 10.18653/v1/2021.smm4h-1.4]
10. Jones J, Pradhan M, Hosseini M, Kulanthaivel A, Hosseini M. Novel approach to cluster patient-generated data into actionable topics: case study of a web-based breast cancer forum. JMIR Med Inform 2018 Nov 29;6(4):e45 [FREE Full text] [doi: 10.2196/medinform.9162] [Medline: 30497991]
11. Gonzalez-Hernandez G, Sarker A, O'Connor K, Savova G. Capturing the patient's perspective: a review of advances in natural language processing of health-related text. Yearb Med Inform 2017 Aug;26(1):214-227 [FREE Full text] [doi: 10.15265/IY-2017-029] [Medline: 29063568]
12. Tapi Nzali MD, Bringay S, Lavergne C, Mollevi C, Opitz T. What patients can tell us: topic analysis for social media on breast cancer. JMIR Med Inform 2017 Jul 31;5(3):e23 [FREE Full text] [doi: 10.2196/medinform.7779] [Medline: 28760725]
13. Devlin J, Chang MW, Lee K, Toutanova K. BERT: pre-training of deep bidirectional transformers for language understanding. 2019 Presented at: NAACL-HLT 2019; June 2019; Minneapolis, MN.
14. Saha B, Lisboa S, Ghosh S. Understanding patient complaint characteristics using contextual clinical BERT embeddings. 2020 Presented at: 2020 42nd Annual International Conference of the IEEE EMBC; July 2020; Montreal, QC. [doi: 10.1109/EMBC44109.2020.9175577]
15. Nishioka S, Watanabe T, Asano M, Yamamoto T, Kawakami K, Yada S, et al. Identification of hand-foot syndrome from cancer patients' blog posts: BERT-based deep-learning approach to detect potential adverse drug reaction symptoms. PLoS One 2022;17(5):e0267901 [FREE Full text] [doi: 10.1371/journal.pone.0267901] [Medline: 35507636]
16. Edara DC, Vanukuri LP, Sistla V, Kolli VKK. Sentiment analysis and text categorization of cancer medical records with LSTM. J Ambient Intelligence Humanized Computing 2019 Jul 16:1-17. [doi: 10.1007/s12652-019-01399-8]
17. Mediaid Corporation. Life Palette. URL: https://lifepalette.jp [accessed 2021-07-16]
18. Miyabe M, Shimamoto Y, Aramaki E. Extracting patients' distress of their medical care from web texts: the automatic classification of cancer patients' distress. 2014 Presented at: Forum on Information Technology; September 2014; Tsukuba, Japan.
19. Landis JR, Koch GG. The measurement of observer agreement for categorical data. Biometrics 1977 Mar;33(1):159-174. [Medline: 843571]
20. The voices of 1,275 people who have faced breast cancer. Shizuoka Cancer Center. 2016. URL: https://www.scchr.jp/book/houkokusho/2013nyugan.html [accessed 2022-05-28]
21. Inui Laboratory Tohoku University. cl-tohoku / bert-japanese. GitHub. URL: https://github.com/cl-tohoku/bert-Japanese [accessed 2021-06-07]
22. Kudo T. MeCab: yet another part-of-speech and morphological analyzer. URL: https://taku910.github.io/mecab/ [accessed 2021-10-05]
23. Sato T. mecab-ipadic-NEologd : Neologism dictionary for MeCab. URL: https://github.com/neologd/mecab-ipadic-neologd [accessed 2022-05-28]
24. Kawazoe Y, Shibata D, Shinohara E, Aramaki E, Ohe K. A clinical specific BERT developed using a huge Japanese clinical text corpus. PLoS One 2021;16(11):e0259763 [FREE Full text] [doi: 10.1371/journal.pone.0259763] [Medline: 34752490]
25. Shimomoto K, Ando K. Automatic classification of distress in blogs written by cancer patients or their families. 2018 Presented at: 80th Natl Conv IPSJ; March 2018; Tokyo, Japan p. 441-442.
26. Cronin RM, Fabbri D, Denny JC, Rosenbloom ST, Jackson GP. A comparison of rule-based and machine learning approaches for classifying patient portal messages. Int J Med Inform 2017 Sep;105:110-120 [FREE Full text] [doi: 10.1016/j.ijmedinf.2017.06.004] [Medline: 28750904]
27. Sulieman L, Gilmore D, French C, Cronin RM, Jackson GP, Russell M, et al. Classifying patient portal messages using Convolutional Neural Networks. J Biomed Inform 2017 Oct;74:59-70 [FREE Full text] [doi: 10.1016/j.jbi.2017.08.014] [Medline: 28864104]

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Abbreviations

BERT: Bidirectional Encoder Representations From Transformers
IAA: interannotator agreement
LDA: latent Dirichlet allocation
LSTM: long short-term memory
NLP: natural language processing

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Original Paper

The Experiences of Patients With Adjuvant and Metastatic Melanoma Using Disease-Specific Social Media Communities in the Advent of Novel Therapies (Excite Project): Social Media Listening Study

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Abstract

Background: Immunotherapy and targeted therapy treatments are novel treatments available for patients with metastatic and adjuvant melanoma. As recently approved treatments, information surrounding the patients' and caregivers' experience with these therapies, perceptions of treatments, and the effect the treatments have on their day-to-day life are lacking. Such insights would be valuable for any future decision-making with regard to treatment options.

Objective: This study aims to use health-related social media data to understand the experience of patients with adjuvant and metastatic melanoma who are receiving either immunotherapy or targeted therapies. This study also included caregivers' perspectives.

Methods: Publicly available social media forum posts by patients with self-reported adjuvant or metastatic melanoma (and their caregivers) between January 2014 to October 2019 were programmatically extracted, deidentified, cleaned, and analyzed using a combination of natural language processing and qualitative data analyses. This study identified spontaneously reported symptoms and their impacts, symptom duration, and the impact of treatment for both treatment groups.

Results: Overall, 1037 users (9023 posts) and 114 users (442 posts) were included in the metastatic group and adjuvant group, respectively. The most identified symptoms in both groups were fatigue, pain, or exanthema (identified in 5%-43% of patients dependent on the treatment group). Symptom impacts reported by both groups were physical impacts, impacts on family, and impacts on work. Positive treatment impacts were reported in both groups and covered the areas of work, social and family life, and general health and quality of life.

Conclusions: This study explored health-related social media to better understand the experience and perspectives of patients with melanoma receiving immunotherapy or targeted therapy treatments as well as the experience of their caregivers. This exploratory work uncovered the most discussed concerns among patients and caregivers on the forums including symptoms and their impacts, thus contributing to a deeper understanding of the patient/caregiver experience.

(JMIR Cancer 2022;8(2):e34073) doi:10.2196/34073

KEYWORDS

health-related social media; patient-centric; melanoma; adjuvant; metastatic; immunotherapy; targeted therapy; natural language processing; patient experience; cancer; cancer therapy; patient perspective; social media; patient experience; caregiver experience

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Introduction

Background

Melanoma is a skin cancer that arises from uncontrolled proliferation of melanocytes. It is the fifth most common cancer in the United Kingdom, accounting for nearly 5% of all new cancer cases [1]. In the last 10 years, the incidence of melanoma has increased by more than 50% in the United Kingdom and is further projected to increase by 7% between 2014 and 2035 [2,3]. The worldwide incidence of melanoma has also steadily increased over the last decades, ranging between 4% and 6% in North America, Australia, and New Zealand [4].

Survival rates for melanoma depend on the disease stage; for example, 1-year net survival at stage I is similar to that of the general population; however, survival at stage IV is historically much lower [5], with the median reported at just 6 to 10 months [6]. Surgery, while effective for early stages of melanoma, is a less effective treatment option for patients with metastatic or late-stage disease [7]. Newer therapies such as immunotherapy treatments and targeted therapies (TTs) have shown good efficacy in the treatment of metastatic melanoma and have shifted the treatment paradigm [8,9]. TTs block the growth and spread of cancer by interfering with specific molecules that are involved in the growth, spread, and progression of cancer. These, however, are limited to patients who carry the BRAF V600E/K mutations, the prevalence of which in melanoma is estimated to be ~40% to 50% [10-12]. Dabrafenib plus trametinib combination therapy is routinely used as a TT and was licensed for use in metastatic melanoma with BRAF V600E or V600K mutations in August 2015 [13]. Dabrafenib with trametinib has also been recommended for adjuvant treatment of adults with resected stage III BRAF V600 mutation-positive melanoma [14]. The European Society for Medical Oncology 2019 guidelines for metastatic melanoma suggest that patients be treated with nivolumab, nivolumab/ipilimumab, or pembrolizumab in the first-line setting, and for patients with BRAF V600 mutation, vemurafenib/cobimetinib (not recommended by the National Institute for Health and Care Excellence in the United Kingdom). Dabrafenib/trametinib and encorafenib/binimetinib can also be considered [15].

While trial data on these therapies are shown to have survival benefit, there are few reports regarding patients' experiences while undergoing treatment. Social media provides an opportunity to unveil a more personal and firsthand view on patients' and caregivers' perspectives and experiences with melanoma receiving treatment.

Health-related social media has substantial potential as a sizeable real-world data source due to available posts from thousands of patients and caregivers that would be hard to capture in traditional data sources. These experiences are reported in a setting with no researcher or medical professional present. Furthermore, in June 2018 the US Food and Drug Administration (FDA) encouraged the use of social media to understand the patient perspective [16]. Studies have also suggested that real-world data from social media can provide a better understanding of the patient's behavior, quality of life, adverse events, and any episodes [17,18].

Objectives

The objective of this study was to use publicly available health-related social media data (ie, discussions on melanoma-specific patient online forums) to understand the experience of patients with adjuvant and metastatic melanoma receiving immunotherapy or TTs and their caregivers. The reported symptoms and their associated burden such as physical impacts, impacts on family, and impacts on quality of life were of specific interest in this study.

Methods

This was a retrospective analysis of existing publicly available discussions posted from January 2014 to October 2019 (study period) in social media forums for patients with self-reported adjuvant or metastatic melanoma and their caregivers.

Data Source

To determine the feasibility of addressing the study objectives and to select the forums for inclusion in the study, a feasibility evaluation was conducted via a manual search and inspection of existing social media forums (finalized in May 2019). The search strategy focused on identifying melanoma-specific patient forums using relevant search terms such as "melanoma patient forums" and "melanoma discussion boards." Generic social media forums (eg, Facebook and Twitter) were not considered due to the high level of noise (ie, irrelevant material).

Searches for social media forums were conducted using the Google Search engine for both the United Kingdom and the United States to get a complete picture of the available melanoma forum landscape. The first five pages of results were screened by title, and relevant forums were summarized.

Disease-specific social media forums were selected based on their relevance to disease experience, user profile (melanoma patients or caregivers), being currently active (ie, multiple posts in recent months to accurately reflect the most up-to-date discussions among parents/caregivers), posts in the English language, and material being freely available for anyone to access and read, with no registration required. No geographical restrictions were applied when selecting the social media forums.

Based on these criteria, forums from the following social media forums were included: Melanoma International Foundation, Melanoma Research Foundation, MacMillan Cancer Support, Cancer Compass, and Cancer Survivors Network.

Data Preprocessing and Subsetting

Posts in the public domain on the included forums were programmatically extracted using validated algorithms in the R Programming Language. Upon extraction, data were deidentified by removal of identifiable personal information (ie, name, post or zip code, place names, email addresses, phone numbers, social security numbers, and conversion of raw usernames to unique identifiers). Data were also processed to correct for misspellings, remove non–Unicode Transformation Format-8 text, remove duplicate posts, and standardize all drug names to generic names.

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Data were restricted to posts of users who began posting on or after the start of the study period and who mentioned at least one of the following treatments in their posts: binimetinib, dabrafenib, encorafenib, ipilimumab, nivolumab, pembrolizumab, or trametinib. Machine learning (ML) methods were used to predict whether posts contained actual treatment experiences as opposed to noise. Supervised ML algorithms were trained and tested on a random sample of over 1000 sentences from the collected data, which were manually labelled as "treatment experience related" or "not treatment experience related" to distinguish posts of interest and those containing noise. The best performing model was selected and applied to the data for subsequent analyses so that only users whose posts were predicted to contain actual treatment experiences were retained.

Natural language processing (NLP) methods (eg, inspection of clusters and n-grams) were used to stratify users into mutually exclusive adjuvant or metastatic groups based on lexical terms within posts. Terms derived from users' posts were combined with those determined a priori (ie, "I had surgery" or "received adjuvant") to generate the final list of terms for the population identification. The adjuvant group contained users with a mention of having surgery and no indication of metastatic disease, and the metastatic group consisted of users with terms relating to metastatic disease or treatments indicated at the metastatic setting. Users who could not be assigned to one of the groups were excluded from analyses. NLP methods using mentions of treatments in posts were used to further classify users into one of the following treatment subgroups:

- TT: dabrafenib/trametinib, encorafenib/binimetinib (metastatic group only)
- Immunotherapy: Pembrolizumab, ipilimumab/nivolumab (metastatic group only), or nivolumab

Treatment subgroups were not mutually exclusive, and posts were restricted to those containing the respective treatment to ensure the specificity of the data analyzed.

Data Analysis

Symptom Identification

Symptoms were captured using the Apache Clinical Text Analysis Knowledge Extraction System (cTAKES) [19], a NLP tool that maps concepts from the Unified Medical Language System to clinical terms mentioned within posts. cTAKES was supplemented with custom lexicons to capture lay terms used by patients and caregivers (ie, nonclinical events). The custom lexicons were initially compiled by using the FDA Adverse Event Reporting System reports and further expanded upon inspection of the most frequently occurring lay terms used by users.

The output was manually inspected, and revisions were made where necessary to remove clinical terms incorrectly captured as symptoms a patient experienced. Rates of symptom occurrence were calculated as users with a co-occurrence of a symptom mention and treatment in the same post over the number of users with a mention of the treatment.

Qualitative Data Analyses

Manual qualitative data analysis (QDA) was performed to capture the impacts of symptoms and treatment discussed in the forum. Due to the large volume of posts, random samples of users were generated from the overall population included. Full posting histories from those users were qualitatively reviewed. This exercise was conducted separately for each treatment group. A random sampling strategy was used to include a holistic view of the experience of forum users. Qualitative coding was conducted in ATLAS.ti (version 8.4.4) by two researchers following thematic analysis principles, and codes were assigned to data-driven themes, categories, and subcategories [20,21]. The posts were coded until saturation was reached. Saturation was defined as the point at which no new categories of codes were generated by reviewing additional data. Codes and themes were reviewed by a researcher who did not code the data.

Ethical Conduct

At the time of conducting the study, no strict guidelines on the appropriate use of health-related social media data had been developed. However, this study followed the recently published ethics framework from the University of Sheffield [22]. Only public open-access forums were used, where contents were openly visible and there was no requirement to register or to create a profile to view content. Terms and conditions of included forums were carefully reviewed to ensure compliance. To protect user privacy, no quotations are provided verbatim, and the original post cannot be traced in search engines using the text presented.

Results

Study Population

A total of 1037 users (9023 posts) and 114 users (442 posts) were included in the metastatic group and adjuvant group, respectively. A breakdown by treatment subgroup for each group is provided in Tables 1 and 2. As expected, given the timeline of treatment approvals, the largest treatment subgroups were nivolumab and pembrolizumab, and the smallest was encorafenib/binimetinib.

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Table 1. Users included in the metastatic group by treatment group and analyses.

Treatment subgroup[a]	Symptom identification		Qualitative data analysis	
	Users, n	Posts, n	Users, n	Posts, n
Encorafenib/binimetinib	20	36	34	98
Dabrafenib/trametinib	215	659	18	30
Ipilimumab/nivolumab	499	2723	34	92
Nivolumab	443	3751	27	109
Pembrolizumab	451	3171	28	78

[a]The treatment groups are not mutually exclusive.

Table 2. Users included in the adjuvant group by treatment group and analyses.

Treatment subgroup[a]	Symptom identification		Qualitative data analysis	
	Users, n	Posts, n	Users, n	Posts, n
Dabrafenib/trametinib	18	41	10	27
Nivolumab	63	263	20	61
Pembrolizumab	45	209	24	100

[a]The treatment groups are not mutually exclusive.

Identified Symptoms

In both groups, fatigue, pain, or exanthema were the most mentioned symptoms by patients with metastatic melanoma or their caregivers in the forums (Figures 1 and 2).

In the metastatic group, fatigue was the most mentioned symptom for patients taking nivolumab (189/443, 42.7%), ipilimumab/nivolumab (163/499, 32.7%), and dabrafenib/trametinib (46/215, 21.4%), and pain was the most common symptom in pembrolizumab (144/451, 31.9%) and encorafenib/binimetinib (6/20, 30%). In the adjuvant group, fatigue and pain were the most common symptoms experienced by users in the nivolumab (n=18, 29%, and n=9, 14%, of 63 users, respectively) and pembrolizumab (n=7, 16%, and n=11, 24%, of 45 users, respectively) treatment groups, and chills and fever were the most common symptoms experienced in the dabrafenib/trametinib (n=5, 28%, and 4, 22%, of 18 users, respectively) treatment group.

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Figure 1. Heat map of the most mentioned symptoms, metastatic group, by treatment group.

	Nivolumab	Pembrolizumab	Ipilimumab/ Nivolumab	Dabrafenib/ Trametinib	Encorafenib/ Binimetinib
Fatigue	42.7%	30.2%	32.7%	21.4%	5.0%
Pain	28.9%	31.9%	26.3%	20.5%	30.0%
Exanthema	23.3%	14.9%	19.8%	12.6%	10.0%
Swelling	14.5%	12.6%	10.8%	14.0%	10.0%
Fever	12.0%	9.8%	11.6%	20.9%	0.0%
Nausea	14.9%	9.1%	12.8%	9.8%	10.0%
Tired	14.7%	10.0%	10.8%	6.1%	0.0%
Spots on skin	12.6%	11.5%	7.6%	7.4%	5.0%
Pruritus	15.1%	8.2%	11.6%	2.8%	0.0%
Diarrhea	13.8%	6.2%	13.2%	2.8%	0.0%
Headache	12.4%	7.8%	10.2%	11.2%	10.0%
Arthralgia	11.7%	10.4%	7.8%	6.5%	5.0%
Colitis	12.2%	8.9%	12.0%	0.9%	5.0%
Stomach diseases	12.9%	8.0%	8.6%	3.3%	5.0%
Weakness	7.7%	7.5%	5.6%	6.1%	5.0%
Ache	8.1%	7.8%	6.8%	5.6%	0.0%
Bleeding	7.2%	5.5%	5.8%	7.0%	5.0%
Chills	5.9%	5.8%	5.4%	11.2%	5.0%
Malaise	7.9%	5.3%	5.8%	5.6%	5.0%
Stress	8.4%	7.1%	5.6%	2.8%	5.0%
Seizures	6.3%	5.8%	4.0%	6.5%	0.0%
Fear	7.2%	6.0%	5.2%	4.7%	0.0%
Inflammation	6.1%	7.1%	4.8%	3.7%	0.0%
Influenza	7.2%	4.9%	4.8%	4.2%	5.0%
Vitiligo	9.0%	5.8%	5.8%	0.9%	0.0%
Anxiety	7.2%	4.4%	5.0%	3.3%	5.0%
Coughing	6.3%	5.1%	4.2%	5.1%	0.0%

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Figure 2. Heat map of the most mentioned symptoms, adjuvant group, by treatment group.

	Nivolumab	Pembrolizumab	Dabrafenib/ Trametinib
Fatigue	28.6%	15.6%	11.1%
Pain	14.3%	24.4%	16.7%
Exanthema	11.1%	11.1%	5.6%
Headache	9.5%	6.7%	11.1%
Diarrhea	7.9%	4.4%	11.1%
Pruritus	9.5%	8.9%	0.0%
Tired	12.7%	6.7%	0.0%
Chills	3.2%	2.2%	27.8%
Swelling	9.5%	6.7%	5.6%
Anxiety	6.4%	11.1%	0.0%
Spots on skin	7.9%	8.9%	0.0%
Ache	4.8%	11.1%	5.6%
Colitis	3.2%	11.1%	5.6%
Fever	3.2%	2.2%	22.2%
Lymphedema	11.1%	2.2%	5.6%
Stomach diseases	9.5%	6.7%	0.0%
Common cold	4.8%	6.7%	5.6%
Nausea	4.8%	2.2%	5.6%
Weakness	9.5%	0.0%	5.6%
Arthralgia	9.5%	2.2%	0.0%
Malaise	7.9%	8.9%	0.0%
Muscle cramp	4.8%	2.2%	5.6%
Ulcer	3.2%	4.4%	5.6%
Myalgia	3.2%	6.7%	0.0%
Dizziness	3.2%	2.2%	5.6%

Symptom Impacts

Metastatic Group

Symptom impacts varied by treatment subgroup; however, physical and psychological effects were the most common negative impacts reported. Physical impacts included mobility issues, being unable to drive, and overall reduced activity. Psychological impacts included feelings of anxiety, depression, frustration, worry, and loss of dignity. Negative impact on social life was reported among the dabrafenib/trametinib and nivolumab treatment groups, and disturbed sleep was reported among the binimetinib/encorafenib, nivolumab, and ipilimumab/nivolumab treatment groups; however, they were reported less frequently. Patients in the immunotherapy and TT groups reported impacts on their physical ability, including their day-to-day tasks and ability to perform activities requiring mobility:

His quality of life has extremely deteriorated and he is now unable to perform physical activities [Caregiver]

As treatment continues, I have developed panic attacks [Patient]

Adjuvant Group

Findings for the adjuvant group were limited due to the small sample size; however, adverse impacts on family life ("She is too weak to enjoy spending time with her" [caregiver]) and physical impacts ("heel pain wasn't bad at the start, but now I sometimes feel I can barely walk" [patient]) were identified. In addition, reduction of perceived quality of life ("the fatigue is really bothering the husband" [caregiver]) and impact on work ("I changed my work schedule as I was worried about side effects" [patient]) was reported [Table 3].

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Table 3. Impacts of symptoms by group.

	Metastatic group	Adjuvant group
Physical impacts	• Bedridden • Less active • Difficulty doing physical activity • Difficulty exercising • Difficulty getting out of bed • Difficulty moving • Difficulty walking • General impact on quality of life • Unable to drive	• Inability to walk • Taking a break from running • Unable to exercise as before
Psychological impacts	• Anxiety • Concern • Conflicted • Depression • Frustration • Loss of dignity • Nervous • Panic attack • Worried	• Annoyance • Frustration
Impacts on sleep	• Difficulty sleeping • Inability to stay awake for long	• NR[a]
Impacts on social life	• Needing to plan social outings • Stopped socializing	• NR
Family/caregiver burden	• Feeling angry with patient • Emotional impact to family	• Inability to enjoy time with grandchildren
Impacts on work	• Interruption to work	• Changing work schedule • Taking time off from work

[a]NR: not reported.

Symptom Duration

Metastatic Group

Symptoms lasting less than a week appeared most common among patients receiving dabrafenib/trametinib, and longer-term sequelae appeared most common among patients receiving ipilimumab/nivolumab. Short-term symptoms (ie, those lasting up to 1 week) included fever, headache, fatigue, and soreness. Longer-term ones (ie, lasting longer than 1 week) included liver issues, nausea, diarrhea, and fatigue.

Adjuvant Group

More than one-third of patients receiving dabrafenib/trametinib or nivolumab mentioned symptom duration. Similar to the metastatic group, short-term symptoms appeared more frequently in patients receiving dabrafenib and trametinib, while longer-term issues were most commonly mentioned by patients receiving nivolumab. Examples of longer-term symptoms included liver problems, headache, colitis, and joint issues.

Impacts of Treatment

Metastatic Group

In the metastatic group, the positive impacts mentioned by forum users included effects on their general health and quality of life, physicality, work, and social life or family. Patients mentioned feeling better and happier, and being able to continue life as normal because of their treatment. Positive physical effects included gaining weight, looking better, being able to exercise, and feeling stronger. Examples of the positive influences for TTs include:

> *I can work and complete tasks as usual* [patient]
>
> *This is the first time in months that I have felt like myself* [patient]

For immunotherapy:

> *As time progresses, he is getting stronger and gaining some weight. He is also doing some physical activity everyday* [caregiver]
>
> *I am able to spend time with friends and family as I now believe I have several more years to live* [patient]

Negative effects of treatments on social/family aspects and work included not being able to travel with family, partners wanting time off from job, and the patient having to work less.

Adjuvant Group

In the adjuvant group, forum users had discussions on improvements in general health and quality of life, work, and social/family. Patients reported they felt better, worked as usual, and spent more time with family. A user treated with TT expressed their personal family experience:

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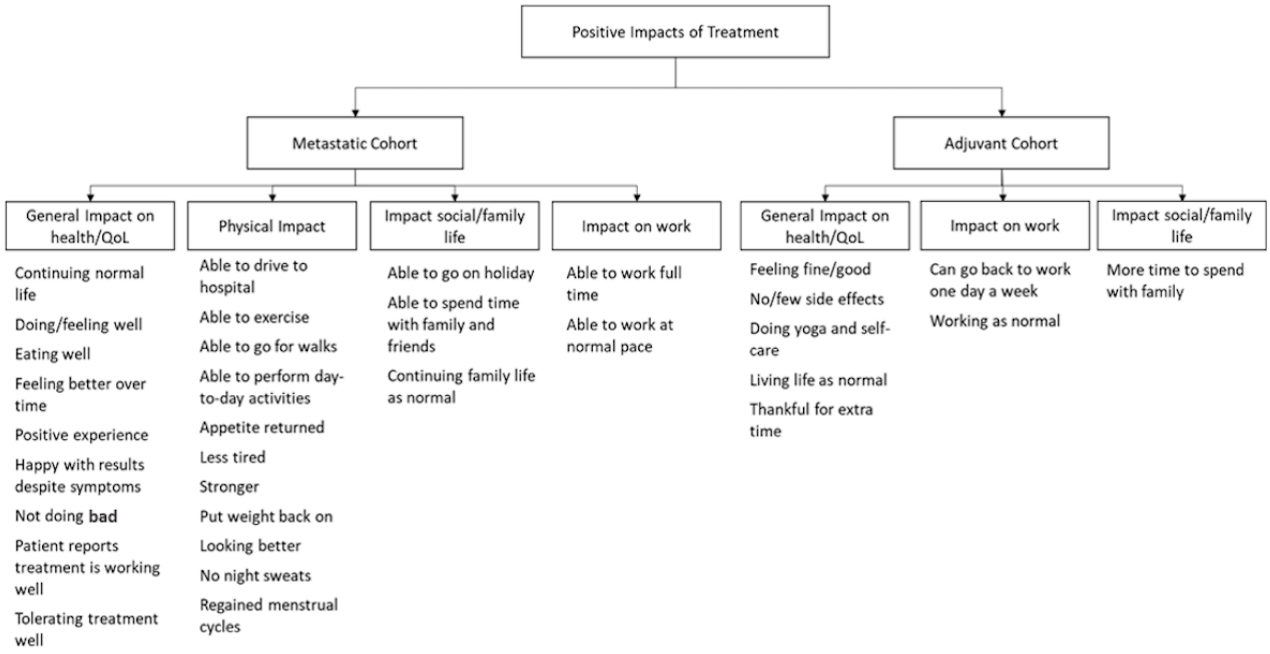
my grandson will be born soon. This treatment has made it possible for me to appreciate moments that I didn't think I would see

In addition, a user who underwent immunotherapy reported the positive impact going to work had on their well-being: "I was still able to work, which made things seem normal." Figure 3 illustrates the positive impacts of treatment in both groups.

Figure 3. Positive impacts of treatment. QoL: quality of life.



Discussion

Principal Findings

This exploratory work uncovered the most common concerns discussed on social media forums among patients with adjuvant and metastatic melanoma receiving immunotherapy or TTs and their caregivers. Symptoms and related physical impacts (eg, inability to perform usual activities) were the most frequently reported issues in both cohorts, while psychological impacts (eg, anxiety) were also discussed among metastatic patients. Where discussed, treatment preferences were primarily focused on reduced risk of adverse events.

To the best of our knowledge, no published research has investigated experiences of patients with adjuvant or metastatic melanoma with immunotherapy and TT using health-related social media data.

Among the metastatic group, the most common symptom reported was fatigue in all treatment groups except for pembrolizumab and encorafenib/binimetinib, where pain was most common. Treatment included perceived improvements in general health, quality of life, physicality, ability to work, and patient's social and family life. In the adjuvant group, comments reflected enhancements of general health, quality of life, work, and social/family interactions.

This study provides a unique perspective on patients' experiences receiving immunotherapy or TTs. It is crucial to consider patient perspectives to ensure that real-life experiences and expectations are understood, especially as new therapies for melanoma become available. Social media not only allows patients to share their story but also provides a platform for patients and caregivers to seek support from others with similar experiences. This creates a sense of community that allows users to share positive experiences and burdens. Symptom impacts varied by treatment subgroups; however, the negative discussions generally featured work, family, and the physical aspects. The patients' and caregivers' point of view is not often incorporated in research but does play a large role in patients' and their families' well-being.

Comparison to Prior Literature and Interpretation

A study that examined the extent to which social media health data could provide insight for relative effectiveness assessment concluded that, within oncology, these real-world data sources can be used to assess adverse events and evaluate quality of life [18].

To the best of the authors' knowledge, this is the first published study examining the impacts of immunotherapy and TT among patients with melanoma and their caregivers using social media forums. The most commonly reported symptoms by patients with metastatic melanoma self-reporting taking pembrolizumab were pain, fatigue, and exanthema, which aligns with some of the common side effects previously reported [23,24]. Fatigue and skin problems are some of the common side effects of Nivolumab, which aligns with the first and third most common symptoms identified in this study, respectively [25]. The same common side effects were identified with ipilimumab-nivolumab again mapping to those symptoms identified in this study [26]. Fatigue, nausea, diarrhea, vomiting, and abdominal pain have been previously identified as common side effects of binimetinib in combination with encorafenib [27,28]; however, our study identified pain as the most mentioned symptom by patients with metastatic melanoma who self-reported receiving this treatment.

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Strengths and Limitations

Patients' and caregivers' firsthand experiences are potentially likely to reflect the true opinions of the users as they are provided spontaneously. Comments are possibly less likely to be impacted by information bias than traditional interview studies with no research or medical professionals present. This exploratory analysis provides insights as to which topics were most frequently discussed by patients with adjuvant or metastatic melanoma using forums receiving immunotherapy or TT. These are likely to reflect those of most importance to patients. The use of QDA allowed for further insight into factors of importance to patients and their caregivers, including those that may not have been considered at study conception.

The study was not free of limitations. First, due to the nature of the data and to respect patient privacy, the researchers were restricted by the amount of detail provided by users. Although all relevant detail on patients' and caregivers' experiences were coded during the qualitative review of posts, researchers could not ask for clarification in instances where users did not provide sufficient information; therefore, some detail may have been missed for a small number of users. Second, as the study was primarily exploratory in nature, all potentially relevant data were included in the analysis resulting in varied sample sizes across treatment groups. Thus, results from the QDA should be interpreted with caution as no statistical tests were conducted to assess differences between treatment groups. Findings were limited in the adjuvant group due to the small sample size, which is likely a result of recent approvals for the treatments of interest at this setting at the time of conducting the study. If repeated for a longer time after approval, a larger sample size could be achieved. Third, patients posting on forums cannot be considered representative of the entire melanoma patient population. Due to a lack of consistent reporting of patient attributes (eg, clinical and demographical characteristics), representativeness is challenging to assess in social media forums; however, this study was exploratory in nature with no comparative analyses. To capture a broad patient population and mitigate bias from nonrepresentativeness, multiple social media forums were included with no geographical restrictions. Finally, biases in health-related social media studies are not well understood, for example, the extent of information bias present in users' posts. However, no study can be considered free of bias and such bias is not a limitation unique to this exploratory study.

Conclusions

This exploratory study uncovered the most discussed symptoms and their associated impacts among patients and caregivers using health-related social media forums. This suggests that these are the topics of utmost importance to patients and caregivers influencing their lives. Future research should aim to validate and investigate less frequently discussed topics and could include patient questionnaires, interviews, or focus groups. Such studies could be used to assess how important these topics are to patients and caregivers, and to validate the findings of this study.

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Authors' Contributions

All authors provided substantial contributions to the conception and design of the work, and interpretation of results and were involved in the review and approval of this manuscript for publication.

Conflicts of Interest

GF is an employee of University Hospitals of Leicester National Health Service Trust. AB, EM, and SH are employees of Evidera (London, UK), who were paid consultants to Novartis in connection with the development of this manuscript. HT, AN, and MS are employees of Novartis (London, UK).

References

1. Melanoma skin cancer statistics. Cancer Research UK. URL: https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/melanoma-skin-cancer [accessed 2019-12-31]
2. Melanoma skin cancer incidence by sex and UK country. Cancer Research UK. URL: https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/melanoma-skin-cancer/incidence#heading-Zero [accessed 2019-12-31]
3. Smittenaar CR, Petersen KA, Stewart K, Moitt N. Cancer incidence and mortality projections in the UK until 2035. Br J Cancer 2016 Oct 25;115(9):1147-1155 [FREE Full text] [doi: 10.1038/bjc.2016.304] [Medline: 27727232]
4. Matthews NH, Li WQ, Qureshi AA, Weinstock MA, Cho E. Epidemiology of melanoma. In: Ward WH, Farma JM, editors. Cutaneous Melanomatiology and Therapy. Brisbane, Australia: Codon Publications; 2017.
5. Cancer survival by stage at diagnosis for England (experimental statistics): adults diagnosed 2012, 2013 and 2014 and followed up to 2015. Office for National Statistics. 2019. URL: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancersurvivalbystageatdiagnosisforenglandexperimentalstatistics/adultsdiagnosed20122013and2014andfollowedupto2015 [accessed 2019-12-31]

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6. Sosman JA, Kim KB, Schuchter L, Gonzalez R, Pavlick AC, Weber JS, et al. Survival in BRAF V600-mutant advanced melanoma treated with vemurafenib. N Engl J Med 2012 Feb 23;366(8):707-714 [FREE Full text] [doi: 10.1056/NEJMoa1112302] [Medline: 22356324]
7. Rughani MG, Gupta A, Middleton MR. New treatment approaches in melanoma: current research and clinical prospects. Ther Adv Med Oncol 2013 Jan;5(1):73-80 [FREE Full text] [doi: 10.1177/1758834012463260] [Medline: 23323148]
8. Pasquali S, Chiarion-Sileni V, Rossi CR, Mocellin S. Immune checkpoint inhibitors and targeted therapies for metastatic melanoma: a network meta-analysis. Cancer Treat Rev 2017 Mar;54:34-42. [doi: 10.1016/j.ctrv.2017.01.006] [Medline: 28189914]
9. Franken MG, Leeneman B, Gheorghe M, Buyukkaramikli N, Gerrits J, van der Helm I, et al. Comparative effectiveness of novel treatments for advanced melanoma: a systematic literature review and network meta-analysis of effectiveness and safety outcomes. Value Health 2017 Oct;20(9):A412-A413. [doi: 10.1016/j.jval.2017.08.090]
10. Ugurel S, Röhmel J, Ascierto PA, Flaherty KT, Grob JJ, Hauschild A, et al. Survival of patients with advanced metastatic melanoma: the impact of novel therapies. Eur J Cancer 2016 Jan;53:125-134. [doi: 10.1016/j.ejca.2015.09.013] [Medline: 26707829]
11. Ascierto PA, Kirkwood JM, Grob J, Simeone E, Grimaldi AM, Maio M, et al. The role of BRAF V600 mutation in melanoma. J Transl Med 2012 Jul 09;10:85 [FREE Full text] [doi: 10.1186/1479-5876-10-85] [Medline: 22554099]
12. BRAF in melanoma: ESMO biomarker factsheet. OncologyPRO. URL: https://oncologypro.esmo.org/education-library/factsheets-on-biomarkers/braf-in-melanoma [accessed 2021-05-31]
13. US Food and Drug Administration. FDA grants regular approval to dabrafenib and trametinib combination for metastatic NSCLC with BRAF V600E mutation. 2017 Jun 22. URL: http://wayback.archive-it.org/7993/20170111231615/http://www.fda.gov/Drugs/InformationOnDrugs/ApprovedDrugs/ucm476837.html [accessed 2019-12-31]
14. Dabrafenib with trametinib for adjuvant treatment of resected BRAF V600 mutation-positive melanoma. NICE. 2018. URL: https://www.nice.org.uk/guidance/TA544/chapter/1-Recommendations [accessed 2021-05-31]
15. Cutaneous melanoma: ESMO clinical practice guidelines. European Society for Medical Oncology. 2019. URL: https://www.esmo.org/Guidelines/Melanoma/Cutaneous-Melanoma [accessed 2019-10-15]
16. Patient-focused drug development: collecting comprehensive and representative input. US Food and Drug Administration. 2018. URL: https://www.fda.gov/downloads/drugs/guidancecomplianceregulatoryinformation/guidances/ucm610442.pdf [accessed 2019-12-31]
17. Sinha A, Porter T, Wilson A. The use of online health forums by patients with chronic cough: qualitative study. J Med Internet Res 2018 Jan 24;20(1):e19 [FREE Full text] [doi: 10.2196/jmir.7975] [Medline: 29367181]
18. Kalf RR, Makady A, Ten Ham RM, Meijboom K, Goettsch WG, IMI-GetReal Workpackage 1. Use of social media in the assessment of relative effectiveness: explorative review with examples from oncology. JMIR Cancer 2018 Jun 08;4(1):e11 [FREE Full text] [doi: 10.2196/cancer.7952] [Medline: 29884607]
19. Apache cTAKES. 2020. URL: http://ctakes.apache.org/ [accessed 2020-12-31]
20. Glaser BG, Strauss AL, Strutzel E. The discovery of grounded theory; strategies for qualitative research. Nurs Res 1968;17(4):364. [doi: 10.1097/00006199-196807000-00014]
21. Charmaz K, Belgrave LL. Grounded theory. In: The Blackwell Encyclopedia of Sociology. Hoboken, NJ: John Wiley & Sons; 2007.
22. Research involving social media data. The University of Sheffield. 2016. URL: https://www.sheffield.ac.uk/polopoly_fs/1.670954!/file/Research-Ethics-Policy-Note-14.pdf [accessed 2020-12-31]
23. Pembrolizumab (Keytruda). Cancer Research UK. 2019. URL: https://www.cancerresearchuk.org/about-cancer/cancer-in-general/treatment/cancer-drugs/drugs/pembrolizumab [accessed 2022-03-18]
24. Side effects. KEYTRUDA. 2020. URL: https://www.keytruda.com/side-effects/#:~:text=Common%20side%20effects%20of%20KEYTRUDA,shortness%20of%20breath%2C%20and%20constipation [accessed 2020-12-31]
25. Nivolumab (Opdivo). Cancer Research UK. URL: https://www.cancerresearchuk.org/about-cancer/cancer-in-general/treatment/cancer-drugs/drugs/nivolumab [accessed 2021-05-31]
26. Ipilimumab and nivolumab. Cancer Research UK. URL: https://www.cancerresearchuk.org/about-cancer/cancer-in-general/treatment/cancer-drugs/drugs/ipilimumab-nivolumab [accessed 2021-05-31]
27. An oral treatment combination for adults with unresectable or metastatic melanoma with a BRAF V600E/K mutation. BRAFTOVI® (encorafenib) + MEKTOVI® (binimetinib). 2020. URL: https://braftovimektovi.pfizerpro.com/adverse-reactions [accessed 2022-03-23]
28. MEKTOVI® (binimetinib) tablets, for oral use. Pfizer. 2020. URL: http://labeling.pfizer.com/ShowLabeling.aspx?id=12988#:~:text=The%20most%20common%20(%E2%89%A5%2025,%2C%20vomiting%2C%20and%20abdominal%20pain [accessed 2022-03-18]

Abbreviations

cTAKES: Clinical Text Analysis Knowledge Extraction System

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FDA: Food and Drug Administration
ML: machine learning
NLP: natural language processing
QDA: qualitative data analysis
TT: targeted therapy

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Original Paper

Understanding the Lived Experiences of Patients With Melanoma: Real-World Evidence Generated Through a European Social Media Listening Analysis

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Abstract

Background: Cutaneous melanoma is an aggressive malignancy that is proposed to account for 90% of skin cancer–related mortality. Individuals with melanoma experience both physical and psychological impacts associated with their diagnosis and treatment. Health-related information is being increasingly accessed and shared by stakeholders on social media platforms.

Objective: This study aimed to assess how individuals living with melanoma across 14 European countries use social media to discuss their needs and provide their perceptions of the disease.

Methods: Social media sources including Twitter, forums, and blogs were searched using predefined search strings of keywords relating to melanoma. Manual and automated relevancy approaches filtered the extracted data for content that provided patient-centric insights. This contextualized data was then mined for insightful concepts around the symptoms, diagnosis, treatment, impacts, and lived experiences of melanoma.

Results: A total of 182,400 posts related to melanoma were identified between November 2018 and November 2020. Following exclusion of irrelevant posts and using random sampling methodology, 864 posts were identified as relevant to the study objectives. Of the social media channels included, Twitter was the most commonly used, followed by forums and blogs. Most posts originated from the United Kingdom (n=328, 38%) and Spain (n=138, 16%). Of the relevant posts, 62% (n=536) were categorized as originating from individuals with melanoma. The most frequently discussed melanoma-related topics were treatment (436/792, 55%), diagnosis and tests (261/792, 33%), and remission (190/792, 24%). The majority of treatment discussions were about surgery (292/436, 67%), followed by immunotherapy (52/436, 12%). In total, 255 posts discussed the impacts of melanoma, which included emotional burden (n=179, 70%), physical impacts (n=61, 24%), effects on social life (n=43, 17%), and financial impacts (n=10, 4%).

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Conclusions: Findings from this study highlight how melanoma stakeholders discuss key concepts associated with the condition on social media, adding to the conceptual model of the patient journey. This social media listening approach is a powerful tool for exploring melanoma stakeholder perspectives, providing insights that can be used to corroborate existing data and inform future studies.

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KEYWORDS

melanoma; social media; social media listening; real-world evidence; patient journey; cancer; mortality rate; health information

Introduction

Melanoma is a poorly differentiated, malignant tumor arising from melanin-producing cells (melanocytes) primarily in the skin [1], with incidence increasing in the last 50 years worldwide [2]. It is an aggressive malignancy with an average 5-year survival rate of 27% once spread to distant sites [3]. According to the latest epidemiological investigations, the worldwide mortality rate of melanoma (standardized for both sexes and ages) is 0.73/100,000 [4], and it is the main cause of skin cancer–related mortality, causing up to 90% of deaths related to cutaneous malignancies [1].

Wide local excision plus sentinel lymph node dissection is the standard treatment for early-stage melanoma, while patients with regional or distant metastases present a continuing clinical challenge. With the introduction of targeted systemic therapies inhibiting kinases of the mitogen-activated protein kinase signaling pathway (specifically BRAF and MEK), as well as immune checkpoint inhibitors, long-lasting or complete remission can be achieved when treating melanoma. These treatments can stabilize the disease, reduce its burden, increase survival, and improve the quality of life (QoL) of patients with melanoma [5]. However, melanoma remains a major public health burden in Europe due to its increasing incidence, high mortality, impact on QoL, and the complexity of care for advanced stages, and it is estimated to cost >20,000 lives every year [6].

Melanoma has marked QoL implications for patients, including emotional, physical, aesthetic, and functional concerns, which are related to high levels of distress and behavioral alterations [7]. Furthermore, melanoma-related anxiety and depression have been noted among patients with high-risk primary tumors [8]. Surgery also impacts patients with melanoma both physically and emotionally [9]. These findings show that a melanoma diagnosis affects patients both physically and psychologically.

Social media provides large-scale qualitative data across countries [10]. Around 59% of European citizens use the internet to access health information, with 47%-48% using disease-specific websites (blogs and forums) and 16%-23% on social networks [11]. Social media is increasingly being used to investigate stakeholder experience in a range of health conditions, including cancer [12-15]. Social media listening (SML) may generate concepts that are more relevant to the lived experience of disease, compared with insights elucidated from interviews and focus groups [16]. After receiving a diagnosis, people often use social media platforms to share experiences and seek answers to health-related questions. Data generated on these platforms provide key stakeholder perceptions not typically shared in other real-world data (RWD) sources, clinical databases (such as registries and electronic health records), and the published literature [13]. Furthermore, insights from stakeholders other than patients (such as caregivers and family members) are also made available through SML. Therefore, SML can provide health care practitioners (HCPs) with insights into how patients and other stakeholders feel about a particular disease and the associated treatment needs [15,17,18]. It can also provide a platform for social influence, disease surveillance, risk assessment, and prevention [19].

The aim of this study was to explore how melanoma stakeholders, including patients, caregivers, and HCPs, describe their experiences on social media. Specifically, this study explored the needs and perceptions of melanoma stakeholders using SML analysis to generate insights from across European countries, in terms of treatments received, predictors of outcome, treatment effectiveness/safety, and burden of illness. The findings provide qualitative insights into the lived experience of melanoma.

Methods

Search Strategy

This study is a retrospective analysis of publicly available social media data, including blogs, forums, and social media platforms. Social media posts were collated between November 1, 2018, and November 30, 2020, from Austria, Belgium, France, Germany, Italy, Netherlands, Portugal, Spain, Switzerland, the Nordic countries (Denmark, Finland, Norway, Sweden), and the United Kingdom in 11 languages (Danish, Dutch, English, Finnish, French, German, Italian, Norwegian, Portuguese, Spanish, and Swedish). Search strings in each language were developed to identify conversations relevant to melanoma, using Boolean operators (AND, OR) to combine keywords (Multimedia Appendix 1).

Data Collection

The Talkwalker Social Analytics database [20] was used to conduct searches across countries. Using the predefined search terms (Multimedia Appendix 1), social media posts were identified from in-scope geographies, and relevant posts were downloaded. The identified posts were sourced from blogs, forums, Twitter, public Facebook, and YouTube. Relevant forums and blog posts were identified using local online community websites and discussion boards (including Healthunlocked, Mumsnet, Medicitalia, 9lives, and Frauenselbsthilfe; Multimedia Appendix 2).

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Ethical Considerations

Even though social media posts are in the public domain, SML studies raise unique ethical challenges, as individuals do not formally consent to the use of their data in the research. Currently, there is little guidance on the lack of consent or anonymity of participants in social media research. However, recommendations include ensuring that the data collected answer specific research questions and presenting data in a way that avoids participant identification [21]. Appropriate steps were taken in this study to follow these recommendations. To anonymize publicly reported posts, information that could identify individual patient or caregivers (such as usernames) was removed before analysis.

Data Analysis

The raw data set was further contextualized by excluding conversations irrelevant to the study. This was done by both an automated relevancy approach (containing keyword-based relevancy algorithms) and a manual review against predefined criteria (Multimedia Appendix 3). This relevancy check ensured conversations provided relevant insights to the patient journey stage and other patient-centric topics.

An iterative random sampling technique was employed to reduce the number of posts as per the agreed proportions of social media records by country (and their respective channels), based on the amount of data available in each country. For countries with high data volume, sampling reduced the number of relevant posts from stakeholders to ensure that a manageable amount of data were obtained for manual review. For countries with low volume, data were taken without sampling. Relevant posts were tagged by channel type and, where possible, categorized by stakeholder (patients, caregivers, family and friends, HCPs, and others, as based on the language used in the post; eg, “I have melanoma” and “I have been diagnosed with this condition”), gender (taking into account profile pictures and content using gender labels such as “daughter,” “father,” “he”/”she,” and “lady,” for example), and age group (specific mention of age in the post). A deep dive into the filtered data set was then conducted to investigate research domains listed in the inclusion criteria (Multimedia Appendix 3). The benefit of an automated methodology is that it allows large amounts of data to be analyzed quickly and efficiently to dismiss irrelevant posts. Using this approach does, however, pose the risk that some relevant posts may have been missed, as the nuances of human expression may not have been captured in some/all cases. The sentiments toward a given treatment were also judged based on the language used to describe the experiences.

Results

Overview of Social Media Posts

A total of 182,400 social media posts were extracted in the initial search using the predefined keyword strings (Multimedia Appendix 1), with 2547 posts identified as relevant to the study objectives (Multimedia Appendix 4). The random sampling methodology selected 864 relevant posts for further analysis (Multimedia Appendix 4).

Twitter emerged as the most commonly used social media channel (n=129,504, 71% contribution to posts), compared with blogs (n=31,008, 17%), forums (n=20,064, 11%), and other platforms (n=1,824, 1%). Most of the posts originated from the United Kingdom (n=69,321, 38%), followed by Spain (n=29,184, 16%), Italy (n=23,712, 13%), France (n=20,064, 11%), and Germany (n=20,064, 11%).

A peak in social media discussion was observed in the spring months of May 2019 (12,140 conversations) and June 2020 (8557 conversations; Figure 1). Fewer posts originated from Nordic countries (n=7296, 4%) and the Netherlands (n=5472, 3%), while posts from Belgium, Switzerland, Portugal, and Austria, each contributed 1% (n=1824) of the total posts (Table 1). Of the 864 analyzed posts (Multimedia Appendix 4), 536 (62%) were categorized as coming from individuals who had melanoma, while 190 (22%) originated from caregivers, 104 (12%) from friends and family, 17 (2%) from HCPs, and a further 17 (2%) from other individuals.

Malignant and metastatic disease accounted for 77% (181/235) of the melanoma types mentioned (Multimedia Appendix 5). Advanced stage melanoma (which included the terms “stage IV,” “late stage,” and “metastatic stage” disease), was the most frequently discussed disease stage (154/245, 63%; Multimedia Appendix 5). Conversations were slightly more female-led (422/768, 55%), which was consistent for most countries, except in Nordic countries, where male-led conversations were more common (34/49, 69%), and Spain, where the gender split was 50% (72/145; Multimedia Appendix 5). More males in Switzerland also contributed to conversations, but the overall social media population size where gender could be determined was small (n=17). Most individuals (53%) were aged between 31 and 50 years (Multimedia Appendix 5).

Figure 1. Data volume trend.

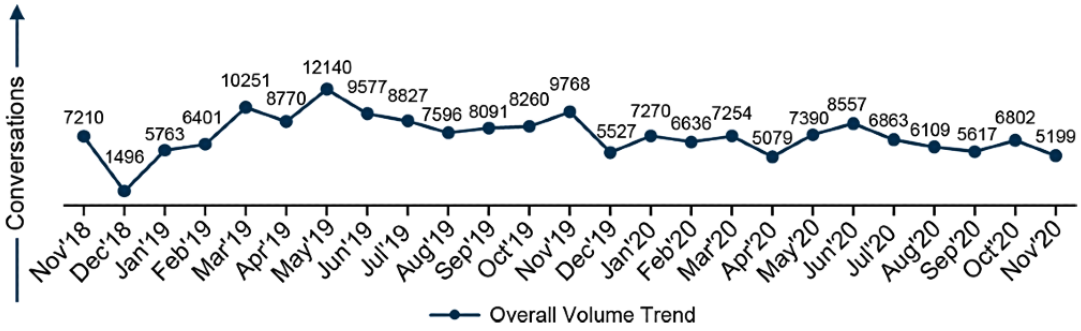

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Table 1. Country of origin of social media posts and percentage usage per social media platform.

Country	Percentage of posts, n (%)
United Kingdom	69,321 (38)
Twitter	61,696 (89)
Blogs	4852 (7)
Forums	2080 (3)
Spain	29,184 (16)
Twitter	26,557 (91)
Blogs	2334 (8)
Forums	0
Italy	23,712 (13)
Twitter	11,145 (47)
Blogs	9959 (42)
Forums	2134 (9)
France	20,064 (11)
Twitter	13,644 (68)
Blogs	4815 (24)
Forums	1404 (7)
Germany	20,064 (11)
Twitter	11,236 (56)
Blogs	5217 (26)
Forums	3612 (18)
Nordic countries[a]	7296 (4)
Twitter	4961 (68)
Blogs	1678 (23)
Forums	730 (10)
Netherlands	5472 (3)
Twitter	3119 (57)
Blogs	1313 (24)
Forums	1040 (19)
Belgium	1824 (1)
Twitter	1496 (82)
Blogs	328 (18)
Forums	0
Switzerland	1824 (1)
Twitter	1532 (84)
Blogs	237 (13)
Forums	55 (3)
Portugal	1824 (1)
Twitter	1094 (60)
Blogs	693 (38)
Forums	0
Austria	1824 (1)
Twitter	967 (53)

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Country	Percentage of posts, n (%)
Blogs	438 (24)
Forums	401 (22)

[a]Denmark, Finland, Norway, Sweden.

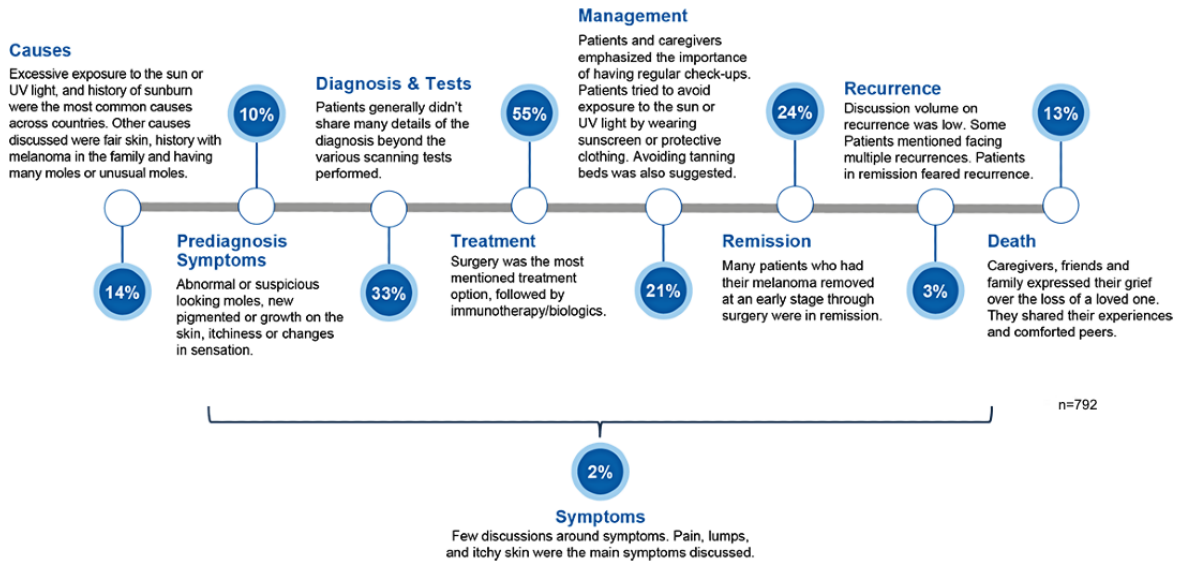
The Patient Journey in Melanoma

This study provided key insights into the patient journeys of those living with melanoma. Treatment (436/792, 55%), diagnosis and tests (261/792, 33%), and remission (190/792, 24%) were the most frequently discussed melanoma-related topics (Figure 2). Discussions around the causation of melanoma contributed to 14% (111/792) of patient journey-related posts (Figure 2), where excessive sun or UV light exposure constituted the majority of discussions (n=95, 87%). Other causes discussed included genetics, such as having fair skin or a family history of melanoma (n=12, 11%) and having many/unusual moles (n=9, 8%).

Only 2% (16/792) of posts referred to postdiagnosis symptoms, with a further 10% (79/792) discussing prediagnosis symptoms (Figure 2). New pigmented growths on the skin (n=30, 38%), suspicious-looking moles (n=20, 25%), and darkening of the skin (n=8, 10%) were the most frequently mentioned prediagnostic symptoms (n=79). The most frequently mentioned postdiagnostic symptoms (n=14) were pain (n=5, 36%) and hardened nodules under the skin (n=3, 21%). Most discussions on diagnosis and tests were around confirmed diagnosis (92/255, 36%; Multimedia Appendix 6). Biopsy (46/255, 18%) was the most commonly mentioned confirmatory diagnostic test (Multimedia Appendix 6). Only 1% (n=10) of posts mentioned mutations (most commonly *BRAF*, *MEK*, and *CDKN2A*). A number of posts (n=170) discussed disease management and highlighted regular skin checks (n=59, 35%), avoiding the sun (n=46, 27%), and applying sunscreen (n=36, 21%). Conversations also mentioned avoiding sunbeds (n=22, 13%), which mostly originated from the United Kingdom (19/22 posts).

Multimedia Appendix 7A provides an overview of the melanoma treatments reported in the social media posts analyzed. The most frequently reported treatment was surgery (293/437, 67%), followed by immunotherapy (52/437, 12%), radiotherapy (22/437, 5%), and targeted therapy (17/437, 4%). Treatment sequence (139/295, 47%) and efficacy (133/295, 45%) were the most commonly discussed topics regarding melanoma treatment features (Multimedia Appendix 8). Treatment posts were dominated by first-line (1L) discussions (n=131), which were mostly about surgery (n=94, 72%; Multimedia Appendix 7). Few negative sentiments were associated with posts discussing surgery (n=9, 3%), which was the lowest among all treatments mentioned (Multimedia Appendix 7B). Although treatment-related discussions mentioning chemotherapy were low (n=13, 3%; Multimedia Appendix 7A), this was the treatment type with the highest associated negative sentiment (n=6, 45%; Multimedia Appendix 7B). In posts that discussed disease end points (n=226), remission/cure (referred to as "being all clear" or "finished with years of check-ups") was the main clinical end point discussed by stakeholders (n=169, 75%), with prolonged survival (n=34, 15%) and morbidity/mortality (n=18, 8%) as the other two most frequently mentioned end points.

Figure 2. Percentage of posts for each stage in the patient journey.



Impacts of Melanoma

A total of 255 posts referred to the impacts that melanoma had on individuals' QoL. The social media population discussed emotional (n=178, 70%), physical (n=61, 24%), social (n=43, 17%), and financial (n=11, 4%) impacts. Frequently mentioned emotional impacts in conversations (Table 2) were negative thoughts, including feeling low/upset/sad (n=59, 33%) and being affected emotionally (n=44, 25%), anxiety (n=30, 17%), distress (n=25, 14%), and fear (n=23, 13%). Melanoma stakeholders also reported being affected physically (n=21, 34%), having

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social behavioral changes/affected social life (n=18, 42%), and facing treatment expenses (n=6, 55%). Table 2 outlines the type of impacts of melanoma reported on social media.

Table 2. Impacts of melanoma (N=225) reported on social media.

Type of impact	n (%)
Emotional impact (n=173)	
Feeling low/upset/sad	59 (33)
Affected emotionally (in general)	45 (25)
Anxiety	30 (17)
Distress	25 (14)
Fear	23 (13)
Negative feelings	12 (7)
Conscious about looks	7 (4)
Confused	5 (3)
Change in outlook on life	5 (3)
Depression	4 (2)
Physical impact (n=61)	
Affected physically (in general)	21 (34)
Issues due to pain	11 (18)
Movement issues	8 (13)
Feeling weak/tired/exhausted	8 (13)
Scar	7 (11)
Struggling with side effects of medications	6 (10)
High risk for COVID-19 infection	5 (8)
Cannot wear revealing clothes	3 (5)
No comfort	2 (3)
Insomnia	2 (3)
Cannot manage household work	1 (2)
Unable to do daily activities	1 (2)
Social impact (n=43)	
Social behavioral changes	18 (42)
Affected social life	18 (42)
Affected work	4 (9)
Affected school	2 (5)
Avoided by others/lost social media followers	1 (2)
Affected family life	1 (2)
Financial impact (n=11)	
Finding treatment expensive	6 (55)
Looking for financial support for treatment	4 (36)
Struggling with insurance coverage	1 (9)

A lack of available or effective treatments (30/121, 25%), access to good HCPs/treatments (30/121, 25%), and safe access to care during the COVID-19 pandemic (25/121, 21%) emerged as key unmet needs of melanoma stakeholders (Multimedia Appendix 9). Concerns were expressed around the impact of COVID-19 on patients with melanoma, including changes to medical appointments, safe access to treatment, and self-isolation. In total, 5% (n=295) of posts on treatment features mentioned treatments being cancelled/postponed/rescheduled, with this being attributed to the pandemic in many countries, and 21% (n=121) of posts discussing unmet needs mentioned problems with safe access to treatment during the COVID-19 pandemic.

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This was a key unmet need in Belgium, France, Spain, and the United Kingdom.

Discussion

Principal Findings

This study identified key concepts relevant to individuals living with melanoma, providing qualitative insights into how the patient journey is discussed online by multiple stakeholders across Europe. A peak in social media discussion was observed on May 13, 2019, which was World Melanoma Day. Interestingly, a peak in posts about melanoma was observed in the early summer of both 2019 and 2020, which may coincide with the promotion of prevention resources ahead of the summer months in the northern hemisphere (such as May being Melanoma and Skin Cancer Awareness Month). European countries with larger population sizes (United Kingdom, Spain, Italy, France, and Germany) contributed to the majority of posts included in the study (89% in total), compared to countries with smaller population sizes (Austria, Belgium, Netherlands, Portugal, Switzerland and the Nordic countries, which contributed to 11% of the total posts).

Key topics highlighted in this study included melanoma treatment and diagnosis, as well as patient QoL. This complements a review of the specific communication needs of cancer patients (including melanoma) from semistructured interviews, focus groups, and questionnaire surveys, which revealed that the main discussion needs were disease-related information and psychological support [22]. Treatment sequencing, in terms of how patients were treated in 1L and later lines of therapy, was the most common treatment feature discussed. A therapy change is often initiated when a treatment fails, is not well-tolerated, or following disease relapse, suggesting that these are experiences that melanoma stakeholders are eager to discuss. Surgery was the most frequently mentioned treatment (particularly in 1L) and had the highest number of positive mentions, which was possibly attributable to its curative effects. Chemotherapy was often associated with negative sentiments, perhaps due to its side effects or noncurative nature. It potentially appears that positivity was driven by the effectiveness of the treatment, while negativity was due to patients experiencing side effects or low efficacy. Among the other treatments mentioned, immunotherapy, radiotherapy, and targeted therapy were also discussed on social media, which is not surprising given the prevalence of their use in the melanoma treatment landscape [23]. Across all treatment types, stakeholders rarely attached a sentiment while discussing specific treatment types, brands, or molecules. Tumor biopsy was the most frequently mentioned diagnostic test for melanoma. Discussions around 1L treatments and diagnosis may be indicative of patients, caregivers, and family members searching for information about melanoma online following an initial diagnosis. This highlights the important role of HCPs in providing detailed information about melanoma early in the treatment journey. Melanoma stakeholders also discussed impacts of the condition; emotional impacts were frequently mentioned, with many expressing negative thoughts.

There is currently limited qualitative research on melanoma in the social media population. Studies using patient narratives obtained from cancer support organization websites and web-based forums have highlighted the psychosocial and emotional impact following a melanoma diagnosis [24-26], consistent with the findings from this SML study. Similarly, proactive management of the condition and treatment by patients with melanoma have also been reported online [24]. Many of the topics identified by SML were consistent with those reported in other qualitative studies, in particular interviews of melanoma stakeholders [27-30]. These topics include the symptoms discussed, which, not surprisingly, are dominated by skin changes [27] and patients engaging in activities to prevent recurrence, including sun avoidance/protection [28,29]. Negative emotional impact, anxiety, distress, and fear were identified as the major impacts of living with melanoma. This is consistent with other qualitative studies, highlighting the emotional impact of the treatment journey for patients with melanoma [24,25,27,28,31,32]. Systematic reviews of qualitative and quantitative studies demonstrate that major unmet psychological needs are reflective of the emotional impact of melanoma on patients [32]. Taken together, the high level of emotional impacts identified from this SML analysis and other studies emphasizes the acute need for emotional support for patients with melanoma. This is an important finding given the consequences that negative emotional impacts, such as depression, can have on increasing cancer mortality [33]. It is also noteworthy that in addition to the psychological and emotional impacts commonly associated with melanoma and its treatment journey, this study highlights important unmet needs for patients with melanoma that might have been specifically affected by delayed cancer diagnosis and management due to the COVID-19 pandemic, a concern also shared by HCPs [30]. In fact, almost a quarter of posts, especially in Belgium, France, Spain, and the United Kingdom, were concerned with safe access to treatment during the COVID-19 pandemic. It is also probable that the pandemic might have caused heightened levels of anxiety and an overall negative emotional impact for patients with melanoma and their caregivers. The findings from this study contribute to the conceptual model of the melanoma patient journey and treatment landscape and provide knowledge on how stakeholders discuss key concepts associated with the condition. SML data provide unfiltered and uninfluenced insights [13], which can help enhance HCP-patient communication. Most SML discussions were around melanoma management and treatment rather than the early stages of disease prevention, symptom identification, and diagnosis. This might be due to the fact that a relatively large proportion (181/235, 77%) of discussions were around malignant and metastatic disease where treatment and management might be the highest priority. On the other hand, patients who were in remission or who had removed their melanomas successfully through surgery at an early disease stage were more likely to engage in discussions around melanoma awareness, for example, by promoting regular checks, banning tanning beds, and reducing sun exposure. Communication issues between patients with melanoma and their treating clinicians, particularly around informational needs at diagnosis, have been identified before in a United

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Kingdom–based study [34]. SML identified diagnosis as a popular discussion topic among melanoma stakeholders, suggesting that patients may have enhanced informational needs at diagnosis. Aside from helping to improve HCP-patient communication priorities, SML studies can also inform the modification of patient-reported outcome (PRO) measures to help evaluate the QoL of patients living with melanoma. This can, in turn, inform adequate measurement of QoL-related parameters in clinical trials and other research studies.

Limitations

The social media population may not be representative of the whole community affected by melanoma. In this study, most participants were between 31 and 50 years of age, and while melanoma disproportionately affects younger people compared with other solid tumors [35], this demographic may be reflective of older people being frequently underrepresented on social media. The SML analysis comprised of a mixed population in terms of disease stage; therefore, it is challenging to identify the different needs of patients with late-stage versus early-stage melanoma due to the lack of patient-level data. Furthermore, the data set does not distinguish between treatments used in different melanoma settings (such as adjuvant or metastatic), and this may impact the interpretation of treatment discussions, including certain treatment features and treatment sequence. While there is an inherent methodological constraint of not having standardized measures to assess the severity of QoL concerns, SML provides a valuable source of information to identify relevant health-related QoL aspects, which could be cross-referenced with current QoL tools and questionnaires to potentially improve the validity of PRO measures [26].

All data were retrospectively collected from social media posts in the public domain. As a result, demographic and clinical information of the social media population could not always be obtained or confirmed. For example, it was not possible to substantiate that all individuals were posting on a confirmed melanoma diagnosis. Therefore, it must be acknowledged that some data may be incorrectly categorized. For example, identifying gender through pictures, pronouns, or family relationships is not necessarily a reliable method to infer a male or female identity. Although the accuracy of correct gender assignment has been noted to be as high as >90% in some studies, other traits including age can be more challenging to predict [36].

Conclusions

Melanoma has a significant impact on people's daily lives; stakeholders affected by melanoma experience significant emotional impacts that affect their QoL. In particular, 1L melanoma treatments were frequently discussed online, especially surgery, which was often associated with positive sentiments. Despite the aforementioned limitations, the findings from this study were consistent with published evidence, supporting insights captured by other RWD studies. This suggests that SML approaches can identify topics that provide person-focused, real-world insights into the lived experiences of melanoma that are not typically available in the published literature and that can be used to corroborate existing data and inform future studies. To monitor what melanoma stakeholders are most concerned about, it is advisable to repeatedly conduct online analysis such as the one in this study. At the same time, efforts should be made to increase the visibility of reliable data sources (such as links to treatment guidelines) on social media.

Acknowledgments

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Conflicts of Interest

JC, SA, ML, and AS are employees of Novartis. ML and AS are also Novartis shareholders. NM reports personal fees from Merck GmBh, Novartis, Roche, and Sun Pharma and grants and personal fees from BMS, MSD, and Pierre Fabre outside the submitted work; in addition, NM has a patent for EP3407911A1 pending, JP2019503384A pending, US20190038763A1 pending, and WO2017129790A1 pending. AF reports personal fees from BMS, MSD, Novartis, Pierre-Fabre, and Roche and grants from BMS and CeGaT outside the submitted work. IMR reports personal fees from AstraZeneca, Bioline Rx, Celgene, GSK, Merck Serono, Regeneron, and Sanofi, and grants and personal fees from BMS, Highlight Therapeutics, Incyte, MSD, Novartis, Pierre Fabre, and Roche outside the submitted work. LF reports personal fees from Celgene, Daiichi Sankyo, Eli Lilly, and Novartis and grants from AIRC and Eli Lilly outside the submitted work. SP reports personal fees from Achilles, Amgen, BMS, EnaraBio, Gritstone, GSK, MSD, Roche, and Zelluna outside of the submitted work. GF reports personal fees from Bayer, BMS, Eisai, Janssen, Merck, MSD, Novartis, Pfizer, Pierre Fabre, Roche, and Sanofi outside the submitted work.

Multimedia Appendix 1
Social media search strings.
[DOCX File , 17 KB - cancer_v8i2e35930_app1.docx]

Multimedia Appendix 2
Sources of forum and blog posts.
[DOCX File , 17 KB - cancer_v8i2e35930_app2.docx]

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Multimedia Appendix 3
Predefined inclusion/exclusion criteria.
[DOCX File , 16 KB - cancer_v8i2e35930_app3.docx]

Multimedia Appendix 4
Analysis process for post relevancy.
[DOCX File , 120 KB - cancer_v8i2e35930_app4.docx]

Multimedia Appendix 5
Stakeholder demographics by country.
[DOCX File , 554 KB - cancer_v8i2e35930_app5.docx]

Multimedia Appendix 6
Percentage of melanoma stakeholder discussion on diagnosis and tests.
[DOCX File , 17 KB - cancer_v8i2e35930_app6.docx]

Multimedia Appendix 7
Melanoma treatments reported in social media posts and associated sentiment. (A) Type of melanoma treatments reported. (B) Melanoma treatments as discussed by sentiment.
[DOCX File , 85 KB - cancer_v8i2e35930_app7.docx]

Multimedia Appendix 8
Melanoma treatment discussions.
[DOCX File , 117 KB - cancer_v8i2e35930_app8.docx]

Multimedia Appendix 9
Key unmet needs of melanoma stakeholders.
[DOCX File , 166 KB - cancer_v8i2e35930_app9.docx]

References

1. Garbe C, Amaral T, Peris K, Hauschild A, Arenberger P, Bastholt L, European Dermatology Forum (EDF), the European Association of Dermato-Oncology (EADO),the European Organization for ResearchTreatment of Cancer (EORTC). European consensus-based interdisciplinary guideline for melanoma. Part 1: Diagnostics - Update 2019. Eur J Cancer 2020 Feb;126:141-158 [FREE Full text] [doi: 10.1016/j.ejca.2019.11.014] [Medline: 31928887]
2. Erdmann F, Lortet-Tieulent J, Schüz J, Zeeb H, Greinert R, Breitbart EW, et al. International trends in the incidence of malignant melanoma 1953-2008--are recent generations at higher or lower risk? Int J Cancer 2013 Jan 15;132(2):385-400 [FREE Full text] [doi: 10.1002/ijc.27616] [Medline: 22532371]
3. Cancer facts and statistics. American Cancer Society. URL: https://www.cancer.org/research/cancer-facts-statistics/all-cancer-facts-figures/cancer-facts-figures-2021.html [accessed 2022-05-23]
4. Global Cancer Observatory. URL: http://gco.iarc.fr/ [accessed 2022-05-15]
5. Schadendorf D, Fisher DE, Garbe C, Gershenwald JE, Grob JJ, Halpern A, et al. Melanoma. Nat Rev Dis Primers 2015 Apr 23;1(12):15003 [FREE Full text] [doi: 10.1038/nrdp.2015.3] [Medline: 27188223]
6. Forsea A. Melanoma epidemiology and early detection in Europe: diversity and disparities. Dermatol Pract Concept 2020 Jul;10(3):e2020033 [FREE Full text] [doi: 10.5826/dpc.1003a33] [Medline: 32642304]
7. Kasparian NA, McLoone JK, Butow PN. Psychological responses and coping strategies among patients with malignant melanoma: a systematic review of the literature. Arch Dermatol 2009 Dec;145(12):1415-1427. [doi: 10.1001/archdermatol.2009.308] [Medline: 20026852]
8. Beesley VL, Hughes MCB, Smithers BM, Khosrotehrani K, Malt MK, von Schuckmann LA, et al. Anxiety and depression after diagnosis of high-risk primary cutaneous melanoma: a 4-year longitudinal study. J Cancer Surviv 2020 Oct;14(5):712-719. [doi: 10.1007/s11764-020-00885-9] [Medline: 32519121]
9. Răducu L, Avino A, Purnichescu Purtan R, Balcangiu-Stroescu A, Bălan DG, Timofte D, et al. Quality of life in patients with surgically removed skin tumors. Medicina (Kaunas) 2020 Feb 09;56(2):66-66 [FREE Full text] [doi: 10.3390/medicina56020066] [Medline: 32050413]
10. Snelson CL. Qualitative and mixed methods social media research. Int J Qual Methods 2016 Mar 01;15(1):160940691562457. [doi: 10.1177/1609406915624574]
11. European citizens' digital health literacy report. Publications Office of the European Union. URL: https://data.europa.eu/doi/10.2759/88726 [accessed 2022-05-22]

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12. Gabriel S, Phillips K, Slater MA, Zhou J, Pathak AK, Lee LK. The emotional journey among caregivers of patients with leukemia: The caregivers' perspective using social media listening. J Clin Oncol 2017 May 20;35(15_suppl):e18568-e18568. [doi: 10.1200/jco.2017.35.15_suppl.e18568]
13. Gries KS, Fastenau J. Using a digital patient powered research network to identify outcomes of importance to patients with multiple myeloma. J Patient Rep Outcomes 2020 Sep 01;4(1):74 [FREE Full text] [doi: 10.1186/s41687-020-00242-5] [Medline: 32870420]
14. Sutton J, Vos SC, Olson MK, Woods C, Cohen E, Gibson CB, et al. Lung cancer messages on twitter: content analysis and evaluation. J Am Coll Radiol 2018 Dec;15(1 Pt B):210-217. [doi: 10.1016/j.jacr.2017.09.043] [Medline: 29154103]
15. Taylor J, Pagliari C. The social dynamics of lung cancer talk on Twitter, Facebook and Macmillan.org.uk. NPJ Digit Med 2019 Dec;2(12):51 [FREE Full text] [doi: 10.1038/s41746-019-0124-y] [Medline: 31304397]
16. Humphrey L, Willgoss T, Trigg A, Meysner S, Kane M, Dickinson S, et al. A comparison of three methods to generate a conceptual understanding of a disease based on the patients' perspective. J Patient Rep Outcomes 2017;1(1):9 [FREE Full text] [doi: 10.1186/s41687-017-0013-6] [Medline: 29757313]
17. Risson V, Saini D, Bonzani I, Huisman A, Olson M. Patterns of treatment switching in multiple sclerosis therapies in US patients active on social media: application of social media content analysis to health outcomes research. J Med Internet Res 2016 Mar 17;18(3):e62 [FREE Full text] [doi: 10.2196/jmir.5409] [Medline: 26987964]
18. Metwally O, Blumberg S, Ladabaum U, Sinha SR. Using social media to characterize public sentiment toward medical interventions commonly used for cancer screening: an observational study. J Med Internet Res 2017 Jun 07;19(6):e200 [FREE Full text] [doi: 10.2196/jmir.7485] [Medline: 28592395]
19. Zhang Y, Cao B, Wang Y, Peng T, Wang X. When public health research meets social media: knowledge mapping from 2000 to 2018. J Med Internet Res 2020 Aug 13;22(8):e17582 [FREE Full text] [doi: 10.2196/17582] [Medline: 32788156]
20. Talkwalker Social Analytics. Talkwalker. URL: https://www.talkwalker.com [accessed 2022-05-23]
21. Moreno MA, Goniu N, Moreno PS, Diekema D. Ethics of social media research: common concerns and practical considerations. Cyberpsychol Behav Soc Netw 2013 Sep;16(9):708-713 [FREE Full text] [doi: 10.1089/cyber.2012.0334] [Medline: 23679571]
22. Li J, Luo X, Cao Q, Lin Y, Xu Y, Li Q. Communication needs of cancer patients and/or caregivers: a critical literature review. J Oncol 2020 Dec;2020(12):7432849 [FREE Full text] [doi: 10.1155/2020/7432849] [Medline: 32454826]
23. Michielin O, van Akkooi ACJ, Ascierto PA, Dummer R, Keilholz U, ESMO Guidelines Committee. Cutaneous melanoma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. Ann Oncol 2019 Dec 01;30(12):1884-1901 [FREE Full text] [doi: 10.1093/annonc/mdz411] [Medline: 31566661]
24. Banerjee SC, D'Agostino TA, Gordon ML, Hay JL. "It's not JUST skin cancer": understanding their cancer experience from melanoma survivor narratives shared online. Health Commun 2018 Feb 16;33(2):188-201 [FREE Full text] [doi: 10.1080/10410236.2016.1250707] [Medline: 27982699]
25. Lamprell K, Braithwaite J. When patients tell their own stories: a meta-narrative study of web-based personalized texts of 214 melanoma patients' journeys in four countries. Qual Health Res 2018 Aug 25;28(10):1564-1583. [doi: 10.1177/1049732317742623] [Medline: 29173015]
26. Kalf RRJ, Delnoij DMJ, Ryll B, Bouvy ML, Goettsch WG. Information patients with melanoma spontaneously report about health-related quality of life on web-based forums: case study. J Med Internet Res 2021 Dec 07;23(12):e27497 [FREE Full text] [doi: 10.2196/27497] [Medline: 34878994]
27. Weitman E, Perez M, Thompson J, Andtbacka R, Dalton J, Martin M, et al. Quality of life patient-reported outcomes for locally advanced cutaneous melanoma. Melanoma Res 2018 Apr;28(2):134-142 [FREE Full text] [doi: 10.1097/CMR.0000000000000425] [Medline: 29261570]
28. Bird J, Coleman P, Danson S. Coping with melanoma-related worry: a qualitative study of the experiences and support needs of patients with malignant melanoma. J Clin Nurs 2015 Apr;24(7-8):937-947. [doi: 10.1111/jocn.12758] [Medline: 25660824]
29. Oliveria SA, Shuk E, Hay JL, Heneghan M, Goulart JM, Panageas K, et al. Melanoma survivors: health behaviors, surveillance, psychosocial factors, and family concerns. Psychooncology 2013 Jan 06;22(1):106-116 [FREE Full text] [doi: 10.1002/pon.2059] [Medline: 23296633]
30. Gharzai LA, Resnicow K, An LC, Jagsi R. Perspectives on oncology-specific language during the coronavirus disease 2019 pandemic: a qualitative study. JAMA Oncol 2020 Sep 01;6(9):1424-1428 [FREE Full text] [doi: 10.1001/jamaoncol.2020.2980] [Medline: 32761102]
31. Bath-Hextall F, Nalubega S, Evans C. The needs and experiences of patients with skin cancer: a qualitative systematic review with metasynthesis. Br J Dermatol 2017 Sep 22;177(3):666-687. [doi: 10.1111/bjd.15148] [Medline: 27775838]
32. Fu H, Teleni L, Crichton M, Chan RJ. Supportive care and unmet needs in patients with melanoma: a mixed-methods systematic review. Support Care Cancer 2020 Aug 27;28(8):3489-3501. [doi: 10.1007/s00520-020-05464-3] [Medline: 32342223]
33. Satin JR, Linden W, Phillips MJ. Depression as a predictor of disease progression and mortality in cancer patients: a meta-analysis. Cancer 2009 Nov 15;115(22):5349-5361 [FREE Full text] [doi: 10.1002/cncr.24561] [Medline: 19753617]

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34. Stamataki Z, Brunton L, Lorigan P, Green AC, Newton-Bishop J, Molassiotis A. Assessing the impact of diagnosis and the related supportive care needs in patients with cutaneous melanoma. Support Care Cancer 2015 Mar 5;23(3):779-789. [doi: 10.1007/s00520-014-2414-x] [Medline: 25189151]
35. Rastrelli M, Tropea S, Rossi C, Alaibac M. Melanoma: epidemiology, risk factors, pathogenesis, diagnosis and classification. In Vivo 2014;28(6):1005-1011. [Medline: 25398793]
36. Cesare N, Grant C, Nsoesie E. Detection of user demographics on social media: a review of methods and recommendations for best practices. arXiv Preprint posted online Feb 6, 2017 [FREE Full text]

Abbreviations

HCP: health care practitioner
PRO: patient-reported outcome
QoL: quality of life
RWD: real-world data
SML: social media listening
1L: first-line

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Original Paper

Communicating Treatment-Related Symptoms Using Passively Collected Data and Satisfaction/Loyalty Ratings: Exploratory Study

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Abstract

Background: Electronic patient-reported outcomes' real time communication of treatment-related symptoms is increasingly associated with better outcomes including longer survival and less health care resource use, but the primary method of collecting this information, static questionnaires, has not evolved.

Objective: The aim of this paper is to describe the use of Noona's three methods of communicating treatment-related symptoms, which are as follows: (1) Noona symptom questionnaires (NSQ), which incorporate branching logic; (2) a diary; and (3) secure messaging, the last two of which have NSQ reporting functionality. It also aims to explore, using multivariable analyses, whether patients find value using these features.

Methods: Noona users (N=1081) who have an active account for more than 30 days, who responded to the satisfaction/loyalty item, and who were undergoing active cancer treatment (systemic or radiotherapy) in the United States were included in this study. All study data were collected via software embedded within Noona code. This includes metadata, patient activities (measured in clicks), and responses to a satisfaction/loyalty question ("How likely are you to recommend Noona to another patient") displayed on the Noona home page.

Results: Noona users expressed a high degree of satisfaction/loyalty when asked to rate how likely they would recommend Noona to another patient. Multivariable analyses indicate small but significant effects for some of the analyses. Use of NSQs were significantly related to satisfaction/loyalty, users of NSQs had significantly higher satisfaction/loyalty than those who did not use any, and secure communication use was significantly higher for those who rated the app highly compared to those who did not. These relationships will likely be further explicated with the use of satisfaction/loyalty questions that focus specifically on feature use.

Conclusions: Noona is well liked by respondents, and exploratory multivariable analyses demonstrate the potential for using passively and minimally invasive data to demonstrate value.

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KEYWORDS

electronic patient-reported outcomes; ePRO; cancer; symptoms; health-related quality of life

Introduction

For over 30 years, the systematic collection of patients' experiences via electronic administration of static measures have been used to facilitate cancer treatment planning [1]. The current generation of devices are powerful, portable, internet accessible, and increasingly loaded with sophisticated capabilities and features. This has enabled real time patient-clinical care team communication of treatment-related symptoms. However, software interfaces have been described as "rudimentary" [2], and the primary method of collecting patient-reported data has been relatively static, which may impede patient engagement and long-term use.

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Generally, research testing the electronic patient-reported outcomes (ePROs) impact can be divided into three groups. The first, randomized controlled trials, have consistently demonstrated the benefits of using this software. Basch et al [3] found those who used a web-based application and rated their treatment experiences using a 12-item questionnaire incorporating Common Terminology Criteria for Adverse Events (CTCAE) items remained on chemotherapy longer, reported significantly slower declines in health-related quality of life, used emergency department services less, and survived longer than those who used standard care. Two other studies have combined patient-reported treatment information with algorithms to improve functionality and better optimize clinical care. The first, a trial focusing on patients with lung cancer, found those in the treatment arm, which involved patients reporting symptoms via a weekly questionnaire, informed the computed tomography scan schedule. As a result, they lived longer and required fewer imaging tests compared to those receiving standard care (reporting symptoms to the family doctor or oncologist and attending regularly scheduled imaging appointments) [4]. The second study found that those who use an app that combines online symptom self-reporting with a clinical algorithm to generate automated advice to facilitate symptom self-management reported less decrement in physical well-being at 12 weeks and improved health-related quality of life in study participants at 18 weeks compared to standard care [5].

Real-world studies have demonstrated that an ePRO can facilitate reporting of common treatment symptoms (eg, tiredness, fatigue, and anxiety) compared with standard medical records [6], and a separate study found population level benefit in patients with cancer, including improved 1-, 3-, and 5-year survival [7]. A third group, feasibility studies, has focused on testing ePRO solutions in various patient populations in which little or no ePRO evidence has been generated including radiotherapy [8], immunotherapy [9,10], surgery [11,12], and palliative care [13].

There has been an increasing recognition that ePRO-associated benefits can only be accrued through durable patient engagement [14] and that current methods can be improved [15]. However, more interactive, engaging, and personalized designs can only be achieved by understanding user behavior patterns [14]. Varian Medical System's ePRO platform, Noona, is a United States Food and Drug Administration Class 1 device. It is a multifunction software that includes three modalities that can be used to communicate and track treatment-related symptoms via CTCAE-based [3] Noona symptom questionnaires (NSQ) to the clinical care team in real time. They are (1) questionnaires administered at regular intervals, which are also available for ad hoc reporting; (2) a diary; and (3) secure messaging, the last two of which incorporate NSQ tracking and reporting functionality. Between November 2020 and January 2021, Noona implemented a code within its software that collects objective app use information and assesses satisfaction and loyalty using a single, minimally invasive question, "How likely are you to recommend Noona to another patient." The patients responded using an 11-point visual analog scale [16]. Variations of this question and the associated statistic, Net Promoter Score [16], are used by two-thirds of Fortune 1000 companies to measure customer satisfaction and loyalty [17]; they have also been used within the field of medicine to gauge the quality of various medical services [18-20], implementation of a telehealth system [21], and evaluation of software developed for patients with cancer [22,23] and cancer survivors [24].

Previous research has demonstrated the efficacy of using electronic devices to collect passive exercise data used by patients with cancer generally [25-27] and that such information is associated with self-reported treatment symptoms [28]. This information can be easily collected without inconveniencing patients or clinical staff; however, it is not clear whether such data, along with the minimally invasive collection of satisfaction/loyalty ratings, can be used to demonstrate ePRO value. Thus, the goal of this real-world study is to report how Noona users employ the three Noona communication and tracking features (scheduled and ad hoc CTCAE-based NSQs; a diary with NSQ tracking functionality; and secure messaging). This study also aims to rate app satisfaction/loyalty and explore, using multivariable analyses, whether patients find value using these features. Our hypotheses are that, regardless of app features or construction, users should value the most important component of communication/tracking of treatment-related symptoms. Thus, the first set of analyses will explore the association between communication and tracking features and satisfaction/loyalty. Next, analyses will test whether those who use these features report greater satisfaction/loyalty than those who do not. The last set will determine whether there is a difference between those who rate the app highly and those who do not, regarding using the three communication and tracking features.

Methods

Noona, Participants, and Procedure

Noona is an ePRO that has been installed in over 100 oncology clinics across 10 countries. It is currently available in 8 languages and has over 100,000 active users. Clinical staff at each site onboard patients and assist them with creating a patient profile. The participants (n=1081) in this study were experienced Noona users, which is defined as users who have an active account for more than 30 days, who responded to the satisfaction/loyalty item, and who were undergoing active cancer treatment (systemic or radiotherapy) in the United States between January 2021 (the first-day objective data and patient satisfaction/loyalty were both collected) and March 17, 2021 (when the data were downloaded and analyzed).

All study data (metadata, patient activities measured in clicks, and satisfaction/loyalty scores) were collected via software embedded within Noona code. Study information was passively collected. The satisfaction/loyalty question is administered randomly every 3 months. It pops up on the Noona home page, and users can either respond to it or opt out.

Ethical Considerations

Data were used for quality improvement purposes and thus not submitted for IRB approval; however, Noona clearly communicates patient rights when they sign on to use the app.

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Specifically, when creating an account, they have the option of authorizing data sharing and are informed of those rights. This includes a statement that Noona collects information for several purposes including data analysis for resource optimization, which is the case for this study. Additionally, Noona ensures that the data used for any analyses will be deidentified. Further, patients are told that if they choose not to share their data, it will not affect the care received from the health care provider, eligibility for benefits, or payment for health care, and that they will still have access to the app. Patients are informed that they can revoke this authorization at any time prior to expiration by contacting Noona (info@Noona.com). Finally, users are informed that this authorization ends upon deletion of the Noona account. When this occurs, any data collected by Noona will remain with Noona, but the health care provider will not further disclose any health information concerning the patient to Noona.

Measures

Days Active

Noona reports the number of days since the patient activated an account. It is a continuous variable and is used as a covariate in this study.

Time on the App

Noona measures use in the number of total minutes the app was used since activation. It is a continuous variable and is used as a covariate in this study.

Age

Approximate patient age was calculated by subtracting the current year (2021) from the patient's birth year, which was extracted as metadata.

Device

Noona captures the operating system of the device that the patients last used to log into the system (eg, Windows or iOS). This information was used to create a dichotomous item representing the device type—computer, smartphone, or tablet. This variable was used a covariate in this study.

Satisfaction/Loyalty

Noona assesses satisfaction/loyalty by asking users to answer the question, "How likely are you to recommend Noona to another patient?" using an 11-point visual analog scale (ranging from 0 to 10) with the anchors "Unlikely" and "Very Likely" at opposite ends of the scale. The respondents click on the rating and then submit it. The information is often grouped into three categories. Patients who rated the app from 0 to 6 were categorized as "Detractors," those who rated it 7 or 8 where considered "Passive," and those who rated the app 9 or 10 were characterized as "Promoters" [16]. For this study, patient responses were reported using this taxonomy or the original 11-point scale.

Noona Symptom Questionnaires

NSQs were created by an advisory board of physicians who have clinical and research expertise within the specific treatment modality. NSQs are used to report treatment symptoms. The specific questionnaire is predicated on the treatment regimen. For example, patients receiving systemic therapy may receive the Chemotherapy-18 module, while those receiving radiotherapy for a pelvic cancer would be administered NSQs with that content. All NSQs include CTCAE-derived items in which patients can report 3 grades of severity (mild, moderate, and severe) and branching logic which reduces patient burden by eliminating the need to respond to items that are not relevant to the patient. Any responses that meet prespecified criteria will trigger alerts that can be viewed by the clinical care team. In turn, the team responds by suggesting an intervention, or in the case of an emergent concern, it instructs the patient to seek immediate medical attention. Some sites may assign a questionnaire by sending notifications asking patients to complete the questionnaire at prespecified times, though patients always have the option of using it any time. In this study, all clicks within this Noona feature are recorded and represent its use. Thus, a patient who clicked on this section once will have a score of 1, and another who clicked on this area 10 times will have a score of 10. Depending on the analysis, this variable was either an outcome or predictor variable.

Diary

Noona's diary feature gives patients the opportunity to save personal clinical and nonclinical information that can be used for a range of purposes including symptom tracking over time. However, this study focuses on the symptom-reporting component, which can be used to communicate with the clinical team in specific circumstances. Thus, similar to the NSQs, every click within this portion of Noona is recorded and represents a single use. Therefore, a patient who clicked on that section once will have a score of 1, and another who clicked within this area 10 times will have a score of 10. Depending on the analysis, this variable was either an outcome or predictor variable.

Secure Messaging

This feature gives patients the ability to directly communicate with the clinical care team regarding clinically relevant and nonrelevant issues. Since this study focuses on clinically relevant issues, only those data are included. Similar to the other two features, every click is recorded and represents a single use. Thus, a patient who clicked on this section once will have a score of 1, and another who clicked on this area 10 times will have a score of 10. Depending on the analysis, this variable was either an outcome or predictor variable.

Feature Preference

The patients were sorted into 1 of 4 categories ("None," "NSQ," "Diary," and "Secure messaging") based on the feature they used most often (defined by number of clicks). Note that those who did not use any of the 3 specific features were included in the "None" category.

Analyses

Four sets of analyses are conducted for this study. The first set used descriptive statistics to report all study variables. Categorical variables were reported using count and percentage, and continuous variables are reported using means and standard deviations.

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The remaining analyses are exploratory and used generalized linear models (GLMs), specifying a negative binomial distribution and a log link function, to test the relationship between the use of the three communication and tracking features and satisfaction/loyalty in accordance with a priori hypotheses. Additionally, the grand estimated marginal mean (the mean response for each factor, calculated as least-squares means presented at the mean of the covariates) and estimated marginal means were calculated using a maximum likelihood algorithm and are reported in their original metric.

The first hypothesis was tested by using separate GLMs to ascertain whether a symptom or tracking feature was associated with satisfaction/loyalty, controlling for Noona use (days active and time on app), age, and device. The next hypothesis, that patients who do not use any of the tracking features will report lower satisfaction/loyalty scores compared with those who have a feature preference, was assessed by testing the association between the categorical variable feature preference and satisfaction/loyalty scores, controlling for Noona use (days active and time on app), age, and device. The reference category for the feature preference variable was "None." The final hypothesis was tested using separate GLMs to ascertain whether the hypothesis that Detractors use each of the three symptoms' reporting and tracking features less than Promoters, controlling for Noona use (days active and time on app), age, and device. The covariates included in the analyses were not the primary focus of the study; thus, only those that were significant predictors across all models are reported at the end of the section to identify trends more easily.

Results

The participants (Table 1 and Table 2) were generally older (mean age 65.16 years, SD 12.29), with active accounts for approximately three-quarters of a year (mean 285.22 days, SD 173.78), spent approximately 1 hour and 15 minutes using Noona (mean 76.41 minutes, SD 77.28), and were more likely to use smartphones or tablets (n=786; 72.4%) the last time they logged in. The overall satisfaction/loyalty rating was 8.05 (SD 2.91).

Table 1. Descriptive data of categorical variables.

Variables	Values, n (%)
Device	
Computer	295 (27.16)
Smartphone	786 (72.38)
Satisfaction/loyalty groupings	
Detractors	227 (20.90)
Passive	187 (17.22)
Promoter	672 (61.88)

Table 2. Descriptive data of continuous variables.

Characteristics	Values
Age (years), mean (SD)	65.16 (12.29)
Duration since activation (days), mean (SD)	285.22 (173.78)
Time on app (min), mean (SD)	76.41 (77.28)
Satisfaction/loyalty, mean (SD)	8.05 (2.91)
NSQ[a], mean (SD)	1.26 (2.64)
Diary, mean (SD)	0.78 (2.21)
Secure messaging	0.69 (1.80)

[a]NSQ: Noona symptom questionnaires.

Of the total 1081 patients, 308 (28.36%) patients used the NQS, 312 (28.73%) used the diary, and 317 (29.19%) used secure communication modalities, respectively. Overall use ranged between 1 and 33 times (Figure 1). Patients tended to use NQS portions of the application most (mean 1.26 clicks, SD 2.64), followed by the diary (mean 0.78 clicks, SD 2.21), and secure messaging (mean 0.69 clicks, SD 1.80). Over half of the participants gave a satisfaction/loyalty rating to Noona. Promoters (scores of 9 or 10: n=672, 61.88%; Table 3) comprised more than 60% of the sample compared to Passives (scores of 7 or 8: n=187, 17.22%) and Detractors (scores between 0 and 6: n=277, 20.90%). The mean rating was 8.05 (SD 2.91).

The GLMs testing the relationship between NSQ use and satisfaction/loyalty were significant (B=0.01, P=.05; Table 4). This indicates that, for every NSQ module click, a 0.01 increase in satisfaction/loyalty score is predicted. The grand estimated marginal mean was 7.91. The confidence intervals were within a tenth of a point indicating a high degree of accuracy. The other

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two models did not find a significant relationship between diary and secure messaging use and patient satisfaction.

The next analysis found that patients who used the NSQ most often reported significantly higher satisfaction/loyalty scores compared to those who did not use any of the three features (*B*=0.71, *P*=.02; Table 5).

Figure 1. Patients' use of symptom, diary, and secure communication modalities by clicks.

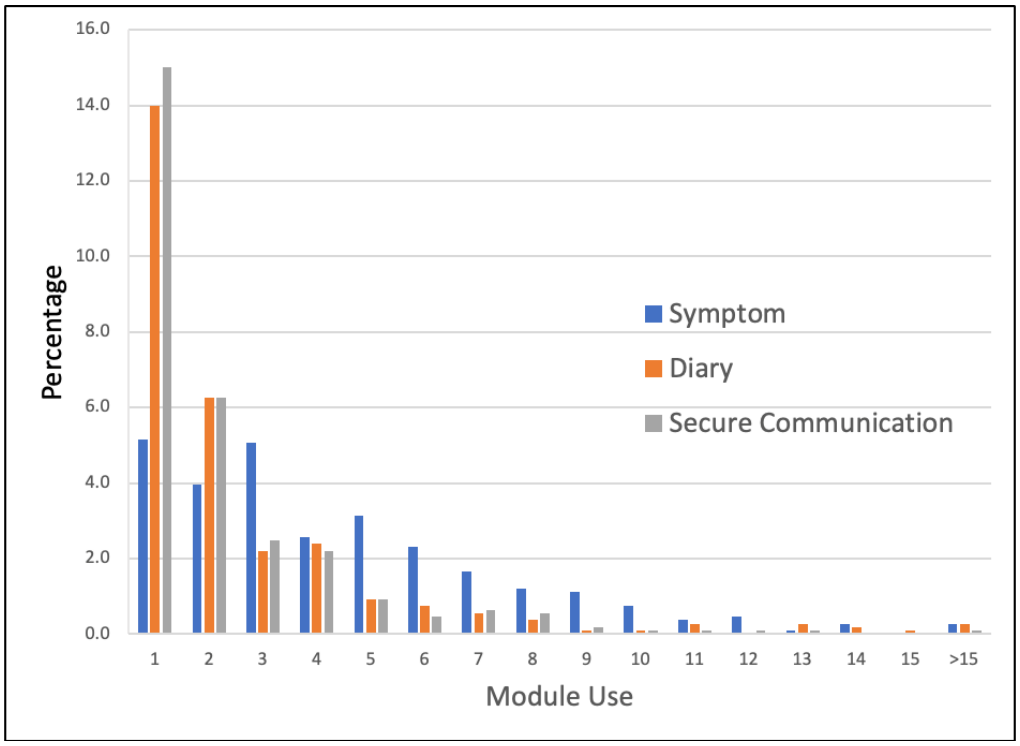

Table 3. Participants' satisfaction/loyalty scores.

Participants and NPS[a]	Frequency	Percentage
Promoters		
0	57	5.25
1	19	1.75
2	21	1.93
3	15	1.38
4	19	1.75
5	75	6.91
6	21	1.93
Passive		
7	53	4.88
8	134	12.34
Detractors		
9	99	9.12
10	573	52.76

[a]NPS: Net Promoter Score.

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Table 4. Generalized linear models testing the relationship between accessing new modules and satisfaction/loyalty.

Modalities and variables	Values					
	B	SE	*P* value	Exp (*B*)	95% CI for odds ratios	
					Lower	Upper
NSQ[a]						
App time	0	0	.47	1.00	1.00	1.00
Days since activation	0	0	.29	1.00	1.00	1.00
Age	0	0	<.001[b]	1.00	1.00	1.00
Device	–0.07	0.03	.01[b]	0.93	0.89	0.98
NSQ use	0.01	0	.05[b]	1.01	1.00	1.02
Diary						
App time	0	0	.20	1.00	1.00	1.00
Days active	0	0	.28	1.00	1.00	1.00
Age	0	0	<.001[b]	1.00	1.00	1.00
Device	–0.07	0.03	.01[b]	0.94	0.89	0.98
Diary	0	0.01	.66	1.00	0.99	1.01
Secure communication						
App time	0	0	.26	1.00	1.00	1.00
Days since activation	0	0	.28	1.00	1.00	1.00
Age	0	0	.01[b]	1.00	1.00	1.00
Device	–0.07	0.03	.01[b]	0.94	0.89	0.98
Secure messaging	0	0.01	.47	1.00	0.99	1.02

[a]NSQ: Noona symptom questionnaires.

[b]*P*<.05

Table 5. Generalized linear models testing the relationship between feature preference and satisfaction/loyalty (“None” was the reference group).

Variables	Values					
	B	SE	*P* value	Exp (*B*)	95% CI for odds ratios	
					Lower	Upper
App time	0	0	.40	1.00	1.00	1.00
Days since activation	0	0	.38	1.00	1.00	1.00
Age	0	0	.99[a]	1.00	1.00	1.00
Device	–0.06	0.03	.02[a]	0.94	0.89	0.99
Secure communication	0.03	0.03	.39	1.03	0.97	1.10
Diary	0.03	0.03	.40	1.03	0.96	1.10
NSQ[b]	0.07	0.03	.02[a]	1.07	1.01	1.14

[a]*P*<.05

[b]NSQ: Noona symptom questionnaires.

The grand estimated marginal mean was 7.94. The estimated marginal means for NSQ (8.26) was 0.57 points higher than the “None” category (7.69). The two other features (diary=7.91; secure messaging=7.91) were also higher than “None.” The confidence intervals were within a tenth of a point, indicating a high degree of accuracy. The final set of analyses (Table 6) found that Detractors and Promoters significantly differ in their use of the secure communication feature (*B*=1.307, *P*=.04). The grand marginal mean was 0.11 clicks, and the estimated marginal mean was 0.13 clicks for Promoters and 0.11 for Detractors. The confidence intervals were within a tenth of a point, indicating a high degree of accuracy.

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Examination of the covariates found a general trend for age; it was a significant predator in all models, but the relationship was small. For example, in the model testing the relationship between NSQ and satisfaction/loyalty, for every minute of app use there was less than a 0.01 increase in clicks predicted. Additionally, the device patients used was also a significant predictor across all models, but the relationship differed depending on the model. For example, for all three models testing the relationship between communication and tracking features and satisfaction/loyalty, patients found consistent estimated marginal means were higher for smartphone or tablet use (8.14) compared with computers (7.81). In the analyses, testing whether Detractors and Promoters differentially predicted the use of the treatment symptom and tracking features, we found that for the models predicting NSQ and secure messaging, the estimated marginal means were higher for smartphone or tablet use (0.25 and 0.13, respectively) compared with computer (0.10 and 0.20, respectively). It was reversed for the model that included the diary (computer=0.11; tablet or smartphone=0.12).

Table 6. Generalized linear models comparing those with low and high satisfaction on communication and tracking features (Detractors was the reference group).

Variables	Values					
	B	SE	*P* value	Exp (*B*)	95% CI for odds ratios	
					Lower	Upper
NSQ[a]						
App time	0.01	0	<.001[b]	1.01	1.01	1.01
Days since activation	0	0	.59	1.00	1.00	1.00
Age	0.02	0	<.001[b]	1.02	1.01	1.03
Device	0.22	0.11	.04[b]	1.25	1.01	1.53
Promoters	0.12	0.11	.28	1.13	0.91	1.41
Diary						
App time	0.01	0	<.001[b]	1.01	1.01	1.01
Days since activation	0	0	.01[b]	1.00	1.00	1.00
Age	–0.03	0	<.001[b]	0.97	0.96	0.98
Device	–0.17	0.13	.21	0.85	0.65	1.10
Promoters	0.11	0.14	.43	1.11	0.85	1.45
Secure communication						
App time	0.01	0	<.001[b]	1.01	1.01	1.01
Days since activation	0	0	.23	1.00	1.00	1.00
Age	–0.03	0	<.001[b]	0.97	0.96	0.98
Device	0.22	0.13	.10[b]	1.24	0.96	1.60
Promoters	0.23	0.14	.10[b]	1.26	0.96	1.66

[a]NSQ: Noona symptom questionnaires.

[b]$P<.05$

Discussion

Real time reporting of treatment symptoms via ePROs will increasingly become a critical component of cancer treatment because patients better recognize symptoms compared with providers [29,30]. There is increasing evidence that ePRO use positively impacts critical outcomes (eg, mortality) [4,5,31], and it will eventually be required for some reimbursement [15]. Therefore, real-world evidence demonstrating patients' use and satisfaction with ePRO software will be a necessary requirement for all stakeholders (patients, providers, and payers) who want to simultaneously mitigate patient distress and realize cost savings. Noona includes, among an array of features, three methods of communicating and tracking treatment-related symptoms that distinguish it among other ePROs and electronic platforms. The addition of capabilities to collect objective app use and satisfaction/loyalty with minimal patient burden is the veritable "win-win" scenario. Certainly, this information can be used descriptively, but its ability to produce real-world evidence, such as a demonstration that the use of these tracking features is associated with patient satisfaction/loyalty, can yield deeper understanding of how patients use and value the app.

An incontrovertible finding is that patients like the app; more than half (n=570, 52.76%) gave it the maximum score of 10,

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and 61.98% (n=670) rated it a 9 or 10. The exploratory multivariate analyses demonstrate some small but significant relationships between objective data use of the three communication modalities in the form of clicks and responses to an item assessing Noona satisfaction/loyalty. They include the findings that NSQ use was a significant predictor of satisfaction/loyalty scores; patients using the NSQ reported significantly higher satisfaction/loyalty scores than those who did not use one of the three Noona communication features; and Promoters used the secure-messaging modality more than Detractors. In general, we think these exploratory analyses are successful because, by making some slight adjustments, it is relatively easy to refine the satisfaction/loyalty item so that respondents can focus on these features to guide ratings rather than other potential facets of the app. This will also likely resolve the obvious ceiling effect—patients rated the application so highly (over 50% reported a score of 10) that it reduced data variability, which also negatively impacting the analyses.

While we see great potential for the use of Net Promoter Scores, the data presented in our study have limitations. For example, we are not able to include more personal or clinically relevant data because they are not embedded within Noona. Additionally, we made some assumptions regarding the relationship between clicks and feature use, which future research may find to be suboptimal.

Conflicts of Interest

Varian, A Siemens Healthineers Company, owns Noona and employs both IK and TP.

References

1. Detmar S, Muller M, Schornagel J, Wever L, Aaronson N. Health-related quality-of-life assessments and patient-physician communication: a randomized controlled trial. JAMA 2002 Dec 18;288(23):3027-3034. [doi: 10.1001/jama.288.23.3027] [Medline: 12479768]
2. Basch E, Charlot M, Dueck AC. Population-level evidence of survival benefits of patient-reported outcome symptom monitoring software systems in routine cancer care. Cancer Med 2020 Nov;9(21):7797-7799 [FREE Full text] [doi: 10.1002/cam4.3480] [Medline: 33029950]
3. Common Terminology Criteria for Adverse Events (CTCAE). National Cancer Institute. URL: https://ctep.cancer.gov/protocoldevelopment/electronic_applications/ctc.htm#ctc_50 [accessed 2022-03-18]
4. Denis F, Lethrosne C, Pourel N, Molinier O, Pointreau Y, Domont J, et al. Randomized Trial Comparing a Web-Mediated Follow-up With Routine Surveillance in Lung Cancer Patients. J Natl Cancer Inst 2017 Sep 01;109(9):djx029. [doi: 10.1093/jnci/djx029] [Medline: 28423407]
5. Absolom K, Warrington L, Hudson E, Hewison J, Morris C, Holch P, et al. Phase III Randomized Controlled Trial of eRAPID: eHealth Intervention During Chemotherapy. JCO 2021 Mar 01;39(7):734-747. [doi: 10.1200/jco.20.02015]
6. Takala L, Kuusinen T, Skyttä T, Kellokumpu-Lehtinen P, Bärlund M. Electronic Patient-reported Outcomes During Breast Cancer Adjuvant Radiotherapy. Clin Breast Cancer 2021 Jun;21(3):e252-e270 [FREE Full text] [doi: 10.1016/j.clbc.2020.10.004] [Medline: 33229222]
7. Barbera L, Sutradhar R, Seow H, Mittmann N, Howell D, Earle C, et al. The impact of routine Edmonton Symptom Assessment System (ESAS) use on overall survival in cancer patients: Results of a population-based retrospective matched cohort analysis. Cancer Med 2020 Oct;9(19):7107-7115 [FREE Full text] [doi: 10.1002/cam4.3374] [Medline: 32794634]
8. Hauth F, Bizu V, App R, Lautenbacher H, Tenev A, Bitzer M, et al. Electronic Patient-Reported Outcome Measures in Radiation Oncology: Initial Experience After Workflow Implementation. JMIR Mhealth Uhealth 2019 Jul 24;7(7):e12345 [FREE Full text] [doi: 10.2196/12345] [Medline: 31342906]
9. Schmalz O, Jacob C, Ammann J, Liss B, Iivanainen S, Kammermann M, et al. Digital Monitoring and Management of Patients With Advanced or Metastatic Non-Small Cell Lung Cancer Treated With Cancer Immunotherapy and Its Impact on Quality of Clinical Care: Interview and Survey Study Among Health Care Professionals and Patients. J Med Internet Res 2020 Dec 21;22(12):e18655 [FREE Full text] [doi: 10.2196/18655] [Medline: 33346738]
10. Iivanainen S, Alanko T, Peltola K, Konkola T, Ekström J, Virtanen H, et al. ePROs in the follow-up of cancer patients treated with immune checkpoint inhibitors: a retrospective study. J Cancer Res Clin Oncol 2019 Mar;145(3):765-774 [FREE Full text] [doi: 10.1007/s00432-018-02835-6] [Medline: 30666409]
11. Avery KNL, Richards HS, Portal A, Reed T, Harding R, Carter R, et al. Developing a real-time electronic symptom monitoring system for patients after discharge following cancer-related surgery. BMC Cancer 2019 May 17;19(1):463 [FREE Full text] [doi: 10.1186/s12885-019-5657-6] [Medline: 31101017]
12. Richards HS, Blazeby JM, Portal A, Harding R, Reed T, Lander T, et al. A real-time electronic symptom monitoring system for patients after discharge following surgery: a pilot study in cancer-related surgery. BMC Cancer 2020 Jun 10;20(1):543 [FREE Full text] [doi: 10.1186/s12885-020-07027-5] [Medline: 32522163]
13. Schuler T, Back M, Hruby G, Carroll S, Jayamanne D, Kneebone A, et al. Introducing Computed Tomography Simulation-Free and Electronic Patient-Reported Outcomes-Monitored Palliative Radiation Therapy into Routine Care: Clinical Outcomes and Implementation Experience. Adv Radiat Oncol 2021;6(2):100632 [FREE Full text] [doi: 10.1016/j.adro.2020.100632] [Medline: 33851063]

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14. Cho Y, Zhang H, Harris MR, Gong Y, Smith EL, Jiang Y. Acceptance and Use of Home-Based Electronic Symptom Self-Reporting Systems in Patients With Cancer: Systematic Review. J Med Internet Res 2021 Mar 12;23(3):e24638 [FREE Full text] [doi: 10.2196/24638] [Medline: 33709929]
15. Basch E, Wilfong L, Schrag D. Adding Patient-Reported Outcomes to Medicare's Oncology Value-Based Payment Model. JAMA 2020 Jan 21;323(3):213-214. [doi: 10.1001/jama.2019.19970] [Medline: 31895416]
16. Reichheld FF. The One Number You Need to Grow. Harvard Business Review. 2003 Dec. URL: https://hbr.org/2003/12/the-one-number-you-need-to-grow [accessed 2021-03-18]
17. Colvin G. The simple metric that's taking over big business. Fortune. 2020 May 18. URL: https://fortune.com/longform/net-promoter-score-fortune-500-customer-satisfaction-metric/ [accessed 2021-03-29]
18. Hamilton DF, Lane JV, Gaston P, Patton JT, MacDonald DJ, Simpson AHRW, et al. Assessing treatment outcomes using a single question. The Bone & Joint Journal 2014 May;96-B(5):622-628. [doi: 10.1302/0301-620x.96b5.32434]
19. Hoorntje A, Koenraadt KLM, Boevé MG, van Geenen RCI. Outpatient unicompartmental knee arthroplasty: who is afraid of outpatient surgery? Knee Surg Sports Traumatol Arthrosc 2017 Mar 22;25(3):759-766 [FREE Full text] [doi: 10.1007/s00167-017-4440-y] [Medline: 28229182]
20. Lynskey SJ, Ling F, Greenberg AM, Penny-Dimri JC, Sutherland AG. The influence of patient resilience and health status on satisfaction after total hip and knee arthroplasty. Surgeon 2021 Feb;19(1):8-14. [doi: 10.1016/j.surge.2020.02.007] [Medline: 32204983]
21. Powell RE, Stone D, Hollander JE. Patient and Health System Experience With Implementation of an Enterprise-Wide Telehealth Scheduled Video Visit Program: Mixed-Methods Study. JMIR Med Inform 2018 Feb 13;6(1):e10 [FREE Full text] [doi: 10.2196/medinform.8479] [Medline: 29439947]
22. Peña A, Qian Z, Lambrechts S, Cabri JN, Weiser C, Liu H, et al. Evaluation of Implementation Outcomes After Initiation of a Shared Decision-making Program for Men With Prostate Cancer. Urology 2019 Oct;132:94-100. [doi: 10.1016/j.urology.2019.06.032] [Medline: 31299329]
23. Srivastava U, Burton S, Lewis M, Patel D, Rasulnia M. Assessing the impact of a digital coaching program for patients with cancer. JCO 2018 Oct 20;36(30_suppl):274-274. [doi: 10.1200/jco.2018.36.30_suppl.274]
24. Duman-Lubberding S, van Uden-Kraan C, Jansen F, Witte B, van der Velden L, Lacko M, et al. Feasibility of an eHealth application "OncoKompas" to improve personalized survivorship cancer care. Support Care Cancer 2016 May 12;24(5):2163-2171 [FREE Full text] [doi: 10.1007/s00520-015-3004-2] [Medline: 26563178]
25. Van Blarigan EL, Kenfield SA, Tantum L, Cadmus-Bertram LA, Carroll PR, Chan JM. The Fitbit One Physical Activity Tracker in Men With Prostate Cancer: Validation Study. JMIR Cancer 2017 Apr 18;3(1):e5 [FREE Full text] [doi: 10.2196/cancer.6935] [Medline: 28420602]
26. Zhang X, McClean D, Ko E, Morgan M, Schmitz K. Exercise Among Women With Ovarian Cancer: A Feasibility and Pre-/Post-Test Exploratory Pilot Study. ONF 2017 May 1;44(3):366-374. [doi: 10.1188/17.onf.366-374]
27. Hooke MC, Gilchrist L, Tanner L, Hart N, Withycombe JS. Use of a Fitness Tracker to Promote Physical Activity in Children With Acute Lymphoblastic Leukemia. Pediatr Blood Cancer 2016 Apr 12;63(4):684-689. [doi: 10.1002/pbc.25860] [Medline: 26756736]
28. Bennett A, Reeve B, Basch E, Mitchell S, Meeneghan M, Battaglini C, et al. Evaluation of pedometry as a patient-centered outcome in patients undergoing hematopoietic cell transplant (HCT): a comparison of pedometry and patient reports of symptoms, health, and quality of life. Qual Life Res 2016 Mar;25(3):535-546. [doi: 10.1007/s11136-015-1179-0] [Medline: 26577763]
29. Atkinson T, Ryan S, Bennett A, Stover A, Saracino R, Rogak L, et al. The association between clinician-based common terminology criteria for adverse events (CTCAE) and patient-reported outcomes (PRO): a systematic review. Support Care Cancer 2016 Aug;24(8):3669-3676 [FREE Full text] [doi: 10.1007/s00520-016-3297-9] [Medline: 27260018]
30. Di Maio M, Gallo C, Leighl NB, Piccirillo MC, Daniele G, Nuzzo F, et al. Symptomatic Toxicities Experienced During Anticancer Treatment: Agreement Between Patient and Physician Reporting in Three Randomized Trials. JCO 2015 Mar 10;33(8):910-915. [doi: 10.1200/jco.2014.57.9334]
31. Basch E, Deal A, Kris M, Scher H, Hudis C, Sabbatini P, et al. Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial. JCO 2016 Feb 20;34(6):557-565. [doi: 10.1200/jco.2015.63.0830]

Abbreviations

CTCAE: Common Terminology Criteria for Adverse Events
ePRO: electronic patient-reported outcomes
GLM: generalized linear model
NSQ: Noona symptom questionnaires

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Short Paper

News Coverage of Colorectal Cancer on Google News: Descriptive Study

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Abstract

Background: Colorectal cancer (CRC) is one of the leading causes of cancer death in the United States. The incidence and prevalence of CRC have historically increased with age. Although rates of CRC in the United States have been decreasing over the past decades among those aged ≥65 years, there has been an uptick among those in younger age brackets. Google News is one of the biggest traffic drivers to top news sites. It aggregates and shares news highlights from multiple sources worldwide and organizes them by content type. Despite the widespread use of Google News, research is lacking on the type of CRC content represented in this news source.

Objective: The purpose of this study was to analyze content related to CRC screening and prevention in Google News articles published during National Colorectal Cancer Awareness Month (March 2022).

Methods: Data collection for this cross-sectional study was conducted in March 2022—National Colorectal Cancer Awareness Month. Using the term *colorectal cancer*, 100 English-language Google News articles were extracted and coded for content. A combined approach—deductive and inductive coding—was utilized. Descriptive analyses were conducted, and frequency distributions were reported. Univariable analyses were performed to assess differences between articles that mentioned CRC screening and those that did not via chi-square tests.

Results: Of the 100 articles reviewed, nearly half (n=49, 49%) were created by health news organizations, and another 27% (n=27) were created by television news services. The predominant themes in the content included age at the onset of disease (n=59, 59%), mortality related to CRC (n=57, 57%), and the severity of disease (n=50, 50%). Only 18% (n=18) of articles discussed CRC disparities, 23% (n=23) mentioned that there are hereditary forms of the disease, 36% (n=36) spoke of colonoscopy to screen for the disease, and 37% (n=37) mentioned how the disease is treated. Although most articles mentioned CRC screening (n=61, 61%), it was striking that sex was only mentioned in 34% (21/61) of these articles, colonoscopy was mentioned in 46% (28/61), and diet was mentioned in 30% (18/61).

Conclusions: Heightening the public's awareness of this disease is important, but it is critical that messages related to how preventable this cancer is, who is the most likely to develop CRC, and what can be done to detect it in the early stages when the disease is the most curable be the critical elements of dialogue, particularly during National Colorectal Cancer Awareness Month. There is a need to disseminate information about early-onset CRC and the importance of screening, especially among populations with low rates of uptake. Web-based news is potentially an underutilized communication mechanism for promoting CRC screenings as secondary prevention measures for high-risk groups.

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KEYWORDS

colorectal cancer; internet; online news; screening; disparities; infodemiology; online health information; content analysis; public awareness; health news; cancer screening; health video; video content analysis

Introduction

Colorectal cancer (CRC) is one of the leading causes of cancer death in the United States [1]. It is estimated that in 2022, 151,030 adults in the United States will be diagnosed with CRC, resulting in 52,580 deaths [1]. Risk factors for CRC include family history and lifestyle factors such as physical inactivity, dietary factors, overweight and obesity, and alcohol and tobacco use [2]. Emerging research also suggests that disruptions to the gut microbiome due to oral antibiotic use [3] and other factors [4-6] related to gut microbiota can also be contributing factors.

The incidence and prevalence of CRC have historically increased with age. According to recent figures, the median age of diagnosis is 69 years in women and 66 years in men [7]. Although rates of CRC in the United States have been decreasing over the past decades among those aged ≥65 years, there has been an uptick among those in younger age brackets [7,8]. According to researchers, the "incidence of colorectal cancer (specifically adenocarcinoma) in adults aged 40 to 49 years has increased by almost 15% from 2000-2002 to 2014-2016" [9]. It is important to note that not only is the incidence of CRC rising in younger Americans, but the rate of mortality is as well [10]. The US Preventive Services Task Force lowered the recommended age for CRC screening from 50 years to 45 years in 2021 [9].

Screening for CRC can drastically reduce morbidity and mortality. The US Preventive Services Task Force recommends stool-based and direct visualization–based (eg, colonoscopy, flexible sigmoidoscopy, and computed tomography colonography) tests for screening [10]. Data from the Behavioral Risk Factor Surveillance Survey indicate that 71.6% of adults aged 50 to 75 years were up-to-date with all CRC screening test types, and 69.7% were up-to-date based on the receipt of a fecal immunochemical test, sigmoidoscopy, or colonoscopy [11]. These numbers do not reflect the 2021 changes that were made to lower the recommended age for screening [11].

The efforts that have been made to increase screening for CRC have included interventions, outreach, and targeted programming, with many aiming to increase knowledge and awareness. Variations in screening uptake among Hispanic [12] and Black [13] individuals are influenced by access to health care [14] and low health literacy [15]. Understudied but important factors that can contribute to behavior change are historical factors. Oftentimes, the most notable historical factors pertain to celebrities' engagement with a health topic [16-18]. With regard to CRC specifically, researchers noted an increase in CRC screening after a newscaster, Katie Couric, announced her CRC awareness campaign in March 2000 on the *Today Show* [19]. More recently, the untimely and tragic death of Chadwick Boseman at the age of 43 has helped to raise awareness about important issues related to CRC morbidity and mortality, specifically early-onset CRC and related CRC health disparities [20].

Researchers have reported on Google News coverage of the recent update to CRC screening recommendations [21]. Others have reported on screening changes covered in web-based newspapers [22], yet research on the extent to which Google News is used to share general CRC information is unknown. News coverage is an important channel that is used by the public to gather health information [23]. Most Americans have shifted their news consumption methods from using print, television, and radio sources to using the internet on digital devices [24]. Google News—an aggregate news hub—captures cancer-related information that is regularly consumed by the general public. Americans search for cancer-related information through search engines [25] that funnel their attention to health information sites that are often reflected in Google News [26].

Google News is one of the biggest traffic drivers to top news sites [27]. It aggregates and shares news highlights from multiple sources worldwide and organizes them by content type [28]. Despite the widespread use of Google News, research is lacking on the type of CRC content represented in this news source. The purpose of this study was to analyze content related to CRC screening and prevention in Google News articles published during National Colorectal Cancer Awareness Month (March 2022).

Methods

Study Design

Data collection for this cross-sectional study was conducted in March 2022—National Colorectal Cancer Awareness Month. A search using the term *colorectal cancer* yielded 100 recent Google News articles. Relevance was determined based on mentions of *colorectal cancer* and the verification that content was related to CRC in some way. All 100 articles were deemed to be relevant. The publication dates ranged between June 2021 and March 2022. The articles included for analysis were written in English and had to mention *colorectal cancer* or a known variation (ie, colon, rectal or bowel cancer). The metadata (URLs, creation dates, and categories selected) for the 100 news articles chosen for inclusion were captured and organized in Microsoft Excel. Any duplicate news articles were excluded.

A combined approach—deductive and inductive coding—was used by a single coder (ETJ). The National Cancer Institute web page [29] and the researchers' interests guided the selection of the predefined variables related to the articles that were coded deductively. Inductive coding commenced while data were analyzed as new themes emerged. Codes included descriptive information, such as the source of the posts; whether any specific individuals were mentioned; and, if so, whether a layperson or public figure was mentioned. Further categories included CRC disease–related characteristics (disparities in outcomes, mortality, the severity of disease, the spread of cancer, treatment, and related research), CRC risk factors (family history and hereditary forms of the disease, age at onset, race, sex, and antibiotic use), and CRC prevention and risk reduction (mentions

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of screening, colonoscopy, diet, the fear of CRC screening, and insurance coverage and costs of screening).

Descriptive analyses were conducted, and frequency distributions were reported. Univariable analyses were performed to assess differences between articles that mentioned CRC screening and those that did not via chi-square tests. A *P* value of <.05 was considered statistically significant. All analyses were performed by using IBM SPSS version 28 (IBM Corporation).

Ethical Considerations

This study did not include the participation of human subjects. Thus, the William Paterson University Institutional Review Board determined that this study did not meet the criteria for ethics review.

Results

Of the 100 articles reviewed, nearly half (n=49, 49%) were created by health news organizations, and another 27% (n=27) were created by television news services (Table 1). The predominant themes in the content included age at the onset of disease (n=59, 59%), mortality related to CRC (n=57, 57%), and the severity of disease (n=50, 50%). Only 18% (n=18) discussed CRC disparities, 23% (n=23) mentioned there are hereditary forms of the disease, 36% (n=36) spoke of colonoscopy to screen for the disease, and 37% (n=37) discussed how the disease is treated. Most articles mentioned CRC screening (n=61, 61%), and when they were compared to articles that did not mention CRC screening, striking differences were observed.

Articles that mentioned CRC screening more often talked about topics related to this particular cancer, such as CRC mortality (45/61, 74% vs 12/39, 31%; *P*<.001), the severity of disease (37/61, 61% vs 13/39, 33%; *P*=.008), and the risk for CRC based on age (46/61, 75% vs 13/39, 33%; *P*<.001). Although most articles mentioned CRC screening (n=61, 61%), it was striking that sex was only mentioned in 34% (21/61) of these articles, colonoscopy was mentioned in 46% (28/61), and diet was mentioned in 30% (18/61). In articles where CRC screening was not mentioned, only the treatment of this cancer was discussed more often than in those that did mention CRC screening (19/39, 49% vs 18/61, 30%; *P*=.05).

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Table 1. Characteristics and content of Google News articles (N=100) related to colorectal cancer (CRC; June 2021 to March 2022).

	Articles, n (%)	CRC screening mentioned, n (%)		*P* value
		Yes (n=61)	No (n=39)	
Article-related characteristics and content				
Source of information				.20
Internet news	9 (9)	7 (12)	2 (5)	
Television news	27 (27)	15 (25)	12 (31)	
Health news organization	49 (49)	26 (43)	22 (56)	
Consumer	1 (1)	1 (2)	0 (0)	
Educational news	7 (7)	6 (10)	1 (3)	
Non–health organization news	1 (1)	0 (0)	1 (3)	
Academic journal	6 (6)	5 (8)	1 (3)	
Government	1 (1)	1 (1.6)	0 (0)	
Specific person mentioned				.36
Yes	20 (20)	14 (23)	6 (15)	
No	80 (80)	47 (77)	33 (85)	
Type of person mentioned				.63
Layperson	16 (80)[a]	11 (79)[b]	5 (83)[c]	
Public figure	4 (20)[a]	3 (21)[b]	1 (17)[c]	
CRC-related characteristics and content				
Disparities in outcomes				.11
Yes	18 (18)	14 (23)	4 (10)	
No	82 (82)	47 (77)	35 (90)	
Mortality				<.001
Yes	57 (57)	45 (74)	12 (31)	
No	43 (43)	16 (26)	27 (69)	
Severity of disease				.008
Yes	50 (50)	37 (61)	13 (33)	
No	50 (50)	24 (29)	26 (67)	
Spread of cancer				.34
Yes	23 (23)	16 (26)	7 (18)	
No	77 (77)	45 (74)	32 (82)	
Treatment				.05
Yes	37 (37)	18 (30)	19 (49)	
No	63 (63)	43 (71)	20 (51)	
Related research				.59
Yes	34 (4)	22 (36)	12 (31)	
No	66 (66)	39 (64)	27 (69)	
Risk				
Family history or hereditary forms of the disease				.34
Yes	23 (23)	16 (26)	7 (18)	
No	77 (77)	45 (74)	32 (82)	
Age				<.001

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	Articles, n (%)	CRC screening mentioned, n (%)		*P* value
		Yes (n=61)	No (n=39)	
Yes	59 (59)	46 (75)	13 (33)	
No	41 (41)	15 (25)	26 (67)	
Race				.10
Yes	15 (15)	12 (19)	3 (8)	
No	85 (85)	49 (80)	26 (92)	
Sex				<.001
Yes	23 (23)	21 (34)	2 (5)	
No	77 (77)	40 (66)	37 (95)	
Antibiotic use				.15
Yes	6 (6)	2 (3)	4 (10)	
No	94 (94)	59 (97)	35 (90)	
Prevention and risk reduction				
Colonoscopy				.01
Yes	36 (36)	28 (46)	8 (21)	
No	64 (64)	33 (54)	31 (80)	
Diet				.009
Yes	21 (21)	18 (30)	3 (8)	
No	79 (79)	43 (71)	36 (92)	
Fear of screening				.84
Yes	3 (3)	2 (3)	1 (3)	
No	97 (97)	59 (97)	38 (97)	
Insurance or cost of screening				.06
Yes	13 (13)	11 (18)	2 (5)	
No	87 (87)	50 (82)	37 (95)	

[a]The denominator for this percentage is 20, per the number of articles in which a specific person was mentioned.

[b]The denominator for this percentage is 14, per the number of articles in which a specific person and CRC screening were mentioned.

[c]The denominator for this percentage is 6, per the number of articles in which a specific person was mentioned and CRC screening was not mentioned.

Discussion

Principal Findings

March is National Colorectal Cancer Awareness Month, and it was designated as such for the express purposes of highlighting the importance of screening for CRC and promoting healthy lifestyles to decrease one's risk for developing CRC [30,31]. On February 28, 2022, the White House released a proclamation signed by the president of the United States to kick off the media blitz [32]. With the heightened public awareness of the disease during this month, we reviewed Google News articles related to CRC during March 2022 to evaluate the content of articles viewed by the public. Notably, only 61% (61/100) of articles mentioned CRC screening in general, and of those, less than half (28/61, 46%) mentioned colonoscopy—the most commonly used method for CRC screening in the United States [23]. As CRC is a potentially preventable cancer (ie, through the detection and removal of adenomatous polyps—a known precursor to malignancy [33]), the lack of mentions of CRC screening is of special concern. Further, with the recent focus of research on early-onset CRC following the tragic passing of Chadwick Boseman from CRC at the age of 43 [34] and the recent change in the age at which to begin CRC screening (from 50 years to 45 years) [9], it is particularly concerning that less than two-thirds (61/100, 61%) of the articles mentioned screening and screening goals were not a topic of coverage.

The results of this study also indicate that news articles aggregated by Google News did not sufficiently emphasize disparities in CRC morbidity and mortality. In fact, this was mentioned in fewer than 20% (18/100, 18%) of the articles included in our sample. Disparities among racial and ethnic minorities persist [35-38], and this is an important point that should be covered in news articles.

Comparisons With Prior Works

The dearth of health-related Google News coverage on CRC disparities aligns with research studies that indicate that Black and Hispanic populations are less likely to be advised to undergo

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CRC screenings [39-41]. These results support existing research that accentuates the need for increased communication efforts as an approach to influence screening uptake. Heightening the public's awareness of this disease is important, but it is critical that messages related to how preventable this cancer is, who is the most likely to develop CRC, and what can be done to detect it in the early stages when the disease is most curable be the critical elements of dialogue, particularly during National Colorectal Cancer Awareness Month.

Limitations

This study is limited by the small sample size and cross-sectional design. The news that was present at the time of this study can fluctuate over time. As these data represent only 1 point in time, there is no point of comparison. The findings cannot be generalized or be considered representative of all web-based news. Further, these findings cannot be used to evaluate behavior. Future studies should determine who is accessing this information and how this does or does not influence actions.

Conclusions

There is a need to disseminate information about early-onset CRC and the importance of screening, especially among populations with low rates of uptake. Web-based news is potentially an underutilized communication mechanism for promoting CRC screenings as secondary prevention measures for high-risk groups.

Conflicts of Interest

CHB serves as an Editorial Board Member for JMIR; she did not have a role in the review or editorial process for this article.

References

1. Colorectal cancer: Statistics. Cancer.Net. URL: https://www.cancer.net/cancer-types/colorectal-cancer/statistics#:~:text=It%20is%20estimated%20that%2052%2C580,for%20men%20and%20women%20combined [accessed 2022-04-30]
2. What are the risk factors for colorectal cancer? Centers for Disease Control and Prevention. URL: https://www.cdc.gov/cancer/colorectal/basic_info/risk_factors.htm [accessed 2022-04-30]
3. McDowell R, Perrott S, Murchie P, Cardwell C, Hughes C, Samuel L. Oral antibiotic use and early-onset colorectal cancer: findings from a case-control study using a national clinical database. Br J Cancer 2022 Apr;126(6):957-967 [FREE Full text] [doi: 10.1038/s41416-021-01665-7] [Medline: 34921228]
4. Wolf PG, Cowley ES, Breister A, Matatov S, Lucio L, Polak P, et al. Diversity and distribution of sulfur metabolic genes in the human gut microbiome and their association with colorectal cancer. Microbiome 2022 Apr 19;10(1):64 [FREE Full text] [doi: 10.1186/s40168-022-01242-x] [Medline: 35440042]
5. Tremaroli V, Bäckhed F. Functional interactions between the gut microbiota and host metabolism. Nature 2012 Sep 13;489(7415):242-249. [doi: 10.1038/nature11552] [Medline: 22972297]
6. Clemente JC, Ursell LK, Parfrey LW, Knight R. The impact of the gut microbiota on human health: an integrative view. Cell 2012 Mar 16;148(6):1258-1270 [FREE Full text] [doi: 10.1016/j.cell.2012.01.035] [Medline: 22424233]
7. Colorectal cancer: Facts and figures 2020-2022. American Cancer Society. 2020. URL: https://tinyurl.com/58r66nee [accessed 2022-04-30]
8. Siegel RL, Miller KD, Sauer AG, Fedewa SA, Butterly LF, Anderson JC, et al. Colorectal cancer statistics, 2020. CA Cancer J Clin 2020 May;70(3):145-164 [FREE Full text] [doi: 10.3322/caac.21601] [Medline: 32133645]
9. US Preventive Services Task Force, Davidson KW, Barry MJ, Mangione CM, Cabana M, Caughey AB, et al. Screening for colorectal cancer: US Preventive Services Task Force recommendation statement. JAMA 2021 May 18;325(19):1965-1977. [doi: 10.1001/jama.2021.6238] [Medline: 34003218]
10. Colorectal cancer in young adults. National Cancer Institute. URL: https://gis.cancer.gov/mapstory/CRC/index.html [accessed 2022-04-30]
11. Use of colorectal cancer screening tests: 2020 behavioral risk factor surveillance system. Centers for Disease Control and Prevention. URL: https://www.cdc.gov/cancer/colorectal/statistics/use-screening-tests-BRFSS.htm [accessed 2022-04-30]
12. Ou JY, Warner EL, Nam GE, Martel L, Carbajal-Salisbury S, Fuentes V, et al. Colorectal cancer knowledge and screening adherence among low-income Hispanic employees. Health Educ Res 2019 Aug 01;34(4):400-414 [FREE Full text] [doi: 10.1093/her/cyz013] [Medline: 31329867]
13. Burgess DJ, van Ryn M, Grill J, Noorbaloochi S, Griffin JM, Ricards J, et al. Presence and correlates of racial disparities in adherence to colorectal cancer screening guidelines. J Gen Intern Med 2011 Mar;26(3):251-258 [FREE Full text] [doi: 10.1007/s11606-010-1575-7] [Medline: 21088920]
14. Jackson CS, Oman M, Patel AM, Vega KJ. Health disparities in colorectal cancer among racial and ethnic minorities in the United States. J Gastrointest Oncol 2016 Apr;7(Suppl 1):S32-S43 [FREE Full text] [doi: 10.3978/j.issn.2078-6891.2015.039] [Medline: 27034811]
15. Liu D, Schuchard H, Burston B, Yamashita T, Albert S. Interventions to reduce healthcare disparities in cancer screening among minority adults: a systematic review. J Racial Ethn Health Disparities 2021 Feb;8(1):107-126. [doi: 10.1007/s40615-020-00763-1] [Medline: 32415578]

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16. Vos SC, Sutton J, Gibson CB, Butts CT. Celebrity cancer on Twitter: Mapping a novel opportunity for cancer prevention. Cancer Control 2019;26(1):1073274819825826 [FREE Full text] [doi: 10.1177/1073274819825826] [Medline: 30816059]
17. Ayers JW, Althouse BM, Noar SM, Cohen JE. Do celebrity cancer diagnoses promote primary cancer prevention? Prev Med 2014 Jan;58:81-84. [doi: 10.1016/j.ypmed.2013.11.007] [Medline: 24252489]
18. Noar SM, Willoughby JF, Myrick JG, Brown J. Public figure announcements about cancer and opportunities for cancer communication: a review and research agenda. Health Commun 2014;29(5):445-461. [doi: 10.1080/10410236.2013.764781] [Medline: 23845155]
19. Cram P, Fendrick AM, Inadomi J, Cowen ME, Carpenter D, Vijan S. The impact of a celebrity promotional campaign on the use of colon cancer screening: the Katie Couric effect. Arch Intern Med 2003 Jul 14;163(13):1601-1605. [doi: 10.1001/archinte.163.13.1601] [Medline: 12860585]
20. Naik H, Johnson MDD, Johnson MR. Internet interest in colon cancer following the death of Chadwick Boseman: Infoveillance study. J Med Internet Res 2021 Jun 15;23(6):e27052 [FREE Full text] [doi: 10.2196/27052] [Medline: 34128824]
21. Krigel A, Prasad VK, Lebwohl B. News coverage of the American Cancer Society's update to colorectal cancer screening guidelines. Mayo Clin Proc 2020 Mar;95(3):617-618. [doi: 10.1016/j.mayocp.2019.12.016] [Medline: 32138893]
22. Elstad EA, Sheridan SL, Lee JGL, Rini C, Earp JA, Brewer NT. Have screening harms become newsworthy? News coverage of prostate and colorectal cancer screening since the 2008 USPSTF recommendation changes. J Behav Med 2014 Dec;37(6):1242-1251. [doi: 10.1007/s10865-014-9572-7] [Medline: 24859436]
23. Martinson BE, Hindman DB. Building a health promotion agenda in local newspapers. Health Educ Res 2005 Feb;20(1):51-60. [doi: 10.1093/her/cyg104] [Medline: 15253997]
24. Shearer E. More than eight-in-ten Americans get news from digital devices. Pew Research Center. 2021 Jan 12. URL: https://www.pewresearch.org/fact-tank/2021/01/12/more-than-eight-in-ten-americans-get-news-from-digital-devices/ [accessed 2022-05-30]
25. Bader JL, Theofanos MF. Searching for cancer information on the internet: analyzing natural language search queries. J Med Internet Res 2003 Dec 11;5(4):e31 [FREE Full text] [doi: 10.2196/jmir.5.4.e31] [Medline: 14713659]
26. Hurley RJ, Tewksbury D. News aggregation and content differences in online cancer news. J Broadcast Electron Media 2012 Mar 02;56(1):132-149. [doi: 10.1080/08838151.2011.648681]
27. Olmstead K, Mitchell A, Rosenstiel T. Navigating news online: Where people go, how they get there and what lures them away. Pew Research Center. URL: https://www.pewresearch.org/wp-content/uploads/sites/8/legacy/NIELSEN-STUDY-Copy.pdf [accessed 2022-04-30]
28. Google News - Daily headlines. Google Play. URL: https://play.google.com/store/apps/details?id=com.google.android.apps.magazines&hl=en_US&gl=US [accessed 2022-04-30]
29. Colorectal cancer—Patient version. National Cancer Institute. URL: https://www.cancer.gov/types/colorectal [accessed 2022-06-06]
30. Colorectal Cancer Awareness Month 2022. International Agency for Research on Cancer, World Health Organization. URL: https://www.iarc.who.int/featured-news/colorectal-cancer-awareness-month-2022/#:~:text=Colorectal%20Cancer%20Awareness%20Month%20is,types%20referred%20to%20collectively%20as [accessed 2022-04-29]
31. March is National Colorectal Cancer Awareness Month. Colorectal Cancer Alliance. URL: https://www.ccalliance.org/about/awareness-month [accessed 2022-04-29]
32. A proclamation on National Colorectal Cancer Awareness Month, 2022. The White House. 2022 Feb 28. URL: https://tinyurl.com/2u6knemt [accessed 2022-06-03]
33. Mandel JS, Bond JH, Church TR, Snover DC, Bradley GM, Schuman LM, et al. Reducing mortality from colorectal cancer by screening for fecal occult blood. Minnesota Colon Cancer Control Study. N Engl J Med 1993 May 13;328(19):1365-1371. [doi: 10.1056/NEJM199305133281901] [Medline: 8474513]
34. Chiu A. Chadwick Boseman's death is making young people think about colon cancer. Here's what to know. The Washington Post. 2020 Sep 4. URL: https://www.washingtonpost.com/lifestyle/wellness/colon-cancer-chadwick-boseman-tips/2020/09/03/13d224f2-ed29-11ea-99a1-71343d03bc29_story.html [accessed 2022-06-03]
35. Augustus GJ, Ellis NA. Colorectal cancer disparity in African Americans: Risk ractors and carcinogenic mechanisms. Am J Pathol 2018 Feb;188(2):291-303 [FREE Full text] [doi: 10.1016/j.ajpath.2017.07.023] [Medline: 29128568]
36. Hao S, Parikh AA, Snyder RA. Racial disparities in the management of locoregional colorectal cancer. Surg Oncol Clin N Am 2022 Jan;31(1):65-79. [doi: 10.1016/j.soc.2021.07.008] [Medline: 34776065]
37. Huguet N, Angier H, Rdesinski R, Hoopes M, Marino M, Holderness H, et al. Cervical and colorectal cancer screening prevalence before and after Affordable Care Act Medicaid expansion. Prev Med 2019 Jul;124:91-97 [FREE Full text] [doi: 10.1016/j.ypmed.2019.05.003] [Medline: 31077723]
38. Koblinski J, Jandova J, Nfonsam V. Disparities in incidence of early- and late-onset colorectal cancer between Hispanics and Whites: A 10-year SEER database study. Am J Surg 2018 Apr;215(4):581-585. [doi: 10.1016/j.amjsurg.2017.03.035] [Medline: 28388972]

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39. Wallace DAC, Baltrus PT, Wallace TC, Blumenthal DS, Rust GS. Black white disparities in receiving a physician recommendation for colorectal cancer screening and reasons for not undergoing screening. J Health Care Poor Underserved 2013 Aug;24(3):1115-1124 [FREE Full text] [doi: 10.1353/hpu.2013.0132] [Medline: 23974385]
40. Wilkins T, Gillies RA, Harbuck S, Garren J, Looney SW, Schade RR. Racial disparities and barriers to colorectal cancer screening in rural areas. J Am Board Fam Med 2012;25(3):308-317 [FREE Full text] [doi: 10.3122/jabfm.2012.03.100307] [Medline: 22570394]
41. Gonzalez JJ, Wahab A, Samalik J, Ramirez E, Saint-Phard T, Gonzalez E, et al. Barriers and facilitators of colorectal cancer screening among a Hispanic community in Michigan. J Racial Ethn Health Disparities 2020 Feb;7(1):137-143. [doi: 10.1007/s40615-019-00643-3] [Medline: 31664675]

Abbreviations

CRC: colorectal cancer

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