JMIR Cancer

Impact Factor (2022): 2.8
Volume 8 (2022), Issue 3   ISSN 2369-1999   Editor in Chief: Naomi Cahill, PhD, RD

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Review

Public Policies and Programs for the Prevention and Control of Breast Cancer in Latin American Women: Scoping Review

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Abstract

Background: Breast cancer has positioned itself worldwide as one of the main public health problems, especially in Latin America. In some countries, several programs for the prevention and control of breast cancer in women have been developed and implemented on a permanent basis, but there are no public reports on the policies that originated such programs.

Objective: A scoping review of scientific publications that identify the type, extent, and scope of policies and programs for the prevention and control of breast cancer in Latin American women was performed, and the main results were presented in this paper.

Methods: This scoping review was carried out according to the method by Arksey and O'Malley based on 3 fundamental questions about breast cancer prevention and control policies in Latin America: their type, extent and scope, and reference framework. The search period was from 2000 to 2019, and the search was carried out in the following databases: MEDLINE (PubMed), MEDLINE (EbscoHost), CINAHL (EbscoHost), Academic Search Complete (EbscoHost), ISI Web of Science (Science Citation Index), and Scopus in English, Spanish, and Portuguese, and Scielo, Cochrane, and MEDES-MEDicina in Spanish and Portuguese. Of the 743 studies found, 20 (2.7%) were selected, which were analyzed using descriptive statistics and qualitative content analysis.

Results: The selected studies identified several Latin American countries that have generated policies and programs to prevent and control breast cancer in women, focusing mainly on risk communication, prevention and timely detection, effective access to health services, improvement of the screening process, and evaluation of screening programs. Evaluation criteria and greater participation of civil society in policy design and program execution are still lacking. This could undoubtedly help eliminate existing barriers to effective action.

Conclusions: Although several Latin American countries have generated public policies and action programs for the prevention and control of breast cancer, a pending issue is the evaluation of the results to analyze the effectiveness and impact of their implementation given the magnitude of the public health problem it represents and because women and civil society play an important role in its prevention and control.

International Registered Report Identifier (IRRID): RR2-10.2196/12624

(JMIR Cancer 2022;8(3):e32370) doi:10.2196/32370

KEYWORDS

breast cancer; scoping review; public policy; prevention programs; systematic review

Introduction

Background

Breast cancer (BC) has become one of the main public health problems worldwide, especially in Mexico, where, in 2020, a prevalence rate of 225.3 cases per 100,000 women over 20 years was reported [1], whereas the reported mortality was 16 cases per 100,000 women over 20 years. In the same year, 2 out of every 10 cancer-related deaths in women were caused by this particular disease [2]. It was also one of the 5 most outstanding types of fatal cancer among the population aged 30 to 59 years in the period from 2011 to 2016 [2].

In February 2020, BC represented 25% of the cancers diagnosed in women in Latin America (LATAM); hence, of the 462,000 cases that were diagnosed that year, approximately 100,000 resulted in death, of which 56% were women younger than 65 years [3]. This represents 1.8% of the total disability-adjusted life years for women in this region [4].

In this context, the World Health Organization (WHO) predicts that, if the trend of this cancer continues as observed in recent years, by the year 2030, diagnoses will increase by 34% in this region of the planet [5].

By contrast, some studies have identified that breast self-examination and early diagnosis are the best strategies to treat this type of cancer in time [5-8]. Therefore, health education becomes relevant as women can then be trained to actively participate in preventive measures through the adoption of healthy lifestyles, timely identification of gynecological neoplasm warning signs [9], modification of risk factors, and decision to visit a health care facility immediately after identifying any abnormality [10].

In this context, the WHO recommends that countries establish forceful measures (eg, adequate prevention and control policies and programs) to effectively fight BC [5]. In Mexico, as in many other countries, these types of actions are carried out constantly [9,11]. However, there are no comprehensive reports on the diversity, number, type, and scope of programs and public policies that have been implemented or their impact on the population. For this reason, a systematic review, in this case a scoping review, was carried out using the strategy proposed by Arksey and O'Malley [12].

Objectives

Although there are current scoping reviews about prevention and control issues of chronic-degenerative diseases such as obesity [13], BC [14], or problems generated by little physical activity [15], there is no evidence of a scoping review about policies and programs defining BC prevention and control actions. Therefore, the main objective of this study was to present the results of a scoping review of scientific publications to identify the type, extent, and scope of policies and programs to prevent and control BC in LATAM women to evaluate how these concepts align with existing actions at an international level, identify knowledge gaps, and establish research agendas. The specific objectives of this scoping review were (1) to identify which policies and programs for the prevention and control of BC in LATAM have been analyzed in the last 20 years; (2) to analyze their type, extent, and scope; and (3) to describe the reference frameworks on which these BC policies and prevention and control programs were based.

Methods

Design

This scoping review was carried out using the 6-stage methodological framework by Arksey and O'Malley [12], which was later modified by the Joanna Briggs Institute [16]. A research protocol was prepared and registered with the number PRR1-10.2196-12624 at the International Reporting Registry Identifier and later published elsewhere [17]. It was also registered with the Department of Public Health of the University of Guadalajara (CISIGS-021-19) in October 2019. Being a documentary study based on secondary data, it was considered a study without any risk to the population.

Stage 1: Identification of Research Questions

An iterative search process was conducted to generate one or more questions to guide the investigation. As a result, the Specific Action Program for the Prevention and Control of Cancer in Women 2013-2018 in Mexico was identified [9], whose general objective was used to generate this review’s basic questions considering that they represent the current actions that are being developed in this regard in LATAM (Multimedia Appendix 1).

Stage 2: Identification of Relevant Studies

Overview

The inclusion and exclusion criteria for articles, databases, and search terms were then established. The inclusion criteria were (1) articles on BC prevention and control, public policies, and programs published between January 2000 and December 2019, preferably in Spanish, English, and Portuguese; (2) articles on BC, public policies, and programs applicable to female human participants of any age group; (3) review articles that included systematic reviews, meta-analyses, meta-syntheses, other scoping reviews, and gray literature; and (4) articles published with a focus on the LATAM population. The exclusion criteria were (1) articles on public policies and programs related to any other type of cancer and (2) advertising articles for profit.

Databases

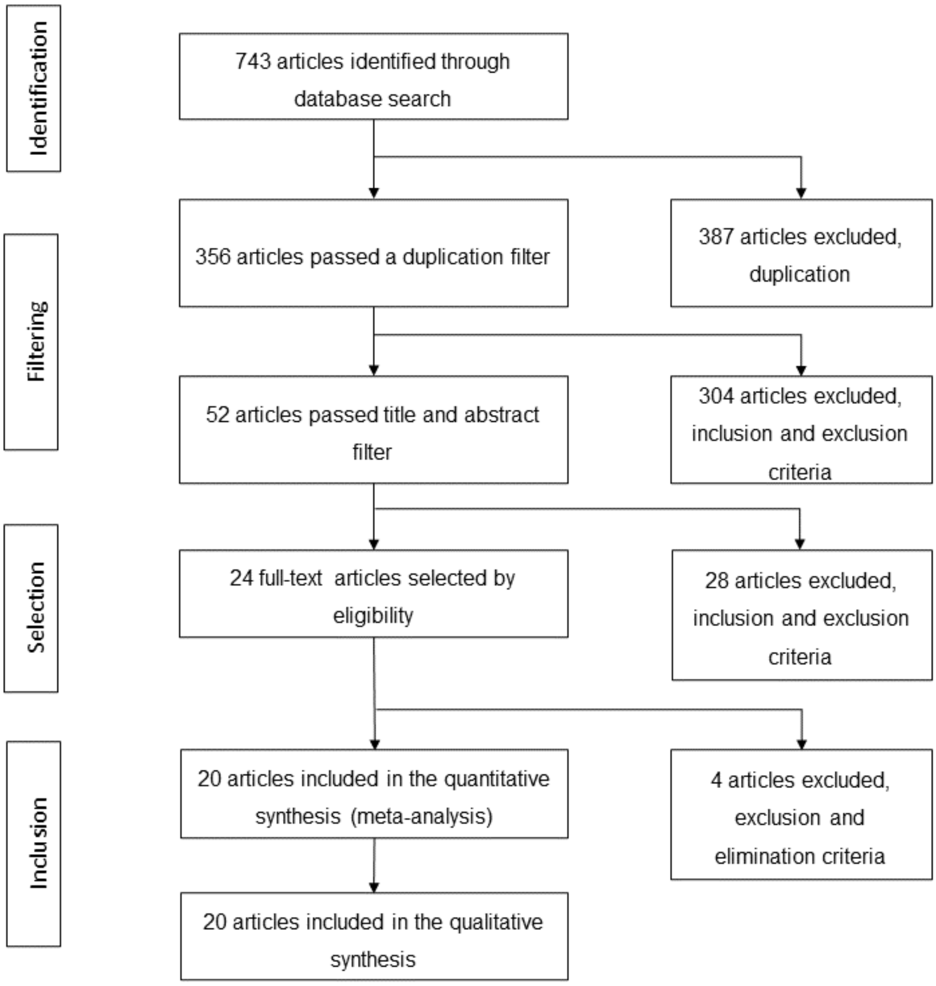
The search was carried out in the main electronic databases available internationally and that could be accessed in full text through the Digital Library of the University of Guadalajara [18]. The consulted databases were MEDLINE (PubMed), MEDLINE (EbscoHost), CINAHL (EbscoHost), Academic Search Complete (EbscoHost), ISI Web of Science (Science Citation Index), and Scopus in English, Spanish, and Portuguese, and Scielo, Cochrane, and MEDES-MEDicina in Spanish and Portuguese.

Search Terms

For the initial search of BC prevention and control policies and programs, the first filter was “Latin America OR Mexico.” From this initial search, the terms of subsequent consultations included those that were verified in the Medical Subject Headings for the databases in English and in the Health Sciences Descriptors of the Pan American Health Organization for the databases in Spanish and Portuguese. The terms used for the searches were "policies," "public policies," "programs," "strategies," "laws," "prevention," and "control" combined with "Breast Cancer" and "malignant neoplasms" in Spanish, English, and Portuguese.

Of interest to this scoping review were those articles that presented information on the policies and programs implemented in LATAM to prevent and control BC. Thus, public policies of the country as well as health education campaigns, promotion of healthy lifestyles, timely detection, and identification of environmental and genetic factors were included in this analysis. Figure 1 shows the steps that were followed and the number of articles that were identified in each step of the process explained previously. As a result of the first step, 743 articles were identified.

Figure 1. Document identification, screening, and inclusion.



Stage 3: Selection of Studies

In total, 2 researchers (IMRH and MGLF) participated in the search and obtainment of the 743 articles in the previous stage. Titles and abstracts were then reviewed by a group of 3 authors (IMRH, MGLF, and FATG) to identify those that complied with the eligibility criteria; as the end result, of the 743 articles, 20 (2.7%) were selected. Note that 28 (3.8%) articles were excluded at the selection step as they did not comply with the inclusion criteria after full-text reading, and <1% (4/743, 0.5%) were eliminated at the last step after we analyzed them owing to the same criteria. The first researcher reviewed the entire process.

Stage 4: Data Representation

These 20 articles were then subjected to the data extraction process by the same group of authors (IMRH, MGLF, and FATG plus ARS and MEGC) through specifically designed forms using descriptive statistics and thematic qualitative analysis.

Finally, the articles were organized according to the Specific Action Program for the Prevention and Control of Cancer in Women 2013-2018 [9] and its basic questions (Multimedia Appendix 1). According to this analysis, policies and programs were identified depending on their specific context: geographical, economic, infrastructure, or issues related to BC detection processes.

Stage 5: Classification of Results, Synthesis, and Report

According to the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) group report guide [19], Table 1 presents the 20 studies that were classified according to the three initially posed questions that, from this point onward, will be treated as analysis categories: (1) BC prevention and control policies, with 5 specific themes; (2) type, extent, and scope of said policies and programs, with 6 specific themes; and (3) reference framework for these policies and programs, with 3 specific themes.

All the studies included in this review (20/20, 100%) analyzed the type, extent, and scope of the addressed policy or program. However, only a few of them explicitly analyzed policies and programs for BC prevention and control (17/20, 85%), mentioned the reference frameworks on which they based their analysis (17/20, 85%), or examined the 3 general categories that guided this review (15/20, 75%).

Table 1. Studies included in this review, organized by categories and specific themes for analysis.

Category and themes	Studies
BC[a] prevention and control policies and programs	
Guaranteeing effective access to quality health services	• Agarwal et al [20] • Anderson and Cazap [21] • Bridges et al [22] • Castrezana [23] • González et al [24] • Knaul et al [25] • Niëns et al [26] • Nigenda et al [27] • Robles and Galanis [28] • Torres et al [29] • Ulloa et al [30]
Improving BC detection and care process	• Anderson and Cazap [21] • Bridges et al [22] • González et al [24] • Knaul et al [25] • Martínez et al [31] • Niëns et al [26] • Nigenda et al [27] • Robles and Galanis [28] • Smith [32] • Strasser et al [33]
Establishing BC risk communication strategies	• Anderson and Cazap [21] • Bridges et al [22] • Gervas and Pérez [34] • González et al [24] • Knaul et al [25] • Magaña et al [35] • Martínez et al [31] • Robles and Galanis [28] • Smith [32] • Tapia et al [36]
Focusing on BC prevention and detection actions	• Agarwal et al [20] • Anderson and Cazap [21] • Bridges et al [22] • Castrezana [23] • Corcoran et al [37] • Knaul et al [25] • Niëns et al [26] • Nigenda et al [27] • Robles and Galanis [28]
Developing and disseminating performance evaluations of BC screening programs	• Anderson and Cazap [21] • Gervas and Pérez [34] • Knaul et al [25] • Martínez et al [31] • Robles and Galanis [28] • Smith [32]
Type, extent, and scope of BC prevention and control policies and programs	

Category and themes	Studies
BC prevention and control strategies: best practices in line with the sociodemographic characteristics of the populations	• Agarwal et al [20] • Anderson and Cazap [21] • Bridges et al [22] • Castrezana [23] • Gervas and Pérez [34] • González et al [24] • Knaul et al [25] • Magaña et al [35] • Martínez et al [31] • Niëns et al [26] • Nigenda et al [27] • Robles and Galanis [28] • Smith [32] • Strasser et al [33] • Tapia et al [36] • Torres et al [29] • Valencia et al [38]
Reduction of health gaps according to the epidemiological trends of female cancer and the sociodemographic characteristics of the populations	• Agarwal et al [20] • Anderson and Cazap [21] • Bridges et al [22] • Strasser et al [33] • Torres et al [29] • Gervas and Pérez [34] • Strasser et al [33]
Participation of organized civil society and citizens in processes that improve access to services and actions with political influence (citizen monitoring and supervision)	• González et al [24] • González et al [39] • Knaul et al [25] • Nigenda et al [27] • Ulloa et al [30]
Health service expenses as a responsible investment in relation to the sociodemographic characteristics of the communities	• Agarwal et al [20] • Anderson and Cazap [21] • Bridges et al [22] • Knaul et al [25] • Smith [32] • Strasser et al [33]
Systematic monitoring and evaluation to improve BC programs permanently	• Agarwal et al [20] • Gervas and Pérez [34] • González et al [24] • González et al [39] • Knaul et al [25] • Martínez et al [31] • Nigenda et al [27] • Smith [32] • Strasser et al [33]
Coordinating the institutions of the national health systems to universalize a BC registry information system and its sources with an ethnic focus and gender perspective to improve epidemiological surveillance	• Anderson and Cazap [21] • Bridges et al [22] • González et al [24] • González et al [39] • Knaul et al [25] • Nigenda et al [27] • Robles and Galanis [28] • Strasser et al [33]
Reference framework for BC prevention and control policies and programs	

Category and themes	Studies
International BC prevention and control programs	Agarwal et al [29] Anderson and Cazap [21] Bridges et al [22] González et al [39] Knaul et al [25] Martínez et al [31] Niëns et al [26] Nigenda et al [27] Robles and Galanis [28] Smith [32] Strasser et al [33] Ulloa et al [30] Valencia et al [38]
National development plans and programs	González et al [24] González et al [39] Knaul et al [25] Martínez et al [31] Niëns et al [26] Nigenda et al [27] Strasser et al [33] Torres et al [29] Ulloa et al [30] Valencia et al [38]
Sectorial health plans and programs	Castrezana [23] González et al [24] González et al [39] Knaul et al [25] Martínez et al [31] Niëns et al [26] Nigenda et al [27] Strasser et al [33]

[a] BC: breast cancer.

Results

Quantitative Synthesis

The number of selected studies for each LATAM country was as follows: Argentina (6/20, 30%), Brazil (5/20, 25%), Chile (3/20, 15%), Colombia (4/20, 20%), Costa Rica (2/20, 10%), Cuba (2/20, 10%), Ecuador (1/20, 5%), Mexico (14/20, 70%), Panama (2/20, 10%), Peru (4/20, 20%), Puerto Rico (1/20, 5%), Trinidad and Tobago (1/20, 5%), Uruguay (3/20, 15%), and Venezuela (4/20, 20%). We decided to include a study from Spain (1/20, 5%) [34] as we considered it would be interesting to see how this country, which shares a lot of traditions and culture with LATAM, addressed the BC problem in their female population. Furthermore, some of these studies (14/743, 1.8%) also yielded results from other countries outside LATAM, such as Asia, Australia, Canada, Croatia, Spain and other European countries, India, the Middle East and North Africa, South Africa, and the United States; however, we did not analyze the situation in those countries. We eventually decided to include a study from the United States as it was a systematic review that analyzed the effectiveness of the interventions designed to increase mammography screening in LATAM women residing there.

The number of selected studies by language was 60% (12/20) in English, 40% (8/20) in Spanish, and none in Portuguese. Their general characteristics are shown in Table 2.

The overall objective of each study was analyzed according to their characteristics and design methods. Thus, four different objectives were identified: (1) to generate a guide for the early detection of BC (2/20, 10%), (2) to identify the factors associated with early BC diagnosis (4/20, 20%), (3) to evaluate intervention effectiveness of screening programs or timely detection of BC (9/20, 45%), and (4) to analyze or generate public policies on BC (5/20, 25%).

In addition, of the 20 articles, 4 (20%) reviews and 16 (80%) empirical articles were identified. Of these 16 empirical articles, 11 (69%) were quantitative, and 5 (31%) were qualitative. A total of 40% (8/20) of the studies based their results on international and national health frameworks simultaneously, 30% (6/20) relied exclusively on international health frameworks, and 30% (6/20) relied only on national health frameworks.

Regarding the studies with international health frameworks (14/20, 70%), four sources were specifically identified: (1) the WHO, (2) the International Agency for Research on Cancer, (3) intervention programs from specific countries, and (4) the Breast Health Global Initiative. Only 10% (2/20) of the studies referred to LATAM policies, particularly from the Pan American

Health Organization, which are based largely on WHO guidelines.

By contrast, the 65% (13/20) of studies based on a national health framework included the following sources: (1) BC Action Program of the Ministry of Health of Mexico; (2) guidelines of the United States National Cancer Institute; (3) screening programs for the detection of BC in Spain; (4) national programs for BC attention in Mexico (the National Institute of Statistics and Geography, the Ministry of Health, and the National Population Council); (5) Mexico’s Sectorial Health Program from 2007 to 2012; and (6) Official Mexican Regulation SSA-041-2011-2 for the prevention, diagnosis, treatment, control, and epidemiological surveillance of BC (Table 2).

Table 2. Characteristics of the selected studies.

Study	Country	Objective	Design and methods	Policy or program addressed	Reference framework
Agarwal et al [20]	Mexico, Croatia, South Africa, and India	Identify possible indicators associated with early diagnosis of BC[a] in lower-income countries	Quantitative descriptive study; analysis of presented articles about "Breast Cancer Care in Developing Countries" at the International Surgery Week in Montreal, Canada, 2007	International Breast Surgery Program	International: intervention programs
Anderson and Cazap [21]	Latin America	Develop guidelines for the early detection, diagnosis, and treatment of BC in low- and middle-income countries	Review article; variables analyzed: prevention of BC, early detection (self-examination), diagnosis (clinical examination and mammography), and treatment	Breast Health Global Initiative	International: Breast Health Global Initiative; national: National Comprehensive Cancer Network
Bridges et al [22]	Latin America and lower-income countries (Asia, the Middle East, and North Africa)	Identify and compare BC control strategies in Latin America, Asia, the Middle East, and North Africa to develop a common framework to guide the development of national BC control strategies	Qualitative study; 221 semistructured interviews with specialists from 29 different countries on the capacity to train qualified nurses, research infrastructure, and health education	Action program (identified control strategies in the aforementioned countries)	International: WHO[b]
Castrezana [23]	Mexico	Relate the presence of BC in certain geographic spaces with the convergence of environmental and socioeconomic variables	Quantitative analytical study; period: 2000-2012; women younger than 14 years; geospatial analysis of possible risk factors for the development of BC; multivariate regression	No specific program mentioned	National: Breast Cancer Action Program of the Ministry of Health of Mexico
Corcoran et al [37]	United States	Analyze the effectiveness of interventions designed to increase mammography testing of Latin American women residing in the United States	Systematic review; study period: 2009-2011	No specific program mentioned	National: US National Cancer Institute
Gervas and Pérez [34]	Spain	Analyze the effectiveness of health programs that focus on mammography screening	Quantitative, descriptive, observational study; a health action review on BC	No specific program mentioned	National: BC screening programs in Spain
González et al [24]	Argentina, Brazil, Colombia, Mexico, and Venezuela	Analyze the focus of government actions to apply in legislative and operational terms and identify challenges and deficiencies	Literature review; retrospective study; study period: 1990-2008; 90 articles included	BC detection programs in the countries studied	International: IARC[c]
González et al [39]	Argentina, Brazil, Colombia, Mexico, and Venezuela	Analysis of BC care policies and programs in several Latin American countries	Qualitative exploratory study; models used: Hogwood and Gunn; BC prevalence, incidence, and mortality statistics were analyzed; interviews with key actors in the countries indicated	The policies of each country were analyzed, and main national BC care and control programs were included.	International: PAHO[d] and WHO international reference framework; national: BC national programs of each country
Knaul et al [25]	Mexico	Present world statistics on BC in developing countries, analyze mortality trends in Mexico, and present available data on health care use and access barriers	Descriptive quantitative study based on secondary sources	The Popular Health Insurance Program and the Official Mexican Standard for Cancer Control	International: WHO; national: INEGI[e], Ministry of Health, and CONAPO[f]

Study	Country	Objective	Design and methods	Policy or program addressed	Reference framework
Magaña et al [35]	Mexico	Describe the strategies and actions developed within a training program for the early detection of BC designed for first-level care personnel	Quantitative, experimental, analytical study; evaluation of skills acquired with the training that was implemented from 2008 to 2014	Analyzed the National Medical Education Program for Health Professionals	National: national policies for BC care and control
Martínez et al [31]	Mexico	Analyze BC mortality in Mexico and international recommendations on screening programs; present key aspects of the BC detection and control action program from 2007 to 2012	Qualitative study; health program focused on BC prevention between 2007 and 2012 that covered previous strategies	Breast Cancer Action Program in Mexico from 2007 to 2012	International: WHO and IARC; national: Breast Cancer Action Program in Mexico 2007-2012
Niëns et al [26]	Costa Rica and Mexico	Identify the most cost-effective interventions for BC control in Costa Rica and Mexico from the perspective of medical care	Quantitative study; cost-effectiveness analysis; the average cost-effectiveness ratio of each intervention was calculated	Intervention programs at the IMSS[g] and the Ministry of Health of Costa Rica	International: WHO
Nigenda et al [27]	Argentina, Brazil, Colombia, Mexico, and Venezuela	Analyze the efforts of 5 Latin American countries in the last 15 years to design and implement BC-related policies	Qualitative study; semistructured interviews with key informants from governmental and nongovernmental organizations; analysis of secondary data from publications in magazines, government reports, and official statistics in each country	Public policies for BC care in the countries included	International: WHO; national: from each country
Robles and Galanis [28]	Latin America, Canada, and the United States	Examine BC mortality in Latin American and Caribbean countries; compare with mortality levels in Canada and the United States; evaluate arguments to develop BC screening programs	Quantitative analytical study; vital statistics records; published data from the cancer registry and information available from the PAHO on disease prevention and control programs, health expenditures, and health service organizations in the region of the Americas	PAHO cancer statistics records of the countries included in the study	International: PAHO, WHO, and IARC
Smith [32]	Latin America, North America, the Middle East, Australia, Asia, and Europe	Analyze BC programs and policies in the countries of the 5 global regions of the WHO to propose programs based on the criteria of the WHO and on each country's local contexts (type D)[h]	Review study that analyzed national organized screening policies and programs vs opportunistic screening; only low- to middle-income countries were included in the study	Comparative analysis of organized screening policies and programs vs opportunistic screening, mammography, and BC detection programs	International: WHO; national: from each analyzed country
Strasser et al [33]	Latin America	Highlight structural reforms in health care systems, new programs for disenfranchised populations, expansion of national cancer registries, and policy plans and implementation to improve primary prevention of cancer	Quantitative, descriptive, cross-sectional study; health expenditure variables and fragmentation of health systems were analyzed	Health policies that exist in Latin American countries to prevent and control cancer in general were analyzed	International: WHO; national: policies and regulations of each of the countries included
Tapia et al [36]	Mexico	Show teenager perception of BC campaigns	Qualitative study through 13 focus groups	Several BC prevention and national control programs were analyzed	National: Official Mexican Standard for the prevention and control of BC

Study	Country	Objective	Design and methods	Policy or program addressed	Reference framework
Torres et al [29]	Mexico	Present the patterns of use of female cancer prevention programs during the 2000 to 2012 period: Papanicolaou test, HPV[i] test, and mammography	Quantitative, analytical, cross-sectional study; period: 2000-2012; based on national health surveys	BC screening programs using mammography were analyzed	National: Official Mexican Standard for the prevention and control of BC
Ulloa et al [30]	Mexico	Estimate the cost-effectiveness of the BC screening programs and contribute to the decision-making process about the use of these prevention programs	Quantitative, analytical, comparative study through scenario simulation; analysis focused on estimating survival and mortality as well as relating costs to BC diagnosis	The analyzed programs were simulations based on real parameters	International: WHO; methodology for cost-benefit analysis
Valencia et al [38]	Mexico	Estimate the cost-effectiveness ratio of BC prevention programs	Quantitative, analytical, cross-sectional study based on the Markov model with 4 processes: the natural evolution of BC, BC detection through mammography screening, BC treatment, and dynamics of mortality from other causes	BC prevention and control policies in Mexico were analyzed	International: WHO; national: BC prevention and control programs in Mexico

[a] BC: breast cancer.

[b] WHO: World Health Organization.

[c] IARC: International Agency for Research on Cancer.

[d] PAHO: Pan American Health Organization.

[e] INEGI: National Institute of Statistics and Geography.

[f] CONAPO: National Population Council.

[g] IMSS: Mexican Institute of Social Security.

[h] The type of objective indicated in parentheses in the description of each objective corresponds to the classification made by the authors, which is presented in the *Results* section.

[i] HPV: human papillomavirus.

Qualitative Synthesis

Overview

For a better understanding, the selected studies were analyzed according to the 3 previously defined general categories (Table 3) based on the Specific Action Program for the Prevention and Control of Cancer in Women 2013-2018 [9].

Table 3. Breast cancer care policies and programs reported in the selected studies.

Study	Type	Name of the analyzed public policy and action program	Scope: level of care	Framework
Agarwal et al [20]	Program	The National Breast Cancer Screening Program	First and third level of care	International
Anderson and Cazap [21]	Program	BHGI[a]; NCCN[b]	First, second, and third level of care	International: BHGI; national: NCCN
Bridges et al [22]	Public policy	Breast cancer control strategies in the studied countries; WHO[c]	First, second, and third level of care	International: WHO
Castrezana [23]	Program	Breast Cancer Action Program of the Ministry of Health of Mexico	First level of care	National: Ministry of Health
Corcoran et al [37]	Program	Breast Cancer Action Program of the US Department of Health and Human Services	First level of care	National: US Department of Health and Human Services
Gervas and Pérez [34]	Program	Secondary prevention program; National Cancer Institute of the United States	Second level of care	National: National Cancer Institute
González et al [24]	Public policy and program	Argentina (Early Detection of Genito-Breast Cancer Program and Oncological Diseases Program); Bolivia (Noncommunicable Disease Prevention and Control Management Plan 2005-2009); Brazil (National Cervical and Breast Cancer Control Program "Viva Mulher"); Chile (National Breast Cancer Program); Colombia (National Breast Cancer Program); Mexico (Breast Cancer Action Program 2007-2012); Panama (Comprehensive Women's Health Program); Peru (National Plan to Strengthen Cancer Prevention and Control in Peru); Uruguay (Breast Cancer Early Detection Program); Venezuela (National Breast Cancer Program)	First, second, and third level of care	National: several Latin American countries
González et al [39]	Public policy and program	Argentina (National Cancer Control Program, Breast Cancer Secondary Prevention Subprogram, Compulsory Medical Program, and Program for the Early Detection of Genito-Breast Cancer); Brazil (National Oncology Policy 2439, Comprehensive Women Health Care National Policy, and "Viva Mulher" Program 1998); Colombia (7 Procedures and Interventions Manual and Basic Plan of Care with technical standard for breast cancer detection); Mexico (Specific Action Program); Venezuela (Breast Cancer Control Subprogram)	First, second, and third level of care	International: IARC[d]
Knaul et al [25]	Program	"Oportunidades" program	First level of care	International: WHO; national: INEGI[e], Ministry of Health, and CONAPO[f]
Magaña et al [35]	Public policy	National breast cancer care and control policies	First level of care	National
Martínez et al [31]	Program	Breast Cancer Action Program; Mexico's Sectorial Health Program from 2007 to 2012	First, second, and third level of care	International: WHO and IARC; national: Mexico's Sectorial Health Program
Niëns et al [26]	Public policy	Policies from international organizations	First and third level of care	International: WHO
Nigenda et al [27]	Public policy	Policies from international organizations	First level of care	International: WHO; national: several countries
Robles and Galanis [28]	Public policy	Policies from international organizations	First level of care	International: WHO; national: several countries

Study	Type	Name of the analyzed public policy and action program	Scope: level of care	Framework
Smith [32]	Public policy	Health Insurance Plan of Greater New York; Swedish Board of Health and Welfare; the Breast Health Global Initiative; Mexican Foundation for Education in Prevention and Opportune Detection of Breast Cancer	First level of care	International: WHO; national: several countries
Strasser et al [33]	Public policy	General policies of Latin American countries	First and second level of care	International: WHO; national: several countries
Tapia et al [36]	Program	Alliance with companies; Prevention is in our hands: sit down and explore yourself; Mom, we go together; Save them all and take care! Jalisco wants you alive; Please Touch; mobile units	First level of care	National: Official Mexican Standard for the prevention and control of breast cancer
Torres et al [29]	Program	Breast cancer screening program with mammography, Papanicolaou smear, and HPV[g] test	First and third level of care	National: Official Mexican Standard for the prevention and control of breast cancer
Ulloa et al [30]	Public policy	Methodology for cost-benefit analysis of international organizations	First and second level of care	International: WHO
Valencia et al [38]	Public policy and program	Policies of international organizations; breast cancer prevention and control programs in Mexico	First level of care	International: WHO; national: Ministry of Health

[a] BHGI: Breast Health Global Initiative.

[b] NCCN: National Comprehensive Cancer Network.

[c] WHO: World Health Organization.

[d] IARC: International Agency for Research on Cancer.

[e] INEGI: National Institute of Statistics and Geography.

[f] CONAPO: National Population Council.

[g] HPV: human papillomavirus.

Category 1: BC Prevention and Control Policies and Programs

Overview

The reviewed studies identified that many LATAM countries have developed several BC prevention and control policies and programs. All of them have focused on educational actions and implementing screening tests with different strategies depending on each country's situation. However, we could identify that not all studies presented the results of their implementation, and those that did showed great differences in scope and impact (Table 3). With the applied content analysis, 5 specific themes could be identified (Table 1).

Establishing BC Risk Communication Strategies

The reviews identified the lack of knowledge that the general population has regarding early BC prevention and diagnosis (eg, key symptoms, genetic inheritance, screening methods, time intervals to perform surveillance and control examinations, risk factors, and late clinical stages [22,24,32,34,36]).

Therefore, some studies proposed educational intervention programs for target populations to disseminate useful information and educate the population with the highest BC incidence [22,24,25,34]. In this sense, it is essential to design training programs for health professionals as they are the ones who can educate patients and communities by explaining, for example, what BC is about or by encouraging periodic screening [24,32,35,36].

Focusing on BC Prevention and Detection Actions

On this topic, the selected studies proposed prevention strategies for the community through education on risk factors, exploration methods, and identification of the disease's early signs [20,21,23,26,27], thus highlighting the importance of offering mammography tests at the first level of care (ie, community health centers). Moreover, the need to create official policies and programs to adequately allocate the economic resources for these actions was acknowledged [22,25-28].

Guaranteeing Effective Access to Quality Health Services

A main and frequently mentioned element was the deficient access to quality health services for BC care in women, especially for those who lack economic resources, reside in rural areas, or have a lower academic level [20]. Another identified element was the lack of government funding that would allow, among other things, for the reduction of the BC mortality rate attributable to deficient health service access [27]. In addition, health care centers in rural communities require technology to follow up on probable or confirmed patients as well as computer systems designed for this purpose, which currently do not exist [21,22,24,30].

Improving BC Detection and Care Process

The selected studies referred to the benefits of early BC diagnosis and timely treatment to reduce mortality and increase life quality [25-27,31]. Therefore, they focused on improving detection methods and increasing them in accordance with national and international recommendations (eg, through mammography screening or clinical examination [21,27,28,37]). In addition, the importance of training health professionals to perform BC detection in time was emphasized [32,33].

Developing and Disseminating Performance Evaluations of BC Detection Programs

The studies emphasized the importance of implementing health programs for BC prevention and control. However, only a few presented an impact evaluation even though several were contradictory; that is, the studies by Anderson and Cazap [21], Knaul et al [25], and Martínez et al [31] reported successful programs, whereas others presented only limited results. Therefore, it is necessary to establish evaluation indicators in national programs to know their effectiveness and impact [28,32].

Category 2: Type, Extent, and Scope of BC Prevention and Control Policies and Programs

In total, 6 specific themes were identified in relation to how policies were defined and their content (Table 3), as explained in the following sections.

BC Prevention and Control Strategies: Best Practices in Line With the Sociodemographic Characteristics of the Populations

On this topic, several studies highlighted the relevance of generating health action plans and programs focused on providing quality information to the population about risk factors, screening measures, control and prevention, and treatment but adjusted to age groups and the socioeconomic conditions of women in such a way that the programs and plans comply with specific needs and conform to the best available evidence [22,24,25,31,35,36]. By contrast, they also included the issue of innovation in programs that train new generations of health professionals in the correct identification of BC early stages; the programs must include both a health care component (technical and clinical) and an administrative component to be successful [22-29,31-36,38].

Reduction of Health Gaps According to the Epidemiological Trends of Female Cancer and the Sociodemographic Characteristics of the Populations

The studies referred to the great differences that may exist in several countries regarding women's access to health services depending on their socioeconomic level, whether it is high or low; mortality rates are generally higher in the latter. For example, it is possible that, because of lacking financial resources to obtain an early diagnosis and timely treatment, the region where these women live may not have sufficient technology to provide that, thus forcing them to invest in those services themselves, which could lead patients at risk to decide not to make such investment [20-22,29,33]. Another reason why adequate BC control is not carried out is the lack of mammography equipment in marginalized locations, which compels patients to travel to distant cities and increases the delay in their diagnosis [33,34].

Participation of Organized Civil Society and Citizens in Processes That Improve Access to Services and Actions With Political Influence (Citizen Monitoring and Supervision)

There was consensus regarding the operation of strategies that involve the general population, including remote or marginalized areas, in the design and implementation of BC promotion and prevention programs [27] and the identification of communication deficiencies, provided information, and health services to meet the needs of different age groups as well as adequately use the economic resources assigned by the government to acquire equipment that could really increase the impact of screening [24,25,27,30,39]. An example of this is Brazil, where women of different ethnicities are frequently included in the creation of health programs that focus on improving BC detection and passing on information in their region [27]. By contrast, some civil society initiatives draft policies and define arrangements with organizations in some LATAM countries such as Brazil, Colombia, and Mexico where interaction between legislators, authorities, groups of interest, and the community exists [24,27,39]. However, despite this interaction, more spaces for participation are needed. In these same countries, inclusive participation in the decision-making of governmental and nongovernmental institutions has been proven, whereas, in Venezuela and Argentina, the greatest influence comes from the government.

Health Service Expenses as a Responsible Investment in Relation to the Sociodemographic Characteristics of the Communities

The studies reported high treatment and control costs for patients with advanced BC in public institutions [22] in contrast to the expenses of private institutions that offer screening and control programs that can detect the disease at early stages, which in turn reduces mortality and costs. Another important element is health system saturation in LATAM countries as well as budgetary restrictions, which often lead to treatment delays and favor the progression of the disease [33]. Therefore, the need to invest in programs and action plans according to the context of each country (burden of disease, sociodemographic and epidemiological characteristics, and available resources) was highlighted, and that includes an articulated social response. In this way, the supply of health services could expand, public spending could be reduced, and life quality in communities could improve. Compared with other regions in the world, LATAM in general is not well-equipped to cope with the alarming increase in cancer incidence and the disproportionately high mortality rates [20,33].

Systematic Monitoring and Evaluation to Improve Programs Permanently

The need to establish evaluation standards and parameters for BC screening programs in the community, including physical examination by highly trained health professionals in mammography screenings, is evident as several authors did not approve of screenings performed with only one of these methods because they considered them inefficient [24,34], which implies that the programs must be standardized [27,32,33,39]. As a result of this, it would be possible to measure the effectiveness, costs, and impact of such standards and parameters [31]. The most common mistake in evaluating screening program effectiveness is not recognizing that the general population may be different from the population that is susceptible to screening [20,25].

Coordinating the Institutions of the National Health Systems to Universalize a BC Registry Information System and Its Sources With an Ethnic Focus and Gender Perspective to Improve Epidemiological Surveillance

Through this review, deficiencies in case reporting and registry systems were identified as well as the lack of histopathological reports identifying the BC clinical stage in which women first attended health services, which leads to incomplete clinical records that result in difficult clinical decision-making processes by the health sector to implement a correct strategy for these populations [22,33]. The main factors that generate this situation are (1) lack of reliable data on prevalence and incidence at the national level in most LATAM countries because of the lack of national population-based registries [24,25,39], (2) establishment of quality measures to provide institutions with the necessary equipment to perform diagnoses and reports properly, and (3) clinical underregistration because of the difficulty of achieving early detection [28]. Therefore, achieving reliable statistics, comparative evaluations, high-quality national registries, and epidemiological and ethnic statistics as well as improving the capacity of information systems (eg, the use of technology and adequate data management) is essential [21,27].

Category 3: Reference Framework for BC Prevention and Control Policies and Programs

In this last category, three themes are described detailing the level at which the studies addressed their analysis: (1) international BC prevention and control programs, (2) national development plans, and (3) sectorial health programs. We will review them in detail.

International BC Prevention and Control Programs

This topic brings together most of the health policies, programs, and actions for BC screening and control made by international organizations such as the International Agency for Research on Cancer, which indicates the deficiencies of lower-income countries as opposed to higher-income countries that have better BC control [20,39]. By contrast, it is recognized that most LATAM countries have standards, laws, decrees, and regulations that establish actions and interventions for the early detection, diagnosis, treatment, and follow-up of the population with the disease [20-22,32,33].

In terms of investment, to guarantee screening and treatment coverage for the population and motivate women to participate in screening tests [32], the analysis showed that the greater the access to health institutions, the lower the BC mortality. Among the institutions that design international recommendations, we found the Breast Health Global Initiative [21], which strives to develop guidelines based on economically feasible and culturally appropriate evidence that can be used by countries with limited resources. There is also the Commission on Macroeconomics and Health of the WHO [22,25-28,30,31,33,38], which, based on the gross domestic product, established thresholds where a cost-effective intervention can be considered.

National Development Plans and Programs

Health programs offered in most LATAM countries are designed through government initiatives depending on the structure of their health systems. In countries with fragmented systems such as Mexico, health institutions offer these services [11]. For example, the Institute for Social Security and Services for State Workers offers screening services to populations that belong to the government's workforce, and the Popular Security Program protects populations that have neither of the aforementioned services [24,38,39].

In addition, these studies mentioned health regulations, which include the standards that must be followed to make a proper diagnosis, the average age that patients must be to attend health services, and the treatment that must be offered for each case. In terms of gross domestic product per capita, in 2007, Mexico's expenditure ranged between 0.7 and 1.6 percentage points, which falls within the range of a cost-effective expenditure per life year according to WHO recommendations [25-27].

Some of the implemented programs were also based on national policies, such as the National Program for Sexual Health and Responsible Procreation in Brazil [27]; the Ministerial Resolution 0903 of December 20, 2004, and the 2005-2009 Prevention and Control Plan for Noncommunicable Diseases in Bolivia [24]; Law 19,966, General Regime of Health Guarantees and Supreme Decree 44 of January 2007 in Chile [24]; Resolution 00412 of 2000 and the Technical Standard for the Early Detection of Breast Cancer in Colombia [27]; a set of Benefits of the National Health System based on the 2006 resolution of the National Health Council Directory in Ecuador [24]; the Official Mexican Standard (NOM-041-SSA2-2002) for BC prevention, diagnosis, treatment, control, and epidemiological surveillance in Mexico [29]; the Comprehensive Care Standard for Women, BC Detection Component established in Panama [24]; the Headquarters Resolution 121 in 2008 and the technical-oncological standard for the prevention, detection, and early diagnosis of BC at the national level released in Peru [24]; the Executive Power Decree 202/005 that defines the National Cancer Control Program released in Uruguay [27]; and the Program for the Early Detection of Genito-Breast Cancer and Sexually Transmitted Diseases in Argentina [24]. By contrast, the studies also commented on the deficiencies of health institutions and action programs, which make BC difficult to diagnose in the early stages, and the lack of equipment and human resources to follow up and control this pathology in public institutions [30,31,33].

Sectorial Health Plans and Programs

The selected studies mentioned that health programs with intersectoral involvement chose to divide the action programs, which previously addressed various gynecological pathologies, into specific programs that exclusively treat BC [24,39]. Some mentioned that the process of legitimizing politics through normative action is the one that has advanced the most in the region [31].

Consequently, there is a wide range of extensive and inclusive normative and regulatory frameworks (regarding population and actions to control the disease) as well as clinical management guidelines and protocols agreed upon by health authorities, academic associations, scientists, and civil organizations in all the countries, Mexico in particular [23,27]. Therefore, nongovernmental organizations play an important role in the development and implementation of an integrated response. Although there are several organizations that specialize in BC and work to provide information and raise awareness, this condition seems to be much less integrated in nongovernmental organization programs that provide other types of services to women at risk [25,26,33].

Discussion

Principal Findings

We identified that the studies included in this review analyzed different perspectives on the design and implementation of BC programs and public policies, as reported in the quantitative section of the analysis. The studies focused mainly on risk communication, prevention and timely detection, effective access to health services, improvement of the detection process, and evaluation of screening programs, the latter being the topic that received the least attention. It is useful to generate policies and programs aimed at addressing women's BC problem; however, whether they function properly or have the expected impact in each country and on the sociodemographic characteristics of women must also be evaluated.

BC is an issue of interest to health authorities and governments worldwide. The approach and resources set aside for its attention are similar in different regions, such as Asia, the Middle East and North Africa, Australia, and North America, as reported by Bridges et al [22]. According to these authors, there are 4 themes that comprise the foundation for national BC control strategies in these regions: building capacity, developing evidence, removing barriers, and promoting advocacy. They also found that the discussion of these matters and their dimensions was similar across the regions. However, in Australia and Canada, managing advocacy was discussed more frequently, and organized advocacy was discussed less frequently. On the same line, the experience of local practitioners in different regions is made clear in the comment by Smith [32]: "There is consensus that programs should be designed based on disease burden and available resources, but that even in low resource countries there are opportunities to reduce breast deaths through earlier diagnosis and effective treatment. Screening programs are most effective when they are organized, and program planners should consider WHO criteria and local input data as a basis for tailoring screening programs to the needs of their population." These 2 studies emphasize that the design of new policies and programs should be grounded on the experience of local practitioners, policy makers, and advocacy leaders throughout the regions of the world.

In LATAM countries, the existing barriers that were reported in several studies (9/20, 45%) were the scarcity of funds and the lack of well-prepared human resources to carry out the program's follow-up and to control the disease in public health institutions, as well as the barriers related to the characteristics of the women to whom they are directed and the social determinants that affect them (ie, educational level, marginalized areas, or areas with poor health care accessibility). Furthermore, most LATAM countries still have a fragmented health care system, which involves several separate health coverage schemes and providers. On the one hand, this refers to adequately financed social security systems that insure formally employed people, including cancer treatment coverage. By contrast, there is financially limited health security with poorly managed coverage or without full coverage for the entire population [30]. Finally, there is a large amount of private health services that the population in general can access, even those with low economic resources.

We also found that the situation is not the same for all countries in the region as there are big economic, social, and geographical differences that hinder the implementation of effective programs even though most of the countries have developed BC prevention and control policies in the last 20 years. For instance, according to the World Bank, some of the countries are classified as high-income economies, such as Chile, Uruguay, and, in the case of this review, the United States and Spain. Others belong to upper–middle-income economies, such as Argentina, Brazil, Guatemala, Mexico, and the other 6 countries, and the rest of the region's countries are lower–middle-income economies, such as Bolivia, El Salvador, Honduras, and Nicaragua. No country in the LATAM region is classified as a low-income country [40]. By contrast, some countries have capitalist governments, whereas others have socialist or military governments. Finally, there are large demographic differences as some countries have more than 100 million inhabitants (Brazil and Mexico), whereas other countries have less than 5 million inhabitants (Bahamas, Panama, and Puerto Rico), and their geographical extensions are extremely different as well [40]. All of these elements affect the implementation of policies and programs, and they have a direct impact on BC prevalence and the efficiency with which the problem is addressed. For example, Strasser et al [33] report that countries such as Costa Rica, Chile, Colombia, and Brazil have implemented universal health care systems with high cancer coverage to avoid catastrophic expenses, as well as more screening and detection programs. These countries have reached health coverages of less than 90%, whereas Mexico only covers 45% of its population.

Other indicators, such as palliative care services that reflect the efforts made by some LATAM countries, show that Argentina has recently integrated palliative care courses into training programs; however, Bolivia, El Salvador, Honduras, and Nicaragua still have no specific training in that area. Until recently (2014), there were no action plans, strategies, or policies for cancer care and control in Peru, Ecuador, Belize, Surinam, El Salvador, Panama, and the Dominican Republic; however, they are currently developing national strategies (Peru) or specific programs (El Salvador and Ecuador).

We can point out that the main challenge for LATAM countries is to develop comprehensive and adequately structured BC programs with appropriate resources even though some countries already include them in broader care programs for women [25,27,31,39], such as the initiative proposed by the WHO called the Global Breast Cancer Initiative [41], which aims to reduce BC burden by 25% per year to achieve the goal of saving 2.5 million lives by 2040 and offers guidance to the governments on how to adapt their health care systems and empower preventive measures. Other countries report higher rates of BC detection in late stages [25] owing to the big differences that still exist between different types of insurance coverage for the population, which results in the persistence of fragmented health systems in countries such as Peru, Colombia, and Mexico [33]. Only Brazil, Cuba, and Costa Rica claim to have universal health systems.

To define policies and programs, it is important to consider the predictors of a delayed BC diagnosis. The scoping review by Webber et al [8] reports that the main predictors are those provided by the patient and the diagnosis intervals. This situation is related to the efforts that should be made by health authorities to improve awareness of BC symptoms and encourage disclosure, which could improve timely BC diagnosis as well as provide access to health services for vulnerable groups, all of which should be addressed in programs and policies. These results are similar to what we found in our study. Although studies from countries with high sociodemographic indexes in the American continent, such as the United States or Canada [4], were excluded from this study, those governments and populations are likely to face different pressures regarding access to BC care.

Finally, some of the following are limiting problems that we found in this review: there is no BC follow-up for all women, particularly those belonging to low socioeconomic strata and without health insurance [30]; evidence-based standards must be developed according to the economic and cultural reality of each country [38]; screening programs must be applied to reach an incidence reduction of up to 35% in women who undergo mammography screenings regularly [31]; and, finally, there is limited evidence showing that mammography screening is cost-effective for patients with different income levels [22,25].

Conclusions

LATAM countries have made important efforts to face BC burden and mortality in their populations. However, there is an imperative need to continue those efforts and even develop more programs but based on coherent and comprehensive public policies. In addition, programs and screening efforts should be evaluated after their implementation, and the results should be made publicly available for those who participated and for all women in general in the hope that numbers decrease according to the sustainable development goals [1].

In this context, this review's results will be used to define the grounds for a research project whose purpose is to propose a public policy that supports the design of educational intervention strategies for the open population in Mexico to address the public health problems that were identified in this study. Similarly, this review identified some of the gaps that still exist in public health policies and contribute to the underdevelopment of comprehensive, properly structured, and financed BC programs [24]. Finally, these results, in the end, will be presented to national and international health legislators as a guide to promote the necessary public policies for LATAM countries.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Research questions and operational definitions. Document article identification, screening, and inclusion.
[DOCX File , 15 KB - cancer_v8i3e32370_app1.docx]

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Abbreviations

BC: breast cancer
LATAM: Latin America
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews
WHO: World Health Organization

Edited by A Mavragani; submitted 26.07.21; peer-reviewed by X Li, S Azadnajafabad, MM Rashidi; comments to author 27.11.21; revised version received 13.03.22; accepted 16.05.22; published 06.07.22.

Please cite as:
Ramos Herrera IM, Lemus Flores MG, Reyna Sevilla A, González Castañeda ME, Torres Gutiérrez FA, Crocker Sagastume RC, Robles Pastrana JDD, Vázquez Castellanos JL
Public Policies and Programs for the Prevention and Control of Breast Cancer in Latin American Women: Scoping Review
JMIR Cancer 2022;8(3):e32370
URL: https://cancer.jmir.org/2022/3/e32370
doi:10.2196/32370
PMID:35793130

Review

Web-Based Psychological Interventions for People Living With and Beyond Cancer: Meta-Review of What Works and What Does Not for Maximizing Recruitment, Engagement, and Efficacy

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Abstract

Background: Despite high levels of psychological distress experienced by many patients with cancer, previous research has identified several barriers to accessing traditional face-to-face psychological support. Web-based psychosocial interventions have emerged as a promising alternative.

Objective: This meta-review aimed to synthesize evidence on recruitment challenges and enablers, factors that promote engagement and adherence to web-based intervention content, and factors that promote the efficacy of web-based psychosocial interventions for patients with cancer and cancer survivors.

Methods: We conducted a systematic search of previous reviews that investigated the recruitment, engagement, and efficacy of web-based and app-based psychosocial interventions in adult patients with cancer and cancer survivors. We searched PubMed, CINAHL, PsycINFO, and the Cochrane Library database for relevant literature. The search terms focused on a combination of topics pertaining to neoplasms and telemedicine. Two independent authors conducted abstract screening, full text screening, and data extraction for each identified article.

Results: A total of 20 articles met eligibility criteria. There was inconsistency in the reporting of uptake and engagement data; however, anxiety about technology and perceived time burden were identified as 2 key barriers. Web-based psychosocial oncology interventions demonstrated efficacy in reducing depression and stress but reported weak to mixed findings for distress, anxiety, quality of life, and well-being. Although no factors consistently moderated intervention efficacy, preliminary evidence indicated that multicomponent interventions and greater communication with a health care professional were preferred by participants and were associated with superior effects.

Conclusions: Several consistently cited barriers to intervention uptake and recruitment have emerged, which we recommend future intervention studies address. Preliminary evidence also supports the superior efficacy of multicomponent interventions and interventions that facilitate communication with a health care professional. However, a greater number of appropriately powered clinical trials, including randomized trials with head-to-head comparisons, are needed to enable more confident conclusions regarding which web-based psychosocial oncology interventions work best and for whom.

Trial Registration: PROSPERO CRD42020202633; https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=202633

(JMIR Cancer 2022;8(3):e36255) doi:10.2196/36255

KEYWORDS

cancer; neoplasms; survivors; psychosocial oncology; internet-based intervention; psychosocial intervention

Introduction

Background

The physical, financial, and existential challenges of living with cancer pose significant threats to psychological well-being [1-3]. Up to 52% of patients with cancer report clinically significant psychological distress [2,4], which can affect quality of life (QoL) [5] and is associated with higher mortality in some cancers, even after controlling for age, sex, education, socioeconomic status, BMI, smoking, and alcohol intake [6].

A range of therapeutic approaches are commonly used to support the psychological well-being of patients with cancer and cancer survivors [7,8]. For example, cognitive behavioral therapy (CBT) is currently considered the gold standard treatment for managing distress and improving psychological outcomes in populations living with or beyond cancer [7]. CBT techniques, as applied to patients with cancer and cancer survivors, commonly include psychoeducation, thought monitoring and challenging exercises, and activity planning and pacing activities [8,9]. Other interventions include mindfulness-based interventions and acceptance and commitment therapy [7], as well as meaning-centered psychotherapy, which has particularly promising evidence for patients with advanced cancer [8]. In addition, a growing number of guided self-management interventions aim to support psychological well-being based on the principles of self-determination theory [10,11]. These interventions aim to support the basic needs of patients for autonomy, competence, and relatedness [12].

However, despite the range of available therapeutic options, many patients experience difficulties in accessing traditional face-to-face psychological support [13]. For example, a previous systematic review identified that 17% of patients experienced transport and parking as barriers to psychosocial care [13]. In addition, a recent scoping review further highlighted that distance to the treatment center can increase the likelihood of disengagement with psychosocial support [14]. To overcome these barriers, researchers have increasingly investigated web-based psychosocial interventions for patients with cancer [15], including self-guided app-based programs, self-guided web-based programs, web-based peer support, videoconferencing with a health care professional, and combinations of these approaches [16,17].

Qualitative studies have indicated that cancer survivors have positive attitudes toward internet-based interventions [18,19], and several recent reviews of web-based psychosocial interventions for cancer survivors have been published [20-22]. However, these reviews differ in scope, considering varying populations and differing types of web-based and app-based psychosocial interventions. Consequently, a wide range of conclusions have been reached across existing systematic reviews, varying from negligible effects for QoL [16] to significant effects reported for all studies in which depressive symptoms were described as an outcome [22]. This wide discrepancy establishes a conflicting evidence base.

In addition, there is a dearth of evidence on the factors promoting uptake and engagement with web-based psychosocial interventions for people living with and beyond cancer [23]. Previous evidence examining the uptake of psychological interventions for patients with cancer has found that telephone-based interventions are more popular than face-to-face delivery [24], suggesting that removing barriers related to transport and commuting time may be important [13]. However, it is unclear which features of web-based psychosocial interventions are likely to enhance the perceived utility and acceptability of some interventions. Given the previous evidence of dose-response effects, such that greater module completion is associated with more improved outcomes in web-based interventions [25], it is also important to identify factors that promote greater engagement.

Meta-reviews offer an effective approach for addressing the discrepancies in the existing review findings [26]. In particular, where several recent reviews have been conducted on a single or highly similar topic, meta-reviews allow the integration of data and emergence of consensus to better inform clinical practice and research design decisions [27,28].

Study Aim and Objectives

This meta-review aimed to identify and critically appraise existing systematic reviews of web-based and app-based psychosocial interventions for patients with cancer and cancer survivors. Our specific objectives were to synthesize evidence on the following: (1) recruitment challenges and enablers; (2) factors that promote engagement and adherence; and (3) factors that promote efficacy in improving psychosocial outcomes, including distress, depressive symptoms, anxiety, stress, QoL, and subjective well-being.

Methods

Study Method

We conducted a systematic search to identify existing reviews of web-based and app-based psychosocial interventions for cancer survivors, according to recommended methodological guidance [27]. This systematic meta-review was preregistered on PROSPERO (CRD42020202633).

Search Strategy

We searched PubMed, CINAHL, Cochrane Review Library, and PsycINFO databases. These databases are respectively associated with different search functionalities, such that PubMed and the Cochrane Review Library provide the option to search Medical Subject Headings terms to organize and retrieve records using a common hierarchically organized vocabulary. CINAHL uses a similar but separate taxonomy of content organized under CINAHL Subject Headings. By contrast, PsycINFO does not have functionality for searching records using a standardized vocabulary system. Therefore, we optimized our search terms for each database to best use the functionality offered by each database. Search terms and Medical Subject Headings focused on a combination of neoplasms (and related terms), reviews (and related terms), and internet-based interventions or telemedicine. Multimedia Appendix 1 provides the full search strategy.

We conducted a systematic search on August 5, 2020. We did not specify time limits in our systematic search given that the earliest possible publication of relevant publications was naturally limited by the relatively recent emergence of web-based psychosocial interventions.

Following the identification of eligible articles in our database searches, we screened the reference lists of these articles to identify other eligible articles.

Inclusion Criteria

Articles were eligible for inclusion if they met the Population, Intervention, Comparison, Outcomes, and Study design criteria [29] shown in Textbox 1 and were published in English.

Textbox 1. Inclusion criteria.

Inclusion criteria

- *Population*: adults, defined as participants meeting the minimum age of independent research consent in their respective country (ie, aged 16 or 18 years), who received a diagnosis of cancer at some point in their lives.
- *Interventions*: internet and mobile app-based psychosocial interventions with a primary aim of improving psychological outcomes through the provision of interactive psychological or social support. Information-only or noninteractive psychoeducational resources were excluded.
- *Control group*: studies with any type of control group or single-arm trials without a control group.
- *Outcomes*: psychosocial outcomes including distress, depressive symptoms, anxiety, stress, QoL, and subjective well-being.
- *Study design*: systematic reviews with narrative syntheses or meta-analyses.
- Published in English

Exclusion Criteria

Articles were excluded if they met any of the criteria shown in Textbox 2.

Textbox 2. Exclusion criteria.

Exclusion criteria

- Included data from populations with a current or previous diagnosis of cancer and other clinical groups, where data from cancer populations alone could not be extracted.
- Included data from children and adults, where the data from adult populations alone could not be extracted.
- Included data from studies that combined face-to-face with web-based interventions, where the data from the web-based intervention alone could not be extracted.
- Included interventions that were information-only or exercise-based interventions.
- Were a nonpeer-reviewed publication or book chapter.

Article Screening

After deduplication, title and abstract screening was performed to confirm article eligibility, recording reasons for article exclusion where applicable. Each abstract was independently checked by 2 members of the team.

This process was repeated for articles that had undergone full-text screening. In all, 2 authors (ML and TC) screened the reference lists of eligible articles to identify any additional articles that may not have been identified in the primary systematic search process. We deemed systematic reviews to have an insufficient focus on the Population, Intervention, Comparison, Outcomes, and Study design criteria, where the specificity of the inclusion criteria resulted in the inclusion of only one relevant original study. For example, a systematic review that included only one relevant original study owing to an exclusive focus on CBT-based interventions would be excluded [30]. The exception to this rule was where systematic reviews focused on a specified intervention format (ie, internet-based self-help interventions) [31], given our interest in comparing different modalities of web-based interventions.

Data Extraction

We first piloted our data extraction process to confirm consistency across reviewers. A standardized data extraction form was used to aid independent data extraction (Multimedia Appendix 1). Data extraction for each included paper was conducted in duplicate by 2 members of the review team. Any discrepancies in data extraction were resolved by a third author.

Quality Assessment

The quality of each included review was assessed independently by 2 authors against the 27 PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) statement criteria [32], as shown in Multimedia Appendix 2 [16,17,21,31,33-48]. The PRISMA statement criteria include the assessment of the risk of bias within and across studies. We decided a priori to include all eligible reviews, including those meeting relatively fewer PRISMA criteria, given that these reviews might feasibly contribute to the divergence of findings reported in the literature thus far and were thus relevant to account for in this meta-review. However, although poor-quality reviews were not excluded, our synthesis accounted for relevance and quality in our discussion of similarities and differences reported. We only included articles that performed a systematic search for relevant original studies to minimize the likelihood of selection bias in our data set [49].

Analysis

Narrative synthesis of the results of the included reviews was conducted. This considered the quality of both (1) the systematic review and (2) the original studies included within those reviews. Evidence was synthesized regarding the range of interventions tested; the overall uptake of interventions and factors that promote intervention uptake or trial recruitment; the overall adherence to, and engagement with, interventions reviewed (including facilitating factors for intervention adherence); overall efficacy (including facilitating factors for intervention efficacy); and information on the suitability of outcome assessments. Given that most eligible systematic reviews reported a narrative synthesis of trial outcomes, most of the data included in this study were qualitative in nature. Thus, we opted for an inductive thematic analysis of the review findings, which has been identified as a rigorous method of synthesizing qualitative data while remaining faithful to the original data [50].

Results

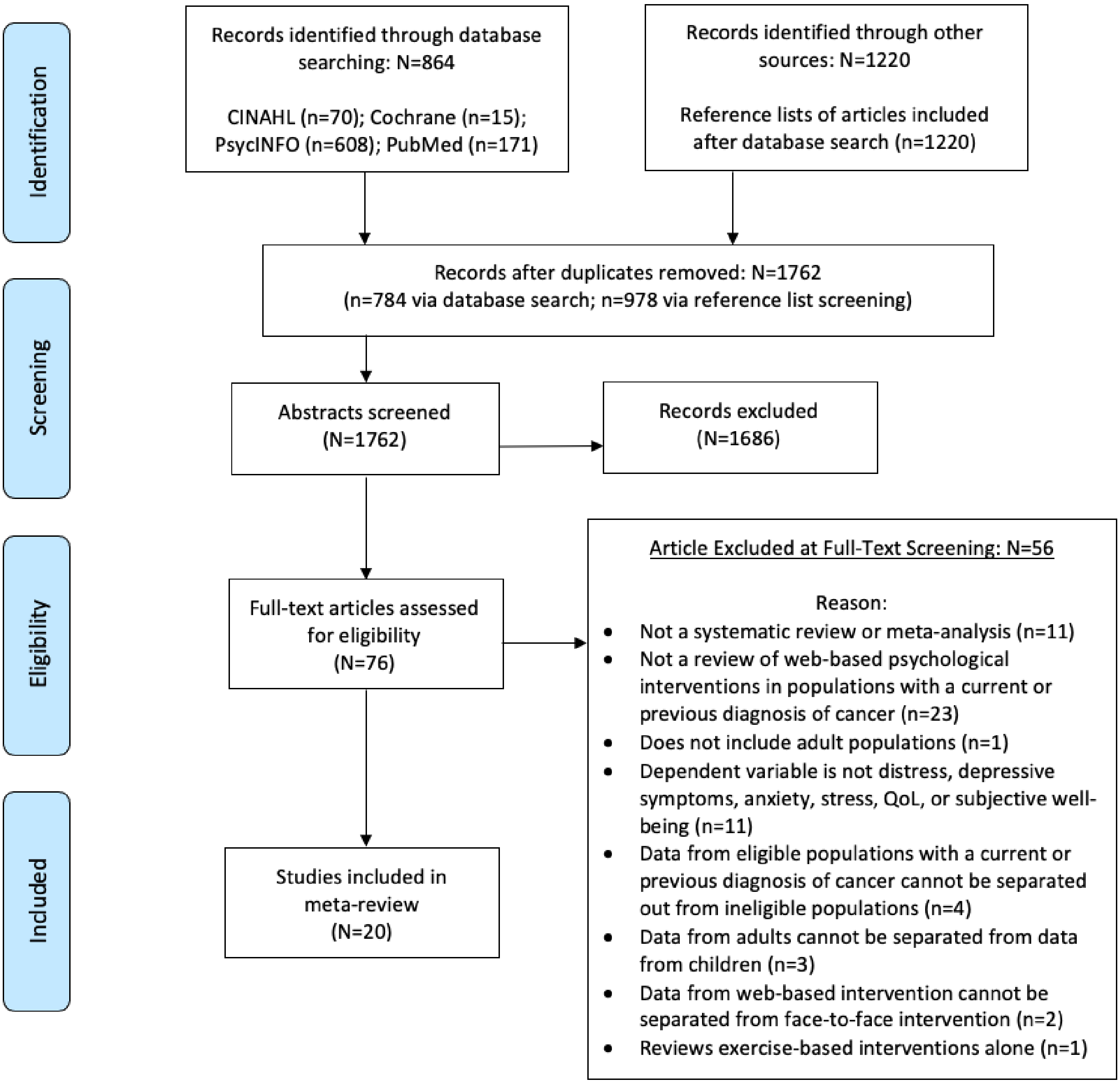
Systematic Search Results

Figure 1 summarizes the screening and eligibility process. The initial search yielded a total of 864 articles. After deduplication (80 articles), 784/864 articles (90.7%) underwent abstract screening. Agreement between reviewers for inclusion and exclusion decisions at the abstract screening stage was 92%, with discrepancies resolved by a third author. A total of 74 articles underwent full-text screening, with a 78% agreement rate between reviewers. Discrepancies at this stage were discussed at an audit meeting of 4 authors (ML, NJHW, LHW, and RP), with final inclusion decisions reached by consensus. A total of 19 reviews were selected for inclusion based on this initial search (Figure 1 provides the reasons for exclusion).

Reference lists of the 19 included articles were examined (N=1220 papers). After removing 242 (19.84%) duplicates, titles of the remaining 978 (80.16%) papers were screened for eligibility. An additional paper identified from the reference lists met the inclusion criteria for this review [33]. Therefore, this meta-review included 20 articles: 5 (25%) meta-analyses, 14 (70%) systematic reviews with narrative synthesis, and 1 (5%) integrative review including both quantitative and qualitative studies. Of the 20 included reviews, 5 (25%) exclusively reviewed randomized controlled trials (RCTs), 4 (20%) reviewed RCTs and quasi-experimental studies, 2 (10%) reviewed RCTs and single-arm feasibility studies, 4 (20%) reviewed both quantitative and qualitative studies, and 5 (25%) did not specify the study design in their inclusion criteria. The year of publication of the included reviews ranged from 2009 to 2020.

Most of the original studies were included in only one review. The full list of original studies included in the systematic reviews, including the frequency with which each study was included in multiple reviews, is presented in Multimedia Appendix 3 [16,17,21,31,33-48,51-57].

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) diagram.



Review Quality

PRISMA items 13, 14, 16, 20, 21, and 23 were deemed not relevant for systematic reviews with narrative syntheses. Therefore, for each paper, we calculated the percentage of applicable PRISMA criteria met, which ranged from 52.4% to 100% (average 77.9%, SD 13.7%, representing moderate review quality) [58]. A total of 6 criteria were met in all 20 papers. Only 4 systematic reviews met criterion 5 (“Indicate if a review protocol exists, if and where it can be accessed [eg, web address], and, if available, provide registration information including registration number”) and 7 met criterion 22 (“Present results of any assessment of risk of bias across studies”). Further details are provided in Table 1.

Table 1. Included reviews.

Study	Number of applicable PRISMA[a] criteria met, n/N (%)	Type of review	Population	Intervention	Comparison	Relevant outcomes captured	Study designs included	Outcome of internet-based psychosocial oncology interventions
Agboola et al [34]	15/21 (71)	Systematic review with narrative synthesis	Patients with cancer	Telephone-based interventions (N/A[b]), telephone-based interventions in conjunction with web-based systems, and web-based interventions	Any	Depression and QoL[c]	RCT[d]	Among internet-based interventions, 4/4 (100%) found improvements in depression and 2/2 (100%) found improvements in health-related QoL.
Beatty and Lambert [31]	16/21 (76)	Systematic review with narrative synthesis	Adults (aged ≥18 years) with a chronic physical health condition	Self-help internet-based psychosocial therapeutic interventions; within cancer: only iCBT[e]	Any	Distress, QoL, and well-being	RCT, quasi-randomized trial, or feasibility RCT study	Did not find significant improvements in distress, QoL, or well-being.
Chen et al [35]	23/27 (85)	Meta-analysis	Patients with breast cancer	Telehealth intervention, defined as that delivered by telephone (N/A), internet-based interfaces, or other remote information systems, which can overcome the barriers of time and distance (N/A)	Usual care alone	QoL, depression, anxiety, distress, and perceived stress	RCT	Meta-analysis found a significant between-group effect for depression but not for QoL.

Study	Number of applicable PRISMA[a] criteria met, n/N (%)	Type of review	Population	Intervention	Comparison	Relevant outcomes captured	Study designs included	Outcome of internet-based psychosocial oncology interventions
Forbes et al [36]	21/21 (100)	Systematic review with narrative synthesis	Prostate cancer survivors	Web-based interventions designed to improve supportive care outcomes	Included single-arm studies and studies with any comparison group	Cancer-related distress, health-related QoL, and depressive symptoms	Single-arm feasibility or acceptability study or randomized trial	Mixed findings for significant between-group effects on distress (1/2, 50% studies). Significant pre-post effects for both depression and QoL but no significant between-group effects for depression and mixed effects for QoL.
Fridriksdottir et al [21]	13/21 (62)	Systematic review with narrative synthesis	Adult patients with cancer	Internet or web-based interventions	Any type of control group (standard care or wait-list or usual face-to-face care or different types of internet-based intervention)	Distress, anxiety, and depression	RCT, pilot RCT, or quasi-experimental studies	Mixed evidence for between-group effects anxiety. Few studies finding significant intervention effects for distress (2/6, 33% studies) and depression (2/7, 28% studies).
Goli ă and Băban [37]	19/21 (90)	Systematic review with narrative synthesis	Adults (aged >18 years) diagnosed with cancer in curative treatment or survivorship phase	Web-based psychotherapeutic interventions	Wait-list, placebo, usual-care, treatment-as-usual, or standard-of-care conditions	Psychological distress and QoL	RCT	In all, 8/11 (73%) studies found significant between-group effects for distress, and 4/10 (40%) studies found significant between-group effects for QoL.

Study	Number of applicable PRISMA[a] criteria met, n/N (%)	Type of review	Population	Intervention	Comparison	Relevant outcomes captured	Study designs included	Outcome of internet-based psychosocial oncology interventions
Griffiths et al [17]	13/21 (62)	Systematic review with narrative synthesis	Individuals part of internet support groups (studies relevant to cancer separated out in results)	Online support groups with a discussion focus on health or psychology	Any or none	Depressive symptoms	Quantitative or qualitative studies	In all, 4/4 (100%) studies without a control group found significant pre-post effects for depression, and 1/3 (33%) with a control group found significant between-group effects.
Hong et al [38]	15/21 (71)	Systematic review with narrative synthesis	Adult cancer survivors	Web-based support or resources	Any or none	Distress, QoL, stress, depression, health-related QoL, psychological well-being, and emotional well-being	Quantitative or qualitative studies	No positive outcomes found for distress, QoL, or well-being compared with control.
Ihrig et al [39]	17/21 (81)	Systematic review with narrative synthesis	Men diagnosed with prostate cancer and their caregivers and significant others	Web-based peer-to-peer support within online support groups or other forms of interactive peer-to-peer communication in social media	Any (eg, face-to-face support groups, psychosocial interventions, standard care, other, or none)	QoL	Not specified	In all, 1/1 (100%) study investigating QoL found significant between-group effects at 6 weeks but not 8 weeks.
Larson et al [40]	20/27 (74)	Systematic review and meta-analysis	Adult patients with cancer, in active treatment	Telehealth or telemedicine, including, but not limited to, telephone calls (N/A) and web-based interventions; focused on emotional support or self-management of symptoms through counseling, educational intervention, or telepsychiatry	Any or none	QoL	Not specified	In all, 1/3 (33%) studies found significant pre-post effects for QoL.

Study	Number of applicable PRISMA[a] criteria met, n/N (%)	Type of review	Population	Intervention	Comparison	Relevant outcomes captured	Study designs included	Outcome of internet-based psychosocial oncology interventions
McAlpine et al [41]	15/21 (71)	Systematic review with narrative synthesis	Adult cancer survivors	Web-based interactive intervention for patient education, to connect patients with each other or connect patients with their health care clinicians	Any or none	QoL, distress, and stress	Not specified	In all, 1/1 (100%) study found favorable results for stress, 1/2 (50%) found favorable results for anxiety, and 3/6 (50%) studies found favorable results for depression. In addition, 0/2 (0%) studies found favorable results for distress, and 2/5 (40%) studies found favorable results for QoL.
Moradian et al [42]	13/21 (62)	Systematic review with narrative synthesis	Adult patients with cancer (aged >18 years) receiving chemotherapy	eHealth, web, and app-based interventions	Any	Health-related QoL, distress, anxiety, and depression	Randomized or nonrandomized controlled trials and pre-post or quasi-experimental intervention studies with a comparison group	Only studies reviewing distress and depression found significant between-group effects. In all, 0/1 (0%) studies found significant between-group effects for QoL, and 1/2 (50%) study found significant between-group effects for anxiety.

Study	Number of applicable PRISMA[a] criteria met, n/N (%)	Type of review	Population	Intervention	Comparison	Relevant outcomes captured	Study designs included	Outcome of internet-based psychosocial oncology interventions
Paul et al [43]	11/21 (52)	Systematic review with narrative synthesis	Patients with common chronic conditions	Web-based interventions designed to improve psychological well-being or QoL	Any or none	Depression, anxiety, QoL, psychological well-being, emotional well-being, and social well-being	Not specified	In all, 2/2 (100%) studies found significant pre-post improvements in depression, stress, and QoL, and 0/2 (0%) studies found positive effects for well-being.
Qan'ir and Song [44]	18/21 (86)	Systematic review with narrative synthesis	Patients with prostate cancer	Technology-based interventions	Any	Depression, anxiety, and QoL	RCT or quasi-experimental research design	In all, 1/4 (25%) study found significant improvements for anxiety, 2/6 (33%) studies found significant improvements for depression, and 1/6 (17%) study found significant improvements for health-related QoL. A study found significant between-group improvement for depression.
Seiler et al [45]	25/27 (93)	Systematic review with meta-analysis	Cancer survivors	eHealth or mHealth[f] interventions	Any or none	Health-related QoL, depression, and psychological distress	RCT, cross - sectional survey, prospective case - control or cohort study, pilot study, longitudinal observational study, or qualitative survey	Meta-analysis found a significant between-group effect for depression and health-related QoL. In all, 1/2 (50%) study found a significant decrease in distress.

Study	Number of applicable PRISMA[a] criteria met, n/N (%)	Type of review	Population	Intervention	Comparison	Relevant outcomes captured	Study designs included	Outcome of internet-based psychosocial oncology interventions
Toivonen et al [33]	19/21 (90)	Systematic review with narrative synthesis	Individuals with chronic physical health conditions	Web-based mindfulness-based interventions	Any or none	Stress and psychological distress	RCTs, non-RCTs, and uncontrolled studies	A study found significant pre-post effects for psychological distress. Another study found significant between-group effects for stress.
Triberti et al [46]	15/21 (71)	Systematic review with narrative synthesis	Patients with breast cancer	Internet-based interventions, support groups, and apps	Any or none	QoL, depression, stress, anxiety, and emotional well-being	Not specified	Overall positive effects found for depression, anxiety, stress, QoL, and emotional well-being.
Wang et al [47]	25/26 (96)[g]	Systematic review and meta-analysis	Patients with cancer	Internet-based psychoeducation interventions	Standard or usual care or a conditional control group	QoL, depression, and distress	RCT or clinical controlled trial	Meta-analysis found significant between-group effects for depression but not distress or QoL.
Xu et al [16]	26/27 (96)	Systematic review and meta-analysis	Adult patients with cancer	eHealth-based health care	Non–eHealth-based control conditions	QoL	RCT	Meta-analysis did not find significant between-group effects for QoL.

Study	Number of applicable PRISMA[a] criteria met, n/N (%)	Type of review	Population	Intervention	Comparison	Relevant outcomes captured	Study designs included	Outcome of internet-based psychosocial oncology interventions
Zhu et al [48]	14/21 (67)	Integrative review	Women with breast cancer	Internet and app-based support and symptom management programs	Any or none	QoL and depression	Quantitative or qualitative studies	In all, 1/2 (50%) study found significant pre-post effects for QoL. A study found that QoL improved more in the control group. A study found a significant between-group effect for depression.

[a] PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

[b] N/A: not applicable.

[c] QoL: quality of life.

[d] RCT: randomized controlled trial.

[e] iCBT: internet-based cognitive behavioral therapy.

[f] mHealth: mobile health.

[g] Item 23 (“Give results of additional analyses, if done [eg, sensitivity or subgroup analyses, meta-regression; see Item 16]”) was not applicable as no additional analyses were conducted in this review.

Participant Characteristics

Reviews included data from an average of 1880 recruited participants (range 62-4084). One review included an analysis of online support groups representing 32,859 users in total. A total of 14 papers reviewed studies of cancer survivors of all disease sites, 3 papers included studies of breast cancer survivors, and 3 papers included studies of prostate cancer survivors. Table 1 provides further details on the population focus of each review.

A total of 7 reviews reported the gender breakdown of the included participants. Of these, 3 (43%) included only women, 2 (29%) included only men, and 2 (29%) were mixed gender (78% and 1034/1220, 84.8% women, respectively). Of the remaining 65% (13/20) reviews, inspection of the original included studies revealed that 6 (46%) included studies mostly or entirely comprised women. Descriptive data for participant demographic characteristics were reported in 13 reviews; the average age of participants in the original studies ranged from 26 years to 69 years, with the most common mean age being between 50 years and 59 years.

Intervention Characteristics

The interventions reviewed included a range of self-guided, clinician-guided, and peer-led approaches, where some interventions combined 2 or more of these approaches into a multicomponent intervention. Most (33/40, 83%) interventions were hosted on self-guided web-based platforms, some of which also facilitated interactions with a clinician or peer group. Other intervention types included web-based videoconferencing with a clinician, online peer support groups, and mobile phone–based symptom management. The full list of interventions represented in the included reviews is available in Multimedia Appendix 3.

Most reviews included at least one study investigating CBT (15/20, 75% reviews), self-determination theory or self-management interventions (14/20, 70% reviews), or interventions focused on increasing access to social support (eg, online peer support groups; 11/20, 55% reviews). Other theoretical frameworks included mindfulness-based approaches, problem-solving therapy, self-efficacy theory, social exchange theory, self-regulatory therapy, therapeutic writing, representational approach, nontheoretically oriented web-based counseling, and combinations thereof (Multimedia Appendix 3). Where reviews focused only on original studies adopting a specific delivery format or theoretical framework, this has been specified in the “Intervention” column in Table 1. None of the reviews explicitly specified a theoretical backdrop in their approach to synthesizing original study data.

Narrative Synthesis

Overview

A true thematic analysis was not possible, as there were insufficient narrative syntheses on uptake, engagement, and our efficacy outcomes of interest to facilitate the identification of convergent codes and themes. Rather than developing convergent codes, we instead categorized the findings and recommendations of each review directly under an inductive thematic structure. Following the initial generation of the thematic structure, themes and subthemes were subsequently audited independently by 2 separate authors to ensure integrity to the original qualitative data set. The final narrative structure was agreed upon through consensus. The following sections will discuss, in turn, the narrative themes identified for intervention uptake, intervention engagement, efficacy, factors promoting efficacy, and recommendations for future research.

Intervention Uptake

The facilitating factors and barriers to intervention uptake and engagement are summarized in Table 2. The dominant theme was difficulties with recruitment. Forbes et al [36] found that 67% (6/9) of the original studies that reported a recruitment goal did not meet their stated recruitment targets, resulting in underpowered analyses. Goli ă and Băban [37] identified several person-related factors predicting greater likelihood of uptake, including education level, being female, being White, and breast cancer diagnosis. However, as 37% (7/19) of the original studies included in the review by Goli ă and Băban [37] only included patients with breast cancer in their eligibility criteria, this finding should be interpreted with caution.

Barriers to intervention uptake were grouped under 2 themes: person factors and contextual factors. Person factors included *greater anxiety around technology*, and contextual factors included *perceived time burden* during an already-stressful period [36,42]. In addition, Moradian et al [42] highlighted that in an original study, 23% of the study participants never logged into the study intervention [51]. Follow-up interviews with the participants of this study revealed several explanations for nonuse of the intervention, including (1) perceived lack of need, given existing access to other resources; (2) preference for telephone or face-to-face over web-based communication with their health care provider; and (3) being put off by aspects of the intervention itself, such as log-in difficulties [59].

Table 2. Facilitating factors and barriers to intervention uptake and engagement[a].

	Facilitating factors	Barriers

Uptake	• Weak evidence for demographic factors
	  • Greater education
	  • Women
	  • White
	  • Breast cancer diagnosis
		• Anxiety around technology
		• Perceived time burden

Engagement	• Tailoring and customizability of the intervention
	• Demographic factors
	  • Younger age
	  • Women
	  • Being married
	  • Greater experience with the internet
	• Email messages and reminders
		• Difficulties with technology
		• Participant clinical profile
		  • Greater fatalism
		  • Poorer coping with anxiety
		  • Less impairment caused by pain
		• Perceived time burden
		• Lack of satisfaction with the intervention

[a] Owing to the paucity of relevant quantitative data in the included reviews, the factors influencing uptake and engagement were identified by extracting narrative syntheses from each review.

Intervention Engagement

The reviews generally reported low dropout rates [35,44]. For example, Qan'ir and Song [44] reported retention rates between 73% and 94% in 8 studies, a retention rate of 31% in 1 study, and 1 study that did not report on participant dropout. Three major themes were found to facilitate intervention engagement: (1) *tailoring and customizability* of the intervention to meet specific needs, (2) participant *demographic* characteristics, and (3) *email messages and reminders*. Regarding tailoring to specific needs, Goli ă and Băban [37] found that interventions focusing on a specific diagnosis or phase of the disease (eg, survivorship) had lower attrition. Greater ability of the participants to customize the intervention to meet their needs and more personalized feedback were also associated with greater retention [37,47]. These findings were supported by qualitative feedback, suggesting that greater provision of cancer-specific information and more personalized feedback, potentially supplemented by telephone or face-to-face contact, were preferred [45]. Regarding participant demographic characteristics, Paul et al [43] found that younger age, being female, being married, and previous experience with the internet predicted greater intervention use. Finally, Wang et al [47] suggested that email reminders may support greater engagement. The importance of including e-messages is further supported by evidence that e-messages and self-care advice are the components most commonly used by patients with low social support and high levels of symptom distress and depression [42,52].

Barriers to intervention engagement included (1) *difficulties with technology*, (2) *participant clinical profile*, (3) *time burden*, and (4) *lack of satisfaction* with the intervention. Paul et al [43] and Seiler et al [45] found that lower levels of computer literacy were associated with lower levels of intervention use. These issues were compounded in some studies by the requirement of additional software and a lack of clarity on how to use unfamiliar software [36]. Griffiths et al [17] highlighted a study, which found that greater fatalism, poorer coping with anxiety, and less impairment caused by pain were associated with a greater likelihood of participant dropout [53].

The finding that perceived time burden was a barrier to intervention use [45,47] maps closely onto similar findings discussed earlier with regard to intervention uptake and relates to reports by some participants that interventions were too difficult to integrate into their daily lives [45]. Finally, a lack of satisfaction with the intervention, including discrepancies with participant expectations [47], and a lack of perceived change in relationships and personal strengths [17] also predicted lower adherence.

Intervention Efficacy

Overview

The key efficacy findings for each study are reported in Table 1, and the summary efficacy findings for each included outcome variable are presented in Table 3. The findings are discussed in further depth in the following sections.

Table 3. Intervention efficacy: proportion of reviews reporting favorable results per outcome.

	Distress (n=9), n (%)	Depression (n=13), n (%)	Anxiety (n=5), n (%)	Stress (n=4), n (%)	Quality of life (n=17), n (%)	Well-being (n=4), n (%)
Mostly favorable outcomes[a]	3 (33)	10 (77)	1 (20)	4 (100)	6 (35)	1 (25)
Mixed findings[a]	1 (11)	1 (8)	3 (60)	0 (0)	2 (12)	0 (0)
Mostly null or negative findings[a]	5 (56)	2 (15)	1 (20)	0 (0)	9 (53)	3 (75)

[a] Mostly favorable outcomes are defined as a majority of studies finding at least significant pre-post effects. Mixed findings refer to reviews where 38% to 50% of the studies found significant pre-post effects. Mostly null or negative findings refer to reviews where <38% (3/8) of the included studies found positive effects.

Distress

In all, 33% (3/9) of the reviews found mostly favorable results for distress reduction, with most (5/9, 56%) reviews reporting mixed findings or null effects. Goli ă and Băban [37] reported that, of the 6 out of 16 studies included in their review which reported clinically significant improvements in distress, only 17% (1/6) of the studies found maintenance of the improvements at the 6-month follow-up, 17% (1/6) of the studies found that benefits decreased over the 6-month follow-up, and 67% (4/6) studies did not investigate long-term maintenance of intervention effect. The results did not clearly indicate an optimum treatment stage or population for addressing distress using internet-based interventions [37]. Fridriksdottir et al [21] reported that of the 3 studies that found significant distress improvement in their review, all (3/3, 100%) were CBT-based interventions including automated information provision, monitoring, feedback, and self-management components.

Depression

A clear majority of reviews [17,34-36,42,43,45-48], including 3 meta-analyses [35,45,47], demonstrated positive effects on depression. Few (3/20, 15%) reviews included a narrative synthesis of efficacy results, with the exception that Forbes et al [36] highlighted a study, which found that web-based CBT was superior to an online chat forum [54]. In addition, Griffiths et al [17] highlighted that most studies reported moderate to large pre-post effect sizes for depression among women with breast cancer, although most of these studies did not include a control group.

Anxiety and Stress

One review reported mostly favorable effects of web-based psychosocial interventions for anxiety [46], 3 found mixed results [21,42], and 1 found mostly null results [44]. By contrast, all 4 reviews including stress as an outcome reported mostly favorable results. The narrative syntheses of the reviews did not offer an explanation for the superior effects found for stress versus anxiety. However, given that few original studies included anxiety and stress as outcome variables, future research is needed to clarify whether these findings indicate true differences in efficacy for these closely related constructs or whether reported efficacy differences may reflect confounding elements of study design.

Quality of Life

Reviews including a narrative synthesis of QoL improvements reported mixed evidence for efficacy. The review that included the largest number of relevant original studies found significant QoL improvement over a control group in 3 out of 10 (30%) studies that fell within the scope of this meta-review [37]. There were no clear intervention factors differentiating studies that found statistically significant effects from those that did not. Indeed, almost all studies investigated a CBT-based intervention, so comparison based on different theoretical frameworks was not possible. However, given that most studies found small to medium effect sizes favoring the web-based interventions, many of these studies may have simply been underpowered to detect small effect sizes.

Well-being

Evidence for the efficacy of web-based psychosocial interventions in improving well-being was weak, with only 1 out of 4 (25%) reviews that included well-being as an outcome finding mostly favorable evidence. The remaining reviews (3/4, 75%) mostly found null results. None of the reviews included a narrative synthesis that specifically pertained to well-being data.

Factors Promoting Intervention Efficacy

We categorized the factors that moderate intervention efficacy into five themes: (1) *study outcomes*, (2) *intervention factors*, (3) *person factors*, (4) *study design*, and (5) *general uncertainty around significant moderating factors*.

Study Outcomes

Regarding study outcomes, 2 reviews reported better outcomes for pain [34] and distress [37] over QoL. Goli ă and Băban [37] proposed that the weaker results reported for QoL may be a function of both the interventions and outcome measures used in the original studies. That is, almost all interventions under investigation were CBT-based, which Goli ă and Băban [37] suggested may prioritize symptom management rather than broader QoL outcomes. Furthermore, inconsistencies in the measurement tools used, including some unvalidated measures for cancer survivors, may render them less appropriate for identifying clinically meaningful changes in this population.

Intervention Factors

There were conflicting findings regarding the efficacy of multicomponent versus single-component interventions. Specifically, Fridriksdottir et al [21] reported that multicomponent interventions were generally associated with superior outcomes for symptom distress, and Triberti et al [46] reported the same findings for QoL, emotional well-being, depression, stress, and anxiety. By contrast, Griffiths et al [17] reported that multicomponent interventions were associated with poorer outcomes for depression. However, given that the finding of Griffiths et al [17] arises from a meta-analysis including populations without a diagnosis of cancer, the findings of Fridriksdottir et al [21] and Triberti et al [46] may be considered more relevant to the aims of this meta-review.

Regarding specific intervention components, the data generally favor interventions that fostered greater communication with a health care professional. For example, the Comprehensive Health Enhancement Support System [55], in combination with remote support from an expert mentor, was generally effective in supporting a range of psychosocial outcomes [46]. Fridriksdottir et al [21] found that a nurse-facilitated email communication forum was the intervention component most valued by participants, being considered both more informative and easier to understand compared with other information provision components. These data suggest that efforts to improve the cost-effectiveness of interventions by minimizing clinician involvement must be balanced against the needs and wishes of cancer survivors.

Griffiths et al [17] assessed the potential moderating effects of several intervention factors that are specifically associated with web-based support. However, this meta-analysis largely yielded null results: intervention efficacy was not moderated by synchronous versus asynchronous chat room engagement, presence versus absence of a chat room moderator, public versus private nature of the support group, length of intervention duration, or length of follow-up. Indeed, the only factor moderating the intervention effect was the degree of engagement, such that greater levels of chat room posting were associated with improved mood. However, this finding is likely confounded by several person-related factors, including strength of motivation and positive expectations for the intervention effect, thus shedding little light on any inherent intervention features that better support psychosocial outcomes.

Person Factors

Several reviews have presented a narrative synthesis of person factors moderating intervention efficacy, including a review that conducted a meta-analysis across populations with and without cancer [17]. No clear demographic or sociodemographic factors emerged that were consistently associated with the intervention outcomes. An original study found that older age and greater baseline distress were associated with greater QoL improvements [60], whereas another original study found that younger age was associated with greater stress reduction [56]. Another original study found that higher emotional communication competence was associated with greater improvements in psychological QoL [57]. However, the overall evidence base assessing the suitability of web-based psychosocial interventions for subpopulations of cancer survivors is limited and is characterized by more null than positive findings.

Study Design

Griffiths et al [17] found a trend for low-quality studies to be associated with more positive outcomes among a clinically heterogeneous sample of people using internet support groups. However, this finding was not replicated in a more recent meta-analysis that focused exclusively on cancer survivors [45]. On balance, the current evidence therefore does not support a clear association between study quality and outcomes.

Uncertainty Around Moderating Factors

The dominant theme that emerged from the reviews was the lack of any identifiable factors that significantly moderated the intervention effect [37,40,41,44]. Several authors of included meta-analyses commented that there were too few directly comparable studies to enable subgroup analysis [40,47], whereas the meta-analyses that quantitatively investigated potential moderators largely failed to identify any statistically significant moderating person or intervention variables for the dependent variables under investigation in this meta-review [16,45]. Exceptions include the findings of Xu et al [16] that the type of control group and duration of the intervention significantly moderated the intervention effect. Comparison against a wait-list or usual-care control group was associated with more favorable effects than against other support controls. The direction of effect regarding study duration was not reported.

Recommendations for Future Research

Our top recommendations for future research are summarized in Textbox 3, categorized according to five main themes: (1) study design, (2) reporting, (3) study outcomes, (4) study samples, and (5) interventions.

Textbox 3. Top recommendations for future research.

Study design

- Conduct randomized controlled trials
- Conduct fully powered studies
- Investigate potential mediators of intervention effect
- Investigate potential moderators of intervention effect
- Include an active comparison group

Reporting

- Report study findings transparently, adhering to CONSORT (Consolidated Standards of Reporting Trials) guidelines
- Report rates of study uptake
- Report rates of participant engagement with the intervention and with data collection procedures

Study outcomes

- Use standardized, validated measures of common study outcomes
- Measure a broader range of outcomes, including patient empowerment, information support, and clinical outcome

Study samples

- Conduct studies across a broader range of national and cultural contexts
- Conduct further research among underserved communities
- Conduct further research in men with advanced cancer

Interventions

- Ensure that intervention content is guided by relevant theory
- Ensure ease of use across mobile and nonmobile devices
- Tailor interventions to specific populations or specific support needs

Study Design

The dominant recommendation to appear across most reviews was a need for a greater number of high-quality clinical trials [16,17,31,33-36,38,39,43-45,47,48]. There was a preponderance of pilot and feasibility studies, which were largely underpowered and often lacked a control group. The review authors thus highlighted a need for fully powered trials to move the evidence base beyond initial feasibility testing and toward efficacy testing of clinically significant benefits for patients and survivors [31,34,38,43,45].

Reporting

Several reviews have highlighted a need for more transparent reporting of clinical trials following the CONSORT (Consolidated Standards of Reporting Trials) guidelines [31,34], including more transparent and consistent reporting of participant intervention engagement [31,33,36,44,45].

The reviews highlighted a lack of investigation into potential mechanisms of intervention effects, with several authors recommending that mediation analyses should be factored into future study designs [21,37,38]. Moderation analyses, including dose-effect responses [21,37,44] and responses to different intervention modalities [33,38,44] are also required. Reviews have also recommended head-to-head clinical trials comparing different types of web-based psychosocial interventions [33,37,43] to more conclusively determine which form of interventions work best and for whom. This would add to the robustness of trial conclusions, given that wait-list control participants are often less likely to seek contemporaneous support, given the anticipation of future therapeutic benefit from the intervention under investigation [30,37]. Paul et al [43] emphasized the importance of ensuring that head-to-head trials are adequately powered to enable subgroup analyses; for example, to assess differential intervention effects for participants with lower versus higher levels of socioeconomic advantage.

Study Outcomes

Reviews also highlighted the need to use validated and standardized measures of common study outcomes (eg, distress, depression, and QoL) so that different clinical trials can be directly compared [34,41]. Reviews have also recommended expanding the scope of future studies to investigate a broader range of outcomes, such as fatigue, empowerment, information support, knowledge, biomarkers of clinical distress (eg, proinflammatory cytokines and salivary cortisol), long-term clinical outcomes, and patient satisfaction [38,44,45,48].

Study Samples

Reviews commonly recommended that future studies should recruit more heterogeneous populations of cancer survivors

[37,38,44], particularly across different national and cultural contexts [38,45,48]. Hong et al [38] specifically noted a lack of research conducted within historically underserved communities, recommending special attention be paid to assessing literacy needs and ensuring the cultural appropriateness of interventions targeting low socioeconomic and minority cultural groups. Finally, reviews also highlighted a literature gap related to men with advanced cancer [36] and suggested that future studies should investigate the moderating effect of gender [44] and disease site [40] on intervention efficacy.

Interventions

The final category of research recommendations relates to the characteristics of the web-based psychosocial interventions under investigation. Recommendations within this category fall into three subcategories: (1) *theoretical considerations*, (2) *intervention modalities*, and (3) *tailoring of interventions to specific needs*. Regarding theoretical considerations, the authors highlighted the importance of ensuring that the intervention content was guided by relevant psychological theory [21,48]. Furthermore, McAlpine et al [41] highlighted the importance of developing a framework for the *process* of developing interventions following a rational approach to compiling intervention content based on recent evidence and the specific needs of the targeted population. Several reviews have recommended that future studies should investigate the utility of app-based psychosocial interventions [31,45] and ensuring ease of use across both mobile and nonmobile devices [45]. It is important to ensure that all intervention platforms are sufficiently user-friendly [44] and able to evolve in line with developments in technology and updates in relevant research [48]. Finally, reviews commonly recommended ensuring that interventions are tailored to the needs of specific patient and survivor groups [33,37], including different phases of cancer treatment and recovery [38,47]. In line with study design recommendations related to investigating mechanisms of effect, reviews also suggested that future studies seek to identify which components of study interventions are necessary to support specific psychosocial and supportive need outcomes [21,33,42,44,47].

Discussion

Summary of Findings

Overview

This meta-review aimed to identify and critically appraise the existing systematic reviews of web-based psychological and psychosocial interventions for adult patients with cancer and cancer survivors. Specifically, our objectives were to identify the factors that support the uptake, engagement, and efficacy of web-based psychosocial interventions for patients with cancer and cancer survivors. A lack of consistency and transparency in reporting uptake and engagement data in the original intervention studies stymied the ability of previous systematic reviews to identify a consistent set of facilitating factors and barriers to intervention uptake and engagement. Nonetheless, we identified some preliminary themes from the few reviews that reported a narrative synthesis of patterns in participant uptake and engagement.

Factors Associated With Recruitment

Many original studies reported difficulties with study recruitment, leading to analyses that were ultimately underpowered [36,37]. Only one review offered a summary of person factors associated with a greater likelihood of intervention uptake, which included greater levels of education, being female, being White, and a breast cancer diagnosis [37]. However, the fact that studies targeting breast cancer were overrepresented in this review poses an important confounder to the interpretation of these data, and we would therefore caution against firm conclusions regarding the predictive power of these demographic factors for intervention uptake.

Two key barriers to recruitment, however, did clearly emerge from the narrative data: (1) individual anxiety about technology and (2) perceived time burden of the intervention [36,42]. Promisingly, these factors can feasibly be addressed by study teams seeking to support recruitment in future web-based psychosocial oncology interventions. For example, authors have previously suggested the possibility of allowing participants to *reduce* or *expand* content to suit their preferences for the amount and depth of content they would like to engage with [61]. Although this suggestion was originally made with the aim of meeting participants' information monitoring needs, advertising this capability may also address participants' concerns about the time burden of web-based psychosocial interventions.

The authors have also highlighted the importance of using a simple and intuitive interface to support participant interest and engagement [62]. In line with these recommendations, we recommend that interventions are co-designed in an iterative manner with research partners with lived experience who are demographically representative of the target population [61]. This component of intervention design is important to optimize interventions before significant resources are invested in conducting randomized clinical trials investigating these interventions.

Factors Associated With Engagement

In contrast to poor levels of intervention recruitment, studies have generally reported high levels of participant retention [35,44]. Overall, participants engage more with interventions tailored to a specific need set and which allow a greater degree of personalization. Thus, although generic interventions aimed at a heterogeneous range of chronic illnesses appear to carry the benefits of general relevance and subsequent cost savings, any such benefits must be weighed against participant preferences for specificity and likelihood of use. Qualitative data highlighted participant preferences for intervention customizability, personalized feedback, and e-messages, which offer a potential solution to common perceptions concerning the impersonal nature of web-based interventions. Nevertheless, greater clinician involvement carries a clear additional resource cost and must be weighed against demonstrable clinical benefits. Offering participants the opportunity to customize the intervention to meet their needs is a technical feature that can be readily built into most intervention platforms and thus represents a simple, cost-effective way to increase the likelihood of intervention engagement.

Regarding clinical profile, Griffiths et al [17] highlighted a study that found that greater fatalism, poorer coping with anxiety, and less impairment caused by pain were associated with a greater likelihood of participant dropout [53]. It is unsurprising that the participants with greater levels of fatalism would hold less hope for the utility of continuing to engage with the study intervention. In addition, one can speculate that participants with lower coping abilities may have required more intensive one-on-one therapy to see benefits rather than the low-level electronic group support offered in the study intervention [52]. At first glance, it may appear counterintuitive that lower levels of impairment caused by pain were associated with higher levels of dropout. One possible explanation is that this finding reflects a lower level of need for support with physical and psychological concerns associated with pain management. Nevertheless, these findings should be treated with caution given that they were endorsed by only one original study.

Furthermore, 50% (2/4) of the top-cited barriers to engagement, difficulties with technology and time burden, are notably shared in common with our list of barriers to intervention uptake. Thus, the strategies highlighted earlier to address these barriers bear additional importance to successfully maintain intervention engagement after initial study consent. Wang et al [47] also highlighted that a lack of satisfaction with specific interventions was associated with a greater likelihood of dropout, emphasizing the importance of qualitative research to better understand the needs, expectations, and preferences of target cancer survivor groups. Researchers can subsequently use this information to minimize discrepancies between participant expectations and actual features of these interventions.

Factors Associated With Intervention Efficacy

Evidence for the efficacy of web-based psychosocial interventions for patients with cancer and cancer survivors was highly mixed, with significant variation between the different patient-reported outcomes included in this review. Overall, reviews have consistently endorsed web-based interventions for reducing depressive symptoms. Indeed, all meta-analyses including depression as an outcome variable found significant improvements compared with controls [35,45,47]. Reviews have also endorsed mostly favorable findings for addressing stress symptoms, although the evidence is relatively weaker given that fewer original studies have investigated stress. By contrast, the evidence for distress, anxiety, QoL, and well-being is weak to mixed, at best. However, this finding should be interpreted in the context of the paucity of studies investigating anxiety and well-being to date and in light of the inconsistency of the measures chosen to assess distress. Therefore, in future research, it would be useful to measure all 4 outcomes using a consistent battery of psychometric tests. For example, the 3 most commonly used measures of psychological distress in patients with cancer are the Profile of Mood States-Short Form [63], Distress Thermometer [64], and Hospital Anxiety and Depression Scale [65], all of which would yield results that are directly comparable with a large number of previous studies [66].

By contrast, QoL was the most consistently reported outcome across reviews, with 35% (6/17) of the reviews reporting favorable outcomes, 12% (2/17) of the reviews reporting mixed results, and 53% (9/17) of the reviews reporting null or negative results. Only one meta-analysis found a statistically significant benefit for health-related QoL [45], whereas the remaining 3 meta-analyses investigating overall QoL reported no significant differences between the intervention and control groups [16,35,47]. Overall, the existing evidence synthesized in this meta-review does not support the efficacy of web-based psychosocial interventions in supporting general QoL among cancer survivors. However, given the noted inconsistency in the methods used to measure QoL across the original intervention studies, with some studies using measures not explicitly created for populations living with and beyond cancer [37], it is premature to conclude that QoL is not affected by web-based interventions. Rather, future research needs to ensure that QoL is assessed using consistent, validated measures to ensure the validity of the research findings. In addition, it may be useful to explore facets of QoL separately to better identify the benefits that web-based psychosocial interventions may hold for specific domains of functioning [45].

Few conclusive factors associated with superior intervention efficacy were identified. With the exception of intervention duration [16], none of the meta-analyses identified any intervention features that significantly moderated the intervention effect [16,35,45,47]. However, our narrative synthesis provides preliminary indications that (1) multicomponent interventions and (2) interventions facilitating internet-based clinician contact are associated with superior outcomes. To ensure the most efficient use of health care resources, it would be useful to incorporate health economic analyses into future clinical trials to determine whether low-level web-based clinician support in combination with other internet-based content (eg, a self-guided website or online support group) may produce more cost-effective benefits than traditional face-to-face support. Further, RCTs investigating head-to-head comparisons of different web-based psychosocial interventions, or different variations of web-based psychosocial interventions, remain necessary to yield conclusive evidence regarding which features of web-based programs work best and for whom.

Recommendations for Future Research

Our top 5 recommendations for future research are, first, for a greater number of fully powered RCTs, to enable more robust conclusions about the efficacy of web-based psychosocial oncology interventions. Second, we recommend that authors of future studies report study uptake, engagement, and study outcomes transparently, adhering to CONSORT guidelines. Third, we recommend the use of outcome measures that have been validated within the target population, with a preference for measures commonly used in previous research to support a more coherent and robust evidence base. Fourth, we recommend investigating web-based psychosocial intervention effects in a broader range of patient populations, including understudied national and cultural cohorts and men. Finally, we recommend interventions that are directly targeted at specific diagnostic groups or support needs, including customizable feedback and features, to encourage greater intervention engagement.

Strengths and Limitations

This meta-review had several strengths, including our ability to identify and account for inconsistencies in the recommendations of previous relevant systematic reviews, resulting in a comprehensive overview of the efficacy of web-based psychosocial interventions for populations living with and beyond cancer. Synthesizing the recommendations of previous reviews has facilitated the compilation of a clear and commonly endorsed set of research recommendations to advance the field of eHealth in psychosocial oncology. Nevertheless, very few reviews have synthesized data on participant uptake and engagement with web-based interventions, rendering our recommendations in these domains tentative, pending further evidence.

With regard to the limitations of this review, our narrative approach to synthesizing previous review findings has limited our ability to conclusively comment on the statistical significance of variables reported to be associated with the uptake, engagement, and efficacy of web-based psychosocial oncology interventions. Nevertheless, we aimed to transparently report the findings of previous quantitative meta-analyses where present, while also comprehensively reporting on the full range of review findings to date, including where these findings are not commensurable with quantitative aggregation.

Conclusions

Our meta-review supports the efficacy of web-based psychosocial oncology interventions for depression and stress, but there is currently insufficient evidence for distress, anxiety, QoL, and well-being. Future research can seek to promote both intervention uptake and engagement by addressing participant anxiety about technology and perceived time burden. Existing evidence suggests that multicomponent interventions and web-based clinician contact promote intervention efficacy. Future studies including head-to-head comparisons, which are fully powered to conduct subgroup analyses, are needed to conclusively establish what works best for maximizing recruitment, engagement, and efficacy.

Acknowledgments

The Finding My Way UK Trial Steering Group includes all the individual authors in this paper, along with Laura Ashley, Neil S Coulson, Eila K Watson, Bogda Koczwara, Peter S Hall, Sue Millington, Jeni Andrews, Valerie Wakefield, Carey MacDonald-Smith, and Mollie Price. The authors would like to thank Laura Ashley, Neil S Coulson, and Eila K Watson for their contributions to the article screening. This meta-review was funded by North West Cancer Research (grant AR2019.08).

Conflicts of Interest

None declared.

Multimedia Appendix 1
Search strategy and data extraction form.
[DOCX File , 27 KB - cancer_v8i3e36255_app1.docx]

Multimedia Appendix 2
PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) checklist for included studies.
[XLSX File (Microsoft Excel File), 16 KB - cancer_v8i3e36255_app2.xlsx]

Multimedia Appendix 3
Breakdown of original studies and intervention types.
[XLSX File (Microsoft Excel File), 30 KB - cancer_v8i3e36255_app3.xlsx]

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Abbreviations

CBT: cognitive behavioral therapy

CONSORT: Consolidated Standards of Reporting Trials
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
QoL: quality of life
RCT: randomized controlled trial

Edited by A Mavragani; submitted 07.01.22; peer-reviewed by S Lippke, C Forbes, G Pravettoni, J Zhu; comments to author 21.02.22; revised version received 12.04.22; accepted 08.05.22; published 08.07.22.

Please cite as:
Leslie M, Beatty L, Hulbert-Williams L, Pendrous R, Cartwright T, Jackson R, The Finding My Way UK Trial Steering Group, Hulbert-Williams NJ
Web-Based Psychological Interventions for People Living With and Beyond Cancer: Meta-Review of What Works and What Does Not for Maximizing Recruitment, Engagement, and Efficacy
JMIR Cancer 2022;8(3):e36255
URL: https://cancer.jmir.org/2022/3/e36255
doi:10.2196/36255
PMID:35802418

Review

Characterizing the Patient Journey in Multiple Myeloma: Qualitative Review

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Abstract

Background: The patient experience of multiple myeloma (MM) is multifaceted and varies substantially between individuals. Current published information on the patient perspective and treatment of MM is limited, making it difficult to gain insights into patient needs regarding the condition.

Objective: In this review, a combined research method approach (ie, the review of published literature and social media posts) was undertaken to provide insight into patients' perspectives on the burden and treatment of MM, the impact of the COVID-19 pandemic, and the impact of MM on caregivers of patients with MM.

Methods: Targeted searches of PubMed and PsycINFO were conducted from November 16, 2010, to November 16, 2020; in parallel, patient-reported information derived from social media posts from 6 patient advocacy websites and YouTube were searched. The review of patient advocacy websites and YouTube targeted patient-reported information from patients with a self-reported diagnosis of MM who discussed their experience of MM and its treatments.

Results: A total of 27 articles and 138 posts were included (patient-reported information included data from 76 individuals), and results from both sources showed that patients experienced a variety of symptoms and treatment side effects, including neuropathy, fatigue, nausea, and back pain. These can affect areas of health-related quality of life (HRQOL), including physical functioning; emotional, psychological, and social well-being; the ability to work; and relationships. Patients valued involvement in treatment decision-making, and both the patient-reported information and the literature indicated that efficacy and tolerability strongly influence treatment decision-making. For patients, caregivers, and physicians, the preference for treatments was strongest when associated with increased survival. Caregivers can struggle to balance care responsibilities and jobs, and their HRQOL is affected in several areas, including emotional-, role-, social-, and work-related aspects of life. The COVID-19 pandemic has challenged patients' ability to manage MM because of limited hospital access and restrictions that negatively affected their lives, psychological well-being, and HRQOL. Unmet patient needs identified in the literature and patient-reported information were for more productive appointments with health care professionals, better-tolerated therapies, and more support for themselves and their caregivers.

Conclusions: The combination of published literature and patient-reported information provides valuable and rich details on patient experiences and perceptions of MM and its treatment. The data highlighted that patients' HRQOL is impeded not only by the disease but also by treatment-related side effects. Patients in the literature and patient-reported information showed a strong preference for treatments that prolong life, and patients appeared to value participation in treatment decisions. However, there remain unmet needs and areas for further research, including treatment, caregiver burden, and how to conduct appointments with health care professionals. This may help improve the understanding of the journey of patients with MM.

Plain Language Summary: Multiple Myeloma (MM) is the second most common cancer that affects blood cells. In this study, researchers wanted to know patients' views on the effects of MM and the treatments they received. Researchers also looked at the impact of the COVID-19 pandemic on patients' treatment and the impact of MM on caregivers. To this end, the researchers reviewed information from 27 published studies and 138 social media posts by 76 patients with MM. Patients commonly reported nerve pain, tiredness, feeling sick, and back pain caused by MM and the treatments they received. The effects of MM and treatments affected patients' physical function; emotional, psychological, and social well-being; ability to work; and relationships. The researchers found that patients wanted to be involved in decisions related to their treatment. The effectiveness against MM and known negative effects strongly influenced the choice of treatments for patients. Increased survival was the strongest factor in the choice of treatment for patients, caregivers, and doctors. Researchers found that the emotional-, role-, social-, and work-related aspects of caregivers' lives were affected by caring for patients with MM. The COVID-19 pandemic also affected the ability of patients to manage their MM because of limited hospital access and the effects of restrictions that impacted their lives and psychological well-being. Finally, the researchers identified some areas requiring improvement, including unproductive appointments with health care professionals, the need for treatments with fewer negative effects, and more support for patients with MM and their caregivers. This information may be useful to improve and understand the experience of patients with MM.

(JMIR Cancer 2022;8(3):e39068) doi:10.2196/39068

KEYWORDS

multiple myeloma; literature review; patient-centered insights; patient experience; patient perspectives; patient-reported information; social media; YouTube

Introduction

Background

Multiple myeloma (MM) is an incurable systemic hematologic malignancy typically characterized by the neoplastic proliferation of plasma cells and the production of monoclonal immunoglobulins from these cells [1,2]. It accounts for approximately 1% of all cancers and, after lymphoma, is the second most common hematologic malignancy, with an age-standardized incidence of 5 in 100,000 cases in the Western world. Most cases occur in patients aged >65 years and develop from a monoclonal gammopathy of unknown significance, with the risk of progression from monoclonal gammopathy of unknown significance to MM estimated at 1% of cases a year [1,3,4]. MM is a heterogeneous disease that is relapsing-remitting in nature; nearly all patients relapse or become refractory to treatment [1,3]. The overall median survival in patients with MM is >5 years but, because of its unpredictable course of progression, some patients go for extended periods without needing treatment, whereas others experience disease progression and rapid decline in health, often not responding to treatment [1,3,5].

Bone destruction, marrow failure, and complex organ dysfunction are some of the consequences of the characteristic neoplastic proliferation of tumor cells in MM, which can lead to a range of symptoms that are amplified and accelerated during relapses, placing a substantial symptom burden on health-related quality of life (HRQOL) [1,2,6]. Furthermore, nonspecific symptoms are common and may be present for extended periods before diagnosis. These can include impaired renal function, anemia, pain, and weight loss [7]. Thus, patients with MM often require informal care (eg, from partners), which can increase the emotional, social, and work impact on both patient and caregiver [8].

The development of a range of therapies for MM over the past 2 decades has led to an improvement in overall survival [4,7]. However, many therapies are associated with detrimental side effects that can severely affect HRQOL [3,9,10]. Patients are often prescribed disease-modifying therapies such as chemotherapy, immunomodulatory agents, and proteasome inhibitors that can cause side effects such as gastrointestinal symptoms, cognitive effects, and substantial neuropathy [3,10,11]. Analgesics such as steroids and opioids are commonly prescribed for pain caused by disease-modifying therapies or MM itself and are associated with cumulative toxicities that can result in side effects such as pain, fatigue, and sleep disturbances [3,9-11]. Consequently, therapeutic management of MM is challenging and is a significant area to consider when assessing disease burden [1,3,5]. The management and burden of cancer has been further complicated by the COVID-19 pandemic (November 2019-present) because of the increased risk of severe infection and its impact on access to health care and medical services. This may be potentially salient for patients with cancer because of their immunosuppressed status caused by chemotherapy or the disease itself; however, there are limited data available [12,13].

As a result of treatment side effects and the complex nature of MM, the patient experience is multifaceted and varies substantially between patients and at different time points of the disease. Published information on the patient perspective of MM and its treatment is limited, making it difficult to gain insights into patient needs regarding the condition [5]. Patient-reported information provides a valuable source of unsolicited data that could help gain a better understanding of the patient perspective. Social media data have been defined as information reported by patients (or caregivers) outside the formal research context relating to their experience of the disease and its treatment [14]. The US Food and Drug Administration guidance has indicated that social media searches may be useful in complementing literature review findings for insight gained regarding the patient experience of symptoms and disease impact [15].

Objectives

This study used a combined research method approach (ie, review of published literature and social media posts) to identify information in the patients' voice on the burden and treatment of MM, the impact of the COVID-19 pandemic, and the impact on caregivers, providing an up-to-date assessment of the burden of MM from the patient perspective.

Methods

Targeted Literature Review

A targeted review of the published literature in PubMed (via the National Library of Medicine Gateway) and PsycINFO was conducted from November 16, 2010, to November 16, 2020, using a study-specific search strategy to identify recent information in the patients' voice on the burden and treatment of MM. The search strategy was limited to the English language and humans and excluded commentaries, letters, and editorials. Titles and abstracts of the identified articles were screened (single screening; 1 reviewer per record), and the most recent articles describing the patient perspective on MM burden, treatment, costs, caregiver burden, and COVID-19 pandemic impact were selected for inclusion. A targeted desktop search of the American Society of Clinical Oncology and the International Society for Pharmacoeconomics and Outcomes Research websites was also conducted to identify relevant data from recent conferences that were not available in PubMed.

Social Media Review

The targeted literature review was supplemented with a targeted review of social media data to identify patient-reported information on the patient experience of MM. A pragmatic Google search was conducted to identify patient advocacy websites hosting patient-contributed content. The Google advanced search function was used to identify web pages that included "multiple myeloma" in conjunction with the following key search terms: "patient narratives," "patient stories," "patient advocacy," and "patient organization." The results were then reviewed to identify MM patient organizations and other websites that might contain patient-reported information that described the patient experience of MM and its treatment. Website content was reviewed for relevant patient-reported information; sites presenting irrelevant patient-reported information were not included. Six relevant patient advocacy organizations were identified: CURE, The Patient Story, PeopleBeatingCancer, Myeloma Crowd, Multiple Myeloma Research Foundation, and Patient Power [16-21]. Their websites provide information and support for people affected by cancer, including interviews conducted with patients, caregivers, and patient advocates focused on specific cancers and treatments. All 6 websites included relevant patient-reported information. Only publicly available information was reviewed, and permission was sought from the organizations to use content from their websites for the review. A search of YouTube was also conducted using "multiple myeloma" in conjunction with key search terms ("patient narratives," "patient stories," "patient journey," and "COVID-19") to identify any further relevant MM-related patient-reported information. YouTube is a global web-based platform where registered users can easily upload and share videos; videos uploaded with "public" privacy settings can be viewed by any internet user. The social media review was conducted during the COVID-19 pandemic (November 2020); thus, it was important that the review was sensitive to the patient lived experience of the pandemic and the potential consequences for their wider HRQOL. The key search terms used to identify patient-reported information within the websites and YouTube are listed in Multimedia Appendix 1.

The review of patient advocacy websites and YouTube targeted patient-reported information from patients with a self-reported diagnosis of MM who discussed their experience of MM and its treatments. Posts were considered eligible for inclusion if they were shared by adults (aged ≥18 years) with a self-reported MM diagnosis, if the adult patient and not a proxy (eg, caregiver, physician, or relative) contributed to the patient-reported information themselves, if the post was in English, and if the content was relevant to patient MM experience and treatment. All video footage and blog posts were manually reviewed to determine eligibility for inclusion in the review. Where available, patient demographic and disease characteristics were extracted manually (annotation-based) from the social media posts. The content of the social media posts was analyzed thematically by independent researchers—one researcher extracted the patient-reported information and used a combined deductive and inductive approach for coding the text; a second researcher reviewed the coded text and discussed any issues with the first researcher (major themes and codes used to analyze the patient-reported information are presented in Multimedia Appendix 2). The results were then summarized based on agreed themes that were derived from the research questions or that emerged from the social media text.

Ethical Considerations

The RTI International Institutional Review Board determined that this study did not constitute research with human participants (STUDY00021421).

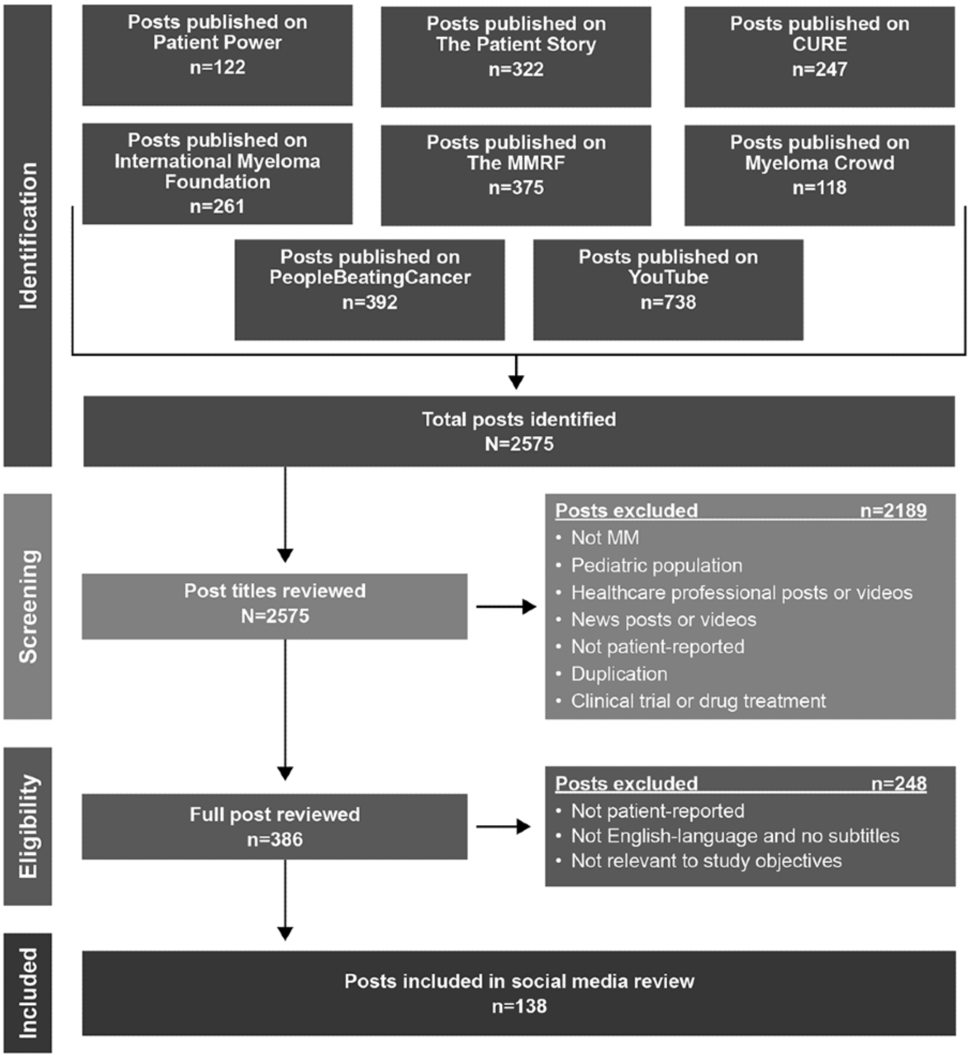
Results

Search Findings

The literature search identified 374 articles, of which 27 (7.2%) relevant ones were selected for potential inclusion in the review. Desktop searches of conference websites identified 5 further abstracts from the American Society of Clinical Oncology and the International Society for Pharmacoeconomics and Outcomes Research. The literature identified covered areas of disease overview and burden to the patient, burdensome symptoms, treatment expectations and goals, patient preferences on treatment attributes, cost burden to the patient, impact on caregivers, decision-making (treatment), adherence, and unmet needs.

The social media review identified 2575 social media posts, which were evaluated against prespecified review criteria, and 138 (5.36%) posts were identified as relevant for the final review (Figure 1): 79 (57.2%) videos (totaling 10 hours, 19 minutes, and 32 seconds of footage), 58 (42%) blog posts, and 1 (0.7%) podcast. The 138 social media posts included patient-reported information from 76 unique contributors, half of whom (n=38, 50%) were male. Age was available for 24% (18/76) of the contributors and ranged from 36 to 71 years.

Figure 1. Social media postidentification flowchart. MM: multiple myeloma; MMRF: Multiple Myeloma Research Foundation.



Key Themes

Table 1 shows a summary of the key themes that emerged from the targeted literature review and social media review.

Table 1. Summary of key topics and themes that emerged from the targeted literature review and social media review.

Topic	Targeted literature review: key themes	Social media review: key themes
Symptom experience of MM[a]	• Pain (back pain and bone pain), fatigue, nausea, and dyspnea	• Pain (back pain, *general pain*[b], *rib pain, sternum pain, hip pain,* and *knee pain*), *neck pain,* and bone pain; *fractures*; fatigue; *infection; lesions;* and *tumors*
Patient HRQOL[c]	• Impact on physical functioning (limitations on physical activity and moving around and increased fatigue and exhaustion) • Impact on role functioning (concerns regarding eating and nutrition) • Impact on social functioning (disrupted day-to-day life because of exhaustion and hospital visits) • Psychological and emotional impact (depression, anxiety, and reduced social satisfaction)	• Impact on physical functioning (restricted physical activity or mobility) • Impact on daily life (day-to-day activities, hobbies and leisure activities, and rest) • Psychological and emotional impact (impact of reaction to diagnosis [devastation and shock], fear of the future, depression, anxiety, denial, frustration, feeling isolated, anger, feeling lost, changed perception of self, and positive emotions [gratitude]) • *Impact on relationships (change in relationships with family and friends, impact on relationship with children, impact on relationship with partner, and partner becoming a caregiver)* • *Impact on work and finances (inability to work, employment issues, and financial burden)*
MM treatment experience	• Type of treatment (opioids, analgesics, chemotherapy, immunomodulatory drugs, proteasome inhibitors, CD38 inhibitors, and steroids) and treatment efficacy (analgesics helped relieve pain but were associated with side effects)	• Type of treatment (*general stem cell transplant,* chemotherapy, *radiation therapy, CAR-T*[d] *therapy, surgery, and clinical trials*), *treatment efficacy (lack of durable efficacy from treatments and quick efficacy from CAR-T treatment), and treatment administration type (infusions were quick and injections were disliked because of bruising)*
Treatment experience	• Treatment impact: • Function and mobility • Uncertainty • Disruption to daily life • Psychological and emotional well-being • Isolation and negative effect on relationships • Financial impact • Sleep disturbances • Treatment side effects: • Neuropathy, tiredness, musculoskeletal pain, fractures, diarrhea, and cognitive impairment • Chemotherapy: gastrointestinal and cognitive side effects (chemo fog) • Opioids: fatigue, constipation, and dizziness • Steroids: pain, fatigue, infections, nausea, and sleep disturbances • Treatment could exacerbate MM symptoms (eg, steroids), and there was an overlap between MM symptoms and side effects • Treatment with opioids was sometimes stopped or reduced to prevent side effects • Experience of treatment side effects can be acute but also chronic	• Treatment impact: • Treatment burden (travel to appointments, isolation from family and friends, cost of medication, and chemotherapy holiday) • *Impact on work (returning to work after treatment and continuing to work while on treatment)* • Treatment side effects: • Neuropathy, fatigue, nausea, infection, chemotherapy-induced cognitive dysfunction (chemo brain or brain fog), sleep disturbance, chemotherapy-induced cardiomyopathy, secondary cancer, graft vs host disease, bone structural problems, water retention, gastrointestinal symptoms, low testosterone levels, blood clots, hair loss, hallucinations, vomiting, diarrhea, headaches, cytokine release storm, rash, low blood pressure, radiotherapy-induced lumbosacral plexopathy, muscle loss, aches, nosebleeds, anemia, general pain, confusion, and forgetfulness • Treatment side effects were long-lasting • *Treatment side effects built up over time* • *Burden of steroid use:* • *Weight gain, sleep disturbances, irritability, acid reflux, increased appetite, fatigue, hyperpigmentation, and anxiety*

Topic	Targeted literature review: key themes	Social media review: key themes
Treatment hopes and preferences	• Treatment hopes: • To increase survival • Treatment preferences: • Increased survival, reduced side effects (physical and cognitive), lower financial impacts, independence, and convenience (home administration) • Caregivers were less cost-sensitive • Physicians were concerned about cost and survival	• *Treatment hopes:* • *Hope to be cured or cancer-free, treatment not being as effective as anticipated, unexpected relapse, and health care professional influence on the patient's expectations* • Treatment preferences: • Caution or skepticism regarding stem cell transplant, fewer drugs, chemotherapy over stem cell transplant, clinical trials to obtain the latest drugs, treatment type and burden, and therapies with a history of good outcomes
Treatment decision-making	• Patients showed a preference for contributing to treatment decisions • Sharing treatment decisions with physicians was preferred by patients who were not treatment-naïve • Trust in health care providers was important for decision-making	• Patient having choice over treatment, physicians deciding treatment, *pressure from physicians regarding treatment choice, choosing to stop treatment, and delaying treatment because of family events*
Patient experience of MM during the COVID-19 pandemic	• Impact on treatment (reduced access to hospitals for administration) • Impact on daily life (pandemic restrictions and boredom) • Emotional impact (anxiety surrounding hospital visits and feelings of loneliness, stress, and missing family)	• Impact on daily life: • Following the COVID-19 guidelines, minimizing time spent outside (eg, walks and shopping), missing out on social life and seeing family and friends, avoiding gyms, and limited information and support from the government • Emotional impact: • Feeling nervous or vulnerable because of MM, feeling safe and confident, worrying about exposure, anxiety, and fear of the immediate future (eg, impact of COVID-19 on cancer) • Impact on treatment: • Treatment as usual, delayed treatment, changes to telehealth medical appointments, adaptations to health services, cautiousness over immunosuppression preparing the patient for COVID-19, and limited or no guidance on treatment delivery updates
Impact on caregivers	• Emotional impact (uncertainty about the future, isolation, stress, and frustration about the disease prognosis and while waiting for test results) • Impact on daily life and work life (hospital visits and running the house restrict time for work and life) • Financial impact (reduced time to work) • Physical impact (tiredness and fatigue) • Strain on relationships (hiding feelings, trying to stay positive, and keeping information from the patient)	• Strain on caregiver and strengthened relationship

[a] MM: multiple myeloma.

[b] The text in italics indicates themes identified in the social media review that were not identified in the literature review.

[c] HRQOL: health-related quality of life.

[d] CAR-T: chimeric antigen receptor T-cell.

The Impact of Disease Symptoms

It is well established that MM is associated with burdensome symptoms, and both the literature (5/27, 19% of the articles) and patient-reported information (44/76, 58% of the patients) identified neuropathy, tiredness, nausea, fractures, and back pain as common MM symptoms [3,10,22-24]. A study that investigated HRQOL concepts reported by patients with MM (N=230) using social media listening methods reported that back pain was a prominent symptom experienced early in the disease course; tiredness, nausea, fatigue, and bone pain were generally reported after MM diagnosis; and neuropathy often came after a relapse [22]. These symptoms affected the physical, functional, emotional, and social aspects of patients' health [23,25]. The patient-reported information (44/76, 58% of the patients) confirmed that symptom burden was an important aspect of the patient experience of living with MM; symptoms were reportedly persistent and had a detrimental impact on patients' HRQOL:

> *Pain, from day to day, is always there, at some level or other, for me.* [Male patient, age not reported; patient-reported information]
>
> *I have fatigue, and people ask me, "Well, how are you able to go out and walk 3, 5 miles, ride your bike, go to the gym?" et cetera. Um, I really push myself, and then I get home, and I collapse.* [Female patient, age not reported; patient-reported information]

Compared with the general population, patients with MM reported a reduced HRQOL [23-25]. A prospective study of patients with MM (n=156) ≤10 years after diagnosis reported that patients experienced substantial symptom burden and poor HRQOL regardless of the time since diagnosis [25]. Both short-term (<5 years) and long-term (≥5 years) survivors had statistically significantly and clinically relevant worse HRQOL scores when compared with a normative population (n=500), and clinically important inferior scores (as measured by the European Organization for Research and Treatment of Cancer Core Quality of Life questionnaire and Multiple Myeloma Module) were greatest for quality of life (42%), physical functioning (42%), role functioning (41%), dyspnea (41%), and social functioning (38%) [25].

Symptoms of MM substantially affect physical function; this limits daily activities and causes psychological distress [24]. Zaleta et al [23] investigated 283 patients with MM using the CancerSupportSource 25-item distress screening tool, which examines physical, social, emotional, and practical concerns. Strongly patient-endorsed concerns regarding MM included eating and nutrition (61%), exercising and being physically active (59%), moving around (56%), and feeling too tired to do things that patients needed or wanted to do (55%). Impaired physical functioning and fatigue were reported by 38% and 33% of patients, respectively. Only 27% of patients reported that they believed that they had control over the course of their MM. Patients also reported impaired psychosocial well-being in areas relating to depression (17%), anxiety (20%), and social satisfaction (29%) [23]. Similar results regarding the debilitating impact of MM on patients' HRQOL emerged from the patient-reported information; Table 2 shows some of the areas of HRQOL affected by MM as well as themes and patient quotes associated with these areas. Over 55% of the patient contributors (44/76, 58%) discussed the impact of MM on various areas of their HRQOL, including physical functioning, emotional and psychological well-being, ability to work, and relationships.

Table 2. Key areas of health-related quality of life (HRQOL) reported by patients with multiple myeloma (MM; source: social media review; N=76).

Area of HRQOL affected	Patients, n (%)	Example of areas of life affected	Quotes from patients with MM from social media
Physical functioning	11 (15)	• Restricted physical activity and mobility • Walking • Stairs • Running and lifting and carrying	"I can't even...sit down or stand up from my laying position. I can only lay down on the bed with limited movement." (Male patient, age NR[a])
Daily activities	9 (12)	• Hobbies and leisure • Sports and fitness • Rest • New "norm"	"I have to limit myself now. That can be a struggle...I don't like not being able to do some of the things I used to be able to do." (Female patient, age NR)
Work finances	8 (11)	• Inability to work • Employment issues • Financial burden	"I had to give up the dream of both starting a health spa...Instead, just surviving multiple myeloma became my full-time job." (Female patient, aged 52 years)
Relationships	13 (17)	• Change in relationships • Change in roles • Lack of understanding • Loss of friends	"It put a lot of stress and strain on our relationship...He [partner] became more of a caregiver while I became a patient." (Female patient, age NR)
Psychological and emotional impact	26 (34)	• Reaction to diagnosis (devastation and shock) • Fear of the future • Uncertainty • Change in self • Mood	"There is a really important psychological aspect to it...If you're feeling down, miserable...you notice your pain a lot more. There's no doubt I do." (Male patient, age NR)

[a] NR: not reported.

The Impact of Treatment

The prognosis of MM has greatly improved in recent years as a result of the changing myeloma treatment landscape, which has seen the development of a range of treatment options. However, according to the published literature, patients on these treatments experience unpleasant side effects or symptoms that they attribute to their medication and that result in negative impacts on patient HRQOL [3,9,10,22]. Results from a study on patient-reported disease- and treatment-related symptoms—which extracted data from a patient-powered research network—noted that neuropathy was the symptom most frequently reported by patients with MM and that patients specifically discussed neuropathy as a consequence of treatment [22].

In total, 11% (3/27) of the published studies described that patients receiving disease-modifying therapy (eg, chemotherapy) experienced physical effects, including severe tiredness, musculoskeletal pain and fractures, and neuropathy that affected overall function and mobility [3,10,26]. Patients also reported gastrointestinal side effects associated with undergoing chemotherapy (including bendamustine, cisplatin, cyclophosphamide, doxorubicin, etoposide, and melphalan). Patients who experienced gastrointestinal side effects were particularly cognizant of their food choices to minimize or avoid the likelihood of experiencing diarrhea, constipation, and nausea. Cognitive side effects, such as "chemo fog," losing their "train of thought," and struggling to retrieve information, were also prominent features of treatment experience with chemotherapy [3,26]. In the patient-reported information, a range of treatments were discussed, including chemotherapy (30/76, 39%), general stem cell transplant (26/76, 34%), radiation therapy (3/76, 4%), chimeric antigen receptor T-cell therapy (2/76, 3%), surgery (2/76, 3%), and treatments in clinical trials (9/76, 12%). Treatment-associated symptoms and the resultant detriments to patients' health were discussed by 29% (22/76) of the patient contributors. The most prominently discussed examples of treatment-associated symptoms were neuropathy (3/76, 4%), fatigue (3/76, 4%), nausea (2/76, 3%), infection (2/76, 3%), chemotherapy-induced cognitive dysfunction (2/76, 3%), sleep disturbance (2/76, 3%), and chemotherapy-induced cardiomyopathy (2/76, 3%).

Since the literature review was conducted, numerous articles have been published discussing patient experience with disease-modifying MM treatment; in these articles, the negative effects attributed to treatment are still being reported [27,28]. In an exploratory investigation into concepts that influenced treatment choices for patients with MM and that analyzed patients (N=30) receiving proteasome inhibitors (66.7%), immunomodulatory drugs (56.7%), chemotherapy (30%; bendamustine, cisplatin, cyclophosphamide, doxorubicin, etoposide, and melphalan), steroids (70%), and CD38 inhibitors (16.7%), peripheral neuropathy (90%) was the most reported symptom attributed to treatment, followed by diarrhea (83%) and cognitive impairment (83%) [28]. Patients also stated that there was an overlap between symptoms of MM and potential treatment side effects, meaning that they were sometimes unsure if symptoms were caused by treatment or MM [28]. A qualitative study by Nathwani et al [29] investigated adult patients with relapsed and refractory MM (RRMM) who had a life expectancy of ≥3 months and had at least one treatment regimen with a proteasome inhibitor and immunomodulator or a steroid in addition to either a CD38 monoclonal antibody or an alkylating agent. At the time of enrollment, patients (N=22) were treated with regimens containing dexamethasone (59.1%), daratumumab (36.4%), carfilzomib (27.3%), and lenalidomide (18.2%). No adverse symptoms of treatment were reported by 27.3% of patients, but back pain and fatigue attributed to treatment were each reported by 40.9% of patients. Treatment-induced physical function limitations (86.4%), emotional impacts (77.3%), MM-related activity limitations (72.7%), and sleep disturbances (63.6%) were reported by most patients [29].

Analgesics are often prescribed for the relief of bone pain owing to MM or pain caused by chemotherapy. However, in both the literature and patient-reported information (7/76, 9% of the patients), patients who had been prescribed opioids reported that they experienced fatigue, constipation, dizziness, and drowsiness, which they associated with their treatment. These treatment-associated symptoms were considered particularly burdensome and affected HRQOL [3,9,10].

The published literature and patient-reported information also identified a range of negative effects that patients associated with the use of steroids. Symptoms such as pain, fatigue, infection, nausea, and sleep and mood disturbances were associated with steroid therapy by patients, particularly those who received dexamethasone [3,9,10]. For some patients, steroid treatment was associated with the exacerbation of symptoms rather than the intended outcome of providing relief [9,22]:

> *Dexamethasone is a steroid and I hated it. It had the opposite effect on me that it should have. It made me exhausted instead of wired. It also made me very puffy, and I had some hyperpigmentation.* [Female patient, age not reported; patient-reported information]

Patients who spent time in the hospital with symptomatic MM (N=21) and had received pain medication were assessed in a study that used semistructured interviews conducted by clinicians [9]. A total of 81% of patients received opioids, 76% took paracetamol, 48% had fentanyl patches, and 33% took oxycodone. Although these therapies relieved patients' pain, patients experienced side effects that included constipation (48%), dizziness (38%), and tiredness and fatigue (38%); almost all treatment-related side effects were rated as severe or moderate. The interviews consisted of questions on pain medications and MM symptoms, and HRQOL was also assessed using items 29 and 30 from the European Organization for Research and Treatment of Cancer Core Quality of Life questionnaire. The pain medication questions focused on side effects directly attributable to patients' analgesic medications. Fentanyl patches were reported to be responsible for the greatest proportion of side effects, followed by codeine, morphine, and oxycodone. A total of 48% of patients reported that they either ceased or reduced the dose of pain medication at some point during their illness owing to treatment side effects; this was most often reported for codeine [9].

The patient-reported information (22/76, 29% of the patients) indicated that the negative effects attributed to treatments varied in intensity, were long-lasting, and could build up over time:

> *My feet are continually numb on the bottom...I mean, it's just—there's little things that drive you nuts, and you can manage to a point, but that's about as far as it goes.* [Male patient, age not reported; patient-reported information]
>
> *I live with 5 serious...long-term and late-stage side effects.* [Male patient, aged 60 years; patient-reported information]

The varying intensity and impact of treatment side effects add uncertainty to patients' lives [3,10]. Maher and de Vries [10] reported that treatment side effects commonly included infection ranging in intensity from the acute setting (eg, a Hickman line infection) to living with chronic neuropathy because of infections. In addition, treatment-induced fatigue disrupted patients' day-to-day lives; patients described the fatigue they experienced as "diabolical," "sheer exhaustion," and feeling "desperately tired," or noted that they were bed-ridden as treatment had the tendency to "take your legs out." These side effects can result in hospital visits or admissions, disruption of daily routines, and impaired well-being [10].

The patient-reported information (14/76, 18% of the patients) included social media posts that discussed the range of limitations and day-to-day life burdens resulting from treatment, including loss of independence (1/76, 1%), diminished psychological well-being (4/76, 5%), disruption because of medical appointments (1/76, 1%), isolation from family and friends (2/76, 3%), and the cost of medication (2/76, 3%). Some patients (2/76, 3%) reported being able to continue working during treatment, whereas others (5/76, 7%) were able to return only after treatment. Patients described taking "treatment breaks" to be free from the negative symptoms associated with treatment so that they could participate in important family activities and life events. The variability in the impact of treatment means that patients are unable to plan for the future and are constantly preoccupied with the threat of physical deterioration [10]. Textbox 1 presents supportive patient quotes from the patient-reported information that illustrate the effect of treatments on patients' day-to-day lives.

Textbox 1. The effect of multiple myeloma treatment on the day-to-day lives of patients (source: social media review; N=14).

Patient-reported treatment effect

- "And then we started with a treatment protocol. Suddenly, your independence is taken away from you. Your entire life is taken away." [Female patient, aged 57 years]
- "Now I've had this window where I haven't had treatment, I realize how much different I feel by it not weighing you down all the time, and frustrating you that you can't do what you want to do." [Female patient, age not reported]
- "During nontransplant times of my life in the past year, or couple months, where I've still been receiving treatments, but they were treatments where I was still able to work, and I was very grateful for that." [Male patient, age not reported]
- "The main reason why I want to take a break [from lenalidomide treatment] is, next month, my son is getting married, and I'm really hoping that this break will help simmer down my stomach, because I certainly don't want to be sick at my son's wedding." [Female patient, age not reported]

Patients' treatment experience can also be influenced by factors such as efficacy and formulation. Of the 76 patients who contributed to the patient-reported information, 41 (54%) discussed treatment experiences—treatment effectiveness, impact on health, and treatment administration were key factors of importance:

> *The doctors that I saw thought that the first transplant would be the best route to go at the time...but unfortunately, 2 months later, the cancer returned.* [Male patient, age not reported; patient-reported information]
>
> *I had come to realize that although chemo had kept me alive for 5 years, it was also slowly destroying my body.* [Female patient, aged 51 years; patient-reported information]

Patients' Treatment Hopes and Preferences

The complex nature of MM treatment can mean that a range of factors affect patients' treatment preferences, including history of efficacy and safety, formulation, and novelty of therapy. However, both the patient-reported information and the published literature asserted that increased life expectancy and tolerability are the most important factors from the patient perspective [3]. Treatment preferences discussed in the patient-reported information were influenced by existing treatment success, the opportunity to be on fewer drugs, previous treatment experience, the type of treatment, the mode of administration, the impact on patients' lives and HRQOL, and the opportunity to experience novel treatments:

> *I would be more willing to trust something that had a long-term track record of success than something new that we really just don't know that much about.* [Male patient, aged 71 years; patient-reported information]
>
> *One of [the] things that I was considering back then was how the treatment was given. And one of the treatments that I chose was an oral treatment, because that allowed me to continue to be employed.* [Female patient, age not reported; patient-reported information]

The literature (4/27, 15% of the articles) reinforced increased survival as the highest priority for treatment [3,26,30,31]. For instance, in 4% (1/27) of the studies, increased survival was rated by patients with newly diagnosed MM or RRMM (N=30) as their top treatment feature [26]. Other important features reported in the published literature included physical side effects, cognitive side effects, financial impacts, and independence [3,26,31]. These additional features were considered by long-term survivors of RRMM as a priority as high as life expectancy [3,26,31]. Neuropathy and cognitive side effects were major concerns for most patients (92% and 94%, respectively) and, thus, were considered important in treatment decision-making [3,26,31]. However, most patients were willing to tolerate some side effects and risks in exchange for treatment benefits, which further emphasized increased life expectancy as an important treatment preference for patients [26].

Treatment preferences can vary among patients with MM, their physicians, and caregivers, as demonstrated in a study by Fifer et al [30]. Caregivers were less cost-sensitive and more concerned with HRQOL than patients, and physicians were generally the most concerned with overall survival and cost. However, all groups valued overall survival as the most important feature of treatment [30].

Patients in the patient-reported information expressed high expectations for treatment outcomes, including the desire for a cure:

> *There is a chance for a cure, but I'm looking for a long remission, drug free.* [Female patient, aged 48 years; patient-reported information]

However, patient expectations regarding high treatment effectiveness were not always met because of unexpected relapses and short remission periods. Consequently, patients were often disappointed and upset following ineffective treatment:

> *I'm really bummed out, 'cause 16 months, I really had thought I was gonna get it down low into a...partial response, and I'm not having that. So it is upsetting to me.* [Female patient, age not reported; patient-reported information]

The attitude of health care professionals also played a role in moderating patients' high expectations for treatment:

> *All of the nurses were really negative; the rounding team that would come around every day...they were kind of lowering my expectations. And I found myself...starting to get a little bit bummed out.* [Male patient, aged 71 years; patient-reported information]

Patient preference and treatment satisfaction can also be influenced by convenience; improved treatment convenience has been shown to be related to preference [26,32]. A study of patients with RRMM (N=160) found that orally administered treatment predicted satisfaction with treatment convenience as patients treated with an all-oral regimen reported statistically significantly higher scores on a convenience scale than patients who received at least one injectable agent ($P<.001$) [32]. Patients also preferred home over hospital administration as it led to improvements in HRQOL, well-being, and activities of daily living because of reduced hospital travel and waiting times [33]. A small study (N=28) of patients treated with subcutaneous or intravenous bortezomib reported that patients may prefer subcutaneous over intravenous administration as the former was reported to be faster and associated with less neuropathy and fewer general side effects. However, no details on this were identified in the patient-reported information, and further research is needed to confirm this finding [34].

Cost to Patients

MM has a multifaceted economic burden, and many patients have some unmet financial needs because of treatment copayments (in some countries) and travel costs, which are often highlighted as a burden. In some European countries and the United States, the treatments received by patients for MM and other comorbidities have a substantial impact on costs, which can often be greater than the patients' ability to pay. The often-unmet financial needs of patients with MM can moderate the relationship between psychological morbidity and HRQOL [32,35,36]. In the United States, a study of 160 patients with RRMM found that treatment copays and the costs associated with visits to the clinic contributed the greatest burden to overall costs [32]. A Portuguese cross-sectional study (N=124) found that 91.9% of previously treated patients with MM reported an unmet financial need, and when financial needs were higher, there was a negative relationship between psychological morbidity and HRQOL [35]. In Finland, an observational study assessed MM-related health care resource use and costs in patients with "active" MM (N=97) treated between 2009 and 2016 [36]. An average travel distance of 35.4 km (approximately 22 miles) was reported for health care visits, which placed a substantial financial burden on patients as the mean per-patient travel costs per 28 days ranged from €75.13 (US $76.42) to €447.99 (US $455.68) [36]. No patient-reported information on the cost of MM to the patient was discussed.

Treatment Decision-making

Patients with MM generally prefer to participate in the treatment decision-making process; evidence from the published literature and patient-reported information suggests that the extent of information available regarding therapy choices and patient confidence in their treating physician are important [37]. Patients were reported to desire a degree of control over their treatment, with a study finding that almost all patients with MM (97%) regarded "involving patients in therapeutic decisions" as important [11]. This was further supported by a study of older patients (aged ≥60 years) with newly diagnosed symptomatic MM (N=20), which found that 95% of patients preferred partial or total control of treatment decisions, 55% preferred sharing control with a physician, and 40% preferred making decisions after seriously considering physician opinions [37].

The patient-reported information supports the perception that patients prefer to participate in treatment decision-making; 25% (19/76) of patients commented on factors related to treatment decisions. Patients expressed a desire to influence treatment decisions but perceived that their views were not always considered. The degree to which patients were able to assert any influence or direct their treatment paths was dependent on external factors, including their own health (5/76, 7% of the patients), relationship with the physician (3/76, 4% of the patients), and available treatment options (5/76, 7% of the patients). Some patients (8/76, 11%) discussed different treatment options with their physicians, whereas 3% (2/76) of the patients reportedly felt pressured to agree to specific treatments. Furthermore, patients reported having to become advocates for themselves in their treatment choices, particularly when they decided to stop or put treatment on hold to participate in family life events:

> *My oncologist gave me 8 different options...We went through the list, the pros and cons of each of those 8 options...It was very important to me to sort of understand what his thinking was and why he liked this option versus that option and so forth.* [Male patient, age not reported; patient-reported information]

A study provided some data to suggest that patients who had previously received treatment for MM showed more of a preference for engaging in increased shared treatment decision-making than treatment-naïve patients [38]. The study used semistructured interviews with patients with MM who had a mean age of 64 years (42% male) and a mean time of 58 months since diagnosis. There were two groups included: (1) patients who had received first-line therapy (n=11) or were in the early relapse phase and (2) patients who had received ≥1 previous lines of therapy (n=10) [38]. As with the patient-reported information, the study reported that trust in one's health care provider was a notable influence on treatment choice for patients on all lines of therapy. However, the first-line group was generally more willing to follow health care provider decisions, whereas the ≥1 previous lines of therapy group considered other sources of information and preferred shared decision-making. Health care professionals discussed treatment factors (eg, efficacy and tolerability) in more general terms with the first-line group but provided more detail to the ≥1 previous lines of therapy group. Although effectiveness and side effects were the greatest influences on patients' treatment preferences, the ≥1 previous lines of therapy group was less concerned with side effects.

Impact of COVID-19

The COVID-19 pandemic has challenged patients' ability to manage their MM by further disrupting their lives, psychological well-being, and HRQOL. The literature review was conducted from 2010 to November 16, 2020; at the time of the review, no articles relating to the impact of COVID-19 on patients with MM were identified. However, the patient-reported information identified 12% (9/76) of the patients who discussed the impact of COVID-19, specifically the fact that the virus exacerbated the psychological impact of MM. Patients expressed concern and anxiety because of their increased vulnerability to infection and, consequently, took additional precautions to limit physical contact with other people:

> *I am hypogammaglobulinemic, as many myeloma patients are. It means that I have virtually no immune system with which to fight any infection, let alone COVID-19.* [Male patient, age not reported; patient-reported information]

Restrictions and a medical focus on COVID-19 also impeded patient treatment because of significant disruptions and delays in medical appointments. Patients in the patient-reported information reported changes to telemedicine appointments, limited or no guidance on treatment delivery updates, and delays to transplantations and suspension of clinical trials of novel MM treatments as effects of COVID-19. However, previous experiences of patients with MM with treatment-related immunosuppression helped with the adjustment to the pandemic-specific social restrictions:

> *Definitely during this current time [having MM has] made things more difficult. I was getting ready to sort of...take back my life in January, but I was having some side effects from the maintenance medication, so it did get pushed back a bit, and then everything closed down. And so I'm still waiting, but I'm used to it now.* [Female patient, aged 35 years; patient-reported information]

It is important to note that, since the literature review was conducted, there has been an increase in the number of articles published on the impact of COVID-19 on patients' disease and treatment experiences for a range of diseases [39-41]. Myeloma Patients Europe published a report in June 2021 on the impact of the COVID-19 pandemic on the health care and lives of people with myeloma and amyloid light-chain amyloidosis and their caregivers. The report identified that living with myeloma in Europe during the pandemic was associated with a number of challenges; approximately 60% of people reported that their treatment was negatively affected during the pandemic. This was particularly true for patients who received their medications in hospitals but less so for those taking oral medications at home. The impact of the COVID-19 pandemic varied in different countries. For example, patients in Belgium stated that hospital services continued as normal, but patients in Romania, Poland, and Scotland reported challenges associated with scheduling appointments and travel restrictions as well as limited hospital access. Some patients also reported that they did not want to visit the hospital because of the risk associated with contracting COVID-19 and that this was an area of stress and anxiety for them. Pandemic restrictions had a substantial impact—a total of 67% of patients and caregivers stated that COVID-19 restrictions negatively affected them. Patients described how social distancing during the pandemic affected their emotional well-being, including feelings of loneliness, anxiety, stress, boredom, and missing friends and family [42].

Impact on Caregivers

Caregivers of patients with MM can experience a substantial impact on their HRQOL as they often neglect their own needs to provide physical and emotional support, which can significantly affect emotional-, role-, social-, and work-related areas of life [8]. In a study of 20 patients with MM and their 16 informal caregivers (mostly spouses), both groups described MM as a "time bomb" because of significant fears and uncertainty about the future [8]. Caregivers reported that they had to stay positive for patients and that there was sometimes a lack of communication between both parties, which led to feelings of isolation and increased the emotional burden. Both groups kept stressful situations regarding MM secret with the aim of protecting the other person, which could stress and strain relationships. The themes and categories contributing to caregiver burden and unmet needs identified in the published literature are reported in Textbox 2 [8].

Textbox 2. Areas of burden and unmet need related to caring for a patient with multiple myeloma for informal caregivers (source: Molassiotis et al [8]).

Practicalities of managing a family member with myeloma and the associated burden for caregivers

- Caregivers experience fear, uncertainty, and frustration surrounding the prognosis of their relative's myeloma, which was associated with a substantial emotional burden.
- Waiting for results from tests and visits to the hospital can add further levels of emotional burden because of stress, nerves, and fear of a sudden decline in the health of their partner or family member.
- Caregivers reported hiding or filtering information from the patient when communicating results about the seriousness of the myeloma.
- Caregivers reported not dwelling on themselves or their own feelings and "putting on a brave face" to stay positive for their partner or other family member.
- The practicalities of myeloma (eg, hospital visits and running the house) restricted daily life and work life, which was associated with a financial and physical burden for the caregivers.
- Caregivers reported feeling like they had a duty to provide care on their own with no outside help.

Areas of unmet need

- Caregivers reported having an unmet need for specific information and communication surrounding the disease and how to properly care for a patient with myeloma.
- There was an unmet need for people or organizations to turn to with problems or questions or for extra support, with caregivers having to rely on family for extra support.
- Caregivers reported an unmet need for someone to talk to for updates on their family member's condition as physicians could be too technical and more interested in the disease than in how the patient was.

Caregivers often assist in managing complex treatment regimens and monitoring side effects, which can cause a range of emotions and anxiety as well as difficulties in balancing care responsibilities and work [43]. In interviews with caregivers of outpatients with MM in Spain (N=12), the following 4 main themes emerged relating to caregiver burden: adapting to a new life because of MM, commitment to the patient, emotional impact, and experiences related to the care and support received [44]. Only 3% (2/76) of the patients who contributed to the patient-reported information noted that partners often took on the caregiver role, which could both positively and negatively affect relationships. Patients were also cognizant of the ongoing stress that their condition put on their partners or caregivers, which placed additional stress on the patient:

> *Unfortunately, he became more of a caregiver while I became a patient. I didn't like that position. I think it brought out a lot of insecurities in me—especially being in a newer marriage. It also has made us stronger throughout the process because we've had to get through us [sic]. We've been able to turn to each other and rely on each other. I trust him more. It's made our connection more solid.* [Female patient, age not reported; patient-reported information]
>
> *My wife bore the brunt of it (diagnosis), and it was so hard on her. I think it was surreal for her. She sold the house, we moved, she was still working, she was traveling to [place name redacted] to see me, trying to take care of our daughter who still lived at home, and so much more. A couple of years ago, I looked at her and said, "I'm okay. You need to refill your tank now. You can't make it 1 more second."* [Male patient, age not reported; patient-reported information]

Discussion

Principal Findings

This review of published literature and social media data provides a unique and valuable combination of information on patient experiences and perceptions of MM and its treatment. A wide range of factors that influence patients' experiences were identified, with the literature and patient-reported information aligning on many aspects. Across the literature and patient-reported information, patients were reported to experience a range of MM symptoms and negative effects from treatment, including neuropathy, fatigue, nausea, and back pain. Symptoms have potentially detrimental effects on HRQOL, and evidence suggested that not only are treatment side effects substantial and long-lasting, but they can also exacerbate symptoms of MM and lead to patients stopping treatment [9,22] (patient-reported information: 22/76, 29% of patients). Both the literature and patient-reported information reported that symptoms and treatment side effects affect areas of HRQOL, including physical functioning; emotional, psychological, and social well-being; the ability to work; and relationships [9]. Furthermore, patients reported economic impacts, and almost all patients reported some form of unmet financial need [32,35,36].

A number of influences can affect MM treatment preference, but both the patient-reported information and literature assert that treatment efficacy and tolerability have a strong influence on treatment decision-making from the patient perspective [3,26,31]. However, increased life expectancy appears to be valued above all else among patients, with evidence from the published literature adding that caregivers and physicians shared this view. Even severe side effects were acceptable in exchange for some treatment efficacy. Owing to heterogeneity in the data, limited sample sizes, and a lack of detail on patient characteristics, conclusions regarding treatment preferences in newly diagnosed MM versus RRMM are limited [26,30,38]. The published literature also suggests that treatment formulation may influence treatment preference, with patients preferring therapy convenience, such as home treatment with reduced travel and treatment duration [26,34]. A desire to be involved in treatment decisions was a strong theme that emerged from both the published literature and patient-reported information [11,37]. Patients valued input on treatment decision-making with physicians as they expressed a desire to share control; however, patients often felt as if their views were not considered [11,37,38]. It may be of value to further explore key themes that emerged from the patient-reported information regarding treatment decisions to investigate if there are additional factors that influence the level to which patients desire to be involved in treatment decisions (eg, whether the line of therapy a patient is on influences their treatment decisions) [38].

Caregivers of patients with MM experience a substantial burden and can struggle to balance care responsibilities and jobs. The published literature and patient-reported information reported that caregiving responsibilities can strain relationships with the patient, but the patient-reported information also found that relationships could be made stronger [8,43-45]. Social media provide patients with platforms to express their opinions and share their experiences in an unstructured way, which can help capture emotions and opinions that may not be captured by traditional research methods. Social media data also allow instant access to unfiltered patient narratives, providing timely information on changes to patients' disease experiences or challenges patients encounter resulting from external events. This was notable in relation to exploring the impact of the COVID-19 pandemic on patients with MM. The patient-reported information included discussion from 12% (9/76) of the patients regarding the impact of COVID-19, whereas, because of the timing of the targeted literature review, only articles that were published before the COVID-19 pandemic were included in the review. This demonstrates the value of patient-reported information in terms of capturing important aspects of the patient experience as they happen in real time. However, the patient-reported information captured was still limited; therefore, future published studies would help confirm the findings of this study. Following the completion of the literature and social media reviews, data were published on the impact of the COVID-19 pandemic on MM; key issues highlighted included limited access to treatment and hospital services as well as the negative effects owing to COVID-19 restrictions, such as isolation and anxiety [42]. The literature review also provided limited evidence on treatment adherence from the patient perspective; some information indicated that adherence to immunomodulatory drugs is good among patients with MM, but published real-world data and patient-reported information were not available [46].

Unmet needs for patients with MM identified in the published literature and patient-reported information included a lack of productive time with health care professionals, with patients stating that earlier access to results and more time for appointments could help reduce anxiety and maximize discussion time [47]. Better-tolerated therapies, particularly with respect to reduced fatigue and peripheral neuropathy, are needed, and gaps in service provision for patients were identified, such as providing support for patients in coming to terms with the chronic nature of MM and providing advice and reassurance for patients and caregivers regarding treatment [47].

Limitations

This combined review has several limitations, one of which is that the quality of the published literature varied and was hard to determine. Some studies included only small populations and no randomization, creating the potential for issues such as selection bias; therefore, conclusions surrounding some of the results presented should be interpreted with caution. Results were also often self-reported by the patients with no clinical validation of disease- and treatment-related factors, which may confound patient-reported outcomes and presents the possibility of confirmation or recall bias. Patients were generally not studied over long periods and, as MM changes over time, the results may not be generalizable to all patients in all settings.

Across the published literature, details regarding disparities in access to health care were lacking, which represents both an unmet need and a limitation. Several studies identified sex, age, ethnicity, and social factors as an influence on the health of patients with MM (ie, findings from studies in which patients of certain populations were overrepresented could be distorted). There were minimal data regarding single patients who live alone, for whom the burden of MM may be heightened. Furthermore, male patients are often overrepresented in MM studies, and wealthier, more educated, and proactive patients generally participate in studies investigating the patient voice. Health disparities could exist for women, patients who are less active in speaking on or addressing their condition, or those who are poorer and less educated [3,8,11,37,45].

Social media data exist outside the formal research context, are not generated to answer a specific research question, and are not regulated or peer-reviewed. There are also limitations in the search being restricted to English-language–only patient-reported information and, in terms of sampling in particular, self-selection bias; social media contributors may include a narrow band of patients who are willing to share their narratives on the web. Social media data are also reliant on patient self-identification and self-reporting, which may not be verifiable. Furthermore, social media data are limited by the availability of patient demographic and clinical characteristics. Age was not reported for all patients included in the study; therefore, it is unknown whether potential age-related aspects of patients' MM and treatment experience may have influenced some of the key themes that emerged from the patient-reported information [28,48].

Conclusions

This study provides valuable and up-to-date information on patient experiences and perspectives regarding the impact of MM and its treatment. Our findings are consistent with recent publications investigating patient perceptions of MM and its treatment [28,48]; patients are affected by side effects and uncertainties in treatment benefits, resulting in psychological and physical burden [48], yet they value some aspects such as the convenience of at-home versus hospital administration [28]. Patient-reported information shared on social networking platforms is unsolicited, publicly available data that can provide insight on the priorities of both patients and caregivers that may not always be captured by more traditional research methods such as interviews or surveys [49]. Furthermore, as patient-reported information is an existing source of data generated independently by individual users, it is not burdened by the limitations associated with interviewer bias or recall challenges [49]. Patient-reported information represents the unfiltered patient voice speaking or writing directly to a web-based audience about the topics of interest and importance to them. Therefore, it may provide a rich source of information about the patient experience that can complement traditional research methods.

The data from this combined review highlighted that the patient journey in MM is multifaceted; patients' HRQOL is impeded not only by the symptoms and progression of the disease but also by treatment-related side effects, which can have a substantial and long-lasting impact on patients' lives. The patient perspective on participation in treatment decisions is an important factor in the journey, and our research shows that, in published literature and on social media, patients appreciate involvement in deciding treatment options. Our review highlights the importance of further understanding patient perspectives on MM as this is an important area for improving the overall quality of care for patients.

Acknowledgments

This research was funded by Pfizer Inc. Employees of Pfizer Inc participated in designing the study, interpreting the data, and writing the manuscript.

Data Availability

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

Authors' Contributions

All authors were involved in the study conception or design or the acquisition, analysis, or interpretation of the data. All authors contributed to the drafting of the manuscript and approved the final version.

Conflicts of Interest

ML, RC, CL, and AH are employees of RTI Health Solutions, and this study was performed under a research contract between RTI Health Solutions and Pfizer Inc. TB, CM, and AN are employees of Pfizer Inc.

Multimedia Appendix 1
Social media review key search terms.
[DOCX File , 16 KB - cancer_v8i3e39068_app1.docx]

Multimedia Appendix 2
Major themes and codes.
[DOCX File , 16 KB - cancer_v8i3e39068_app2.docx]

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Abbreviations

HRQOL: health-related quality of life
MM: multiple myeloma
RRMM: relapsed and refractory multiple myeloma

Edited by A Mavragani; submitted 27.04.22; peer-reviewed by T Lang, G Estey, A Kulanthaivel; comments to author 09.06.22; revised version received 13.07.22; accepted 14.07.22; published 22.09.22.

Please cite as:
Lyall M, Crawford R, Bell T, Mamolo C, Neuhof A, Levy C, Heyes A
Characterizing the Patient Journey in Multiple Myeloma: Qualitative Review
JMIR Cancer 2022;8(3):e39068
URL: https://cancer.jmir.org/2022/3/e39068
doi:10.2196/39068
PMID:36136395

Original Paper

Exploring the Association of Cancer and Depression in Electronic Health Records: Combining Encoded Diagnosis and Mining Free-Text Clinical Notes

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Abstract

Background: A cancer diagnosis is a source of psychological and emotional stress, which are often maintained for sustained periods of time that may lead to depressive disorders. Depression is one of the most common psychological conditions in patients with cancer. According to the Global Cancer Observatory, breast and colorectal cancers are the most prevalent cancers in both sexes and across all age groups in Spain.

Objective: This study aimed to compare the prevalence of depression in patients before and after the diagnosis of breast or colorectal cancer, as well as to assess the usefulness of the analysis of free-text clinical notes in 2 languages (Spanish or Catalan) for detecting depression in combination with encoded diagnoses.

Methods: We carried out an analysis of the electronic health records from a general hospital by considering the different sources of clinical information related to depression in patients with breast and colorectal cancer. This analysis included ICD-9-CM (International Classification of Diseases, Ninth Revision, Clinical Modification) diagnosis codes and unstructured information extracted by mining free-text clinical notes via natural language processing tools based on Systematized Nomenclature of Medicine Clinical Terms that mentions symptoms and drugs used for the treatment of depression.

Results: We observed that the percentage of patients diagnosed with depressive disorders significantly increased after cancer diagnosis in the 2 types of cancer considered—breast and colorectal cancers. We managed to identify a higher number of patients with depression by mining free-text clinical notes than the group selected exclusively on ICD-9-CM codes, increasing the number of patients diagnosed with depression by 34.8% (441/1269). In addition, the number of patients with depression who received chemotherapy was higher than those who did not receive this treatment, with significant differences (*P*<.001).

Conclusions: This study provides new clinical evidence of the depression-cancer comorbidity and supports the use of natural language processing for extracting and analyzing free-text clinical notes from electronic health records, contributing to the identification of additional clinical data that complements those provided by coded data to improve the management of these patients.

(JMIR Cancer 2022;8(3):e39003) doi:10.2196/39003

KEYWORDS

cancer; depression; electronic health records; text mining; natural language processing

Introduction

Background

Cancer continues to be one of the main causes of morbidity and mortality in the world, with approximately 19.3 million new cancer cases in 2020 [1]. Population estimates indicate that the number of new cases will increase in the next 2 decades to 30.2 million cases per year in 2040 [2]. The Global Cancer Observatory estimated that breast, prostate, and colorectal cancers were among the most frequent cancers in 2020 [3]. The Global Cancer Observatory pointed out that in Spain, with a population of 46,754,783, the most prevalent cancers in both sexes and across all age groups were colorectal (14.3%, 40,441/282,421) and breast (12.1%, 34,088/282,421) cancers [2,4]. With the advances in treatment efficacy, cancer is being increasingly viewed and treated as a chronic disease that can be effectively managed for many years [5].

A cancer diagnosis is life-changing; it is a source of important psychological and emotional stress, which is usually maintained for sustained periods of time that may lead to depressive disorders [6]. Depression is one of the most common psychological conditions experienced by patients with cancer [6-9], a frequent comorbidity [6], and one of the factors impairing the life quality of these patients [10]. Depressive disorders are related to psychophysiological side effects, poorer treatment outcomes [6,9], longer hospital stays [6,11], higher mortality rates [5,8], and poorer quality of life [6]. The prevalence of depressive disorders in patients with cancer depends on different aspects such as cancer type and stage, diagnostic criteria applied, or population studied [7]. In patients with cancer, the prevalence of depression is 2 to 3 times higher than in the general population [10,12-14], and in some studies, depression is associated with worse overall survival rates due to impaired immune response and higher rates of suicide in patients with cancer [10,15,16]. Depression is also one of the most common mental disorders among patients with breast and colorectal cancers [17-20], affecting their daily lives and deteriorating the quality of life [18,21]. The consequence of this mental disorder affects patients during cancer treatment and endures beyond the end of the treatment [20,22]. Moreover, depression remains an underdiagnosed disease in patients with cancer and is markedly different from depression in healthy individuals [6,23]. The different symptoms of cancer and its treatment, such as fatigue, anorexia or loss of weight, and sleep and cognitive disorders, overlap with those of depression, which leads to an underdiagnosis of this mental disorder in these patients [6,7,14].

For these reasons, it is critical to detect, diagnose, and treat depression symptoms in patients with cancer and depression. Based on the information available in electronic health records (EHRs), it is possible to have a complete clinical history of these patients, but it is necessary to fully exploit its content to make the most of these information systems [24]. EHRs are increasingly implemented in many health care systems around the world, but the clinical information included in these information systems is underused in general and for research purposes and not exploited to its full potential [25]. The reuse of data from EHRs for biomedical research deals with 2 main types of information. Structured data, such as patient demographics, encoded diagnosis, procedures, or drug information, are the easiest data sources to process using standard statistical methods [26]. Unstructured data, including free-text clinical notes, often requires more complex analysis approaches, relying on text mining and natural language processing (NLP) tools to make it possible to extract relevant, structured information [25]. NLP is used to process large amounts of unstructured text from clinical notes and return structured information about their meaning [27]. The textual content of clinical notes constitutes a valuable source of information that is useful to obtaining a complete knowledge of patients' phenotypes by complementing the information encoded in structured clinical data [27-29]. The capacity to integrate these 2 types of clinical knowledge sources by using biomedical informatics tools is especially critical for the management of complex diseases such as cancer and depression [30].

In this study, we identified and analyzed the presence of depressive disorders in patients with the most common cancers in Spain—breast or colorectal cancer—using 2 different sources of clinical information: diagnosis codes in ICD-9-CM (International Classification of Diseases, Ninth Revision, Clinical Modification) and free-text clinical notes, including mentions of depression diagnoses, their symptoms, and antidepressants.

Objectives

The aim of the study was twofold: (1) to compare the association between depression in patients with breast or colorectal cancer before and after these diagnoses and (2) to determine the usefulness of the free-text clinical notes analysis using NLP for detecting the diagnosis of depression among patients with cancer in combination with encoded structured clinical information.

Methods

Clinical Database

The clinical database used for the study was the EHR of the Parc de Salut Mar Barcelona, a complete health care services organization with its information system database (IMASIS). IMASIS includes the clinical information of 2 general hospitals, 1 mental health care center, and 1 social health care center in the Barcelona city area (Catalonia, Spain) since 1990, including different settings such as admissions, outpatient consultations, and emergency department visits [31]. IMASIS-2 is the anonymized relational database of IMASIS, being the data source used for research purposes. To identify the diagnosis of depressive disorders, we analyzed both structured and free-text clinical notes obtained from the IMASIS-2 database [32].

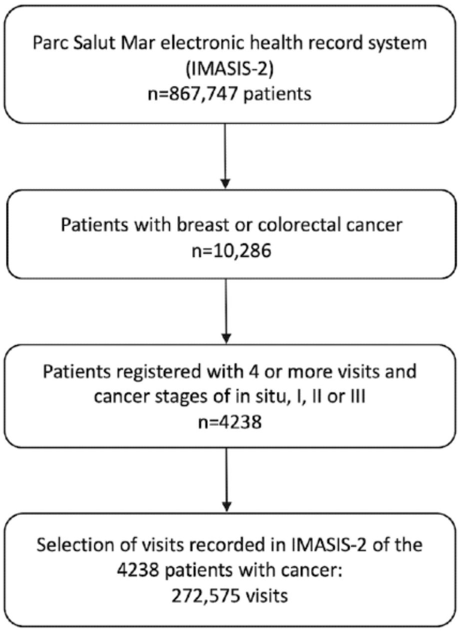
The diagnoses included in IMASIS-2 are encoded using the ICD-9-CM codification [33]. In addition, during the interaction with their patients, physicians generate clinical notes to record the details of the anamnesis such as the diagnosis performed, prescription of drugs, as well as any kind of related information of clinical interest. At the time of the study, IMASIS-2 included the anonymized clinical information of 876,747 patients, with more than 16.7 million visits from the beginning of 1992 to the end of 2018.

The Hospital del Mar Cancer Registry, which included 37,741 diagnosed malignant tumors, was also used as an additional source of information, providing data on the number of cases, characteristics, diagnostic and therapeutic process, and survival of patients with cancer at Parc de Salut Mar Barcelona [34]. Each clinical record includes the timeline of the patient visits. In addition, each visit is characterized by ICD-9-CM diagnosis codes and 1 or more free-text notes written in Spanish or Catalan (both official languages used in Catalonia) generated by physicians during their interactions with patients that include the anamnesis, diagnosis, and prescriptions.

Patients' Selection Criteria

The initial group of patients considered in our study consisted of the 10,668 individuals who were diagnosed with breast cancer (in women; ICD-9-CM–related code 174) and colorectal cancer (ICD-9-CM–related codes 153 and 154). The patients with cancer were classified in the Cancer Registry by stage (one of in situ, I, II, III, or IV stages) and the type of treatment received including chemotherapy. We obtained a sample of 10,668 patients with breast cancer or colorectal cancer. Of the total 10,668 patients, 2485 were excluded due to having more than 1 cancer or incomplete clinical information, with 8147 patients remaining. Of these 8147 patients, we selected 4238 individuals for the study who had (1) at least 4 or more visits recorded in the IMASIS-2, including 2 before and 2 after the cancer diagnosis; (2) breast or colorectal cancer that were in the "in situ" stage or stages I, II, or III; and (3) complete information about the treatments received for cancer. Patients in stage IV were not included because these patients were in an advanced stage of cancer, and they usually received palliative care or experienced depression [9]. Each visit is characterized by the diagnosis codes and 1 or more free-text notes written in Spanish or Catalan generated by physicians during their interaction with the patients. Physicians and health care practitioners usually rely on clinical notes to record the details of the anamnesis and diagnosis they performed, prescriptions and doses of drugs, as well as any kind of related information of interest. Considering that patients with cancer usually have several visits and clinical complexity, we decided to include at least 4 visits to ensure that enough clinical information of the follow-up was analyzed. The flow diagram of the study is depicted in Figure 1.

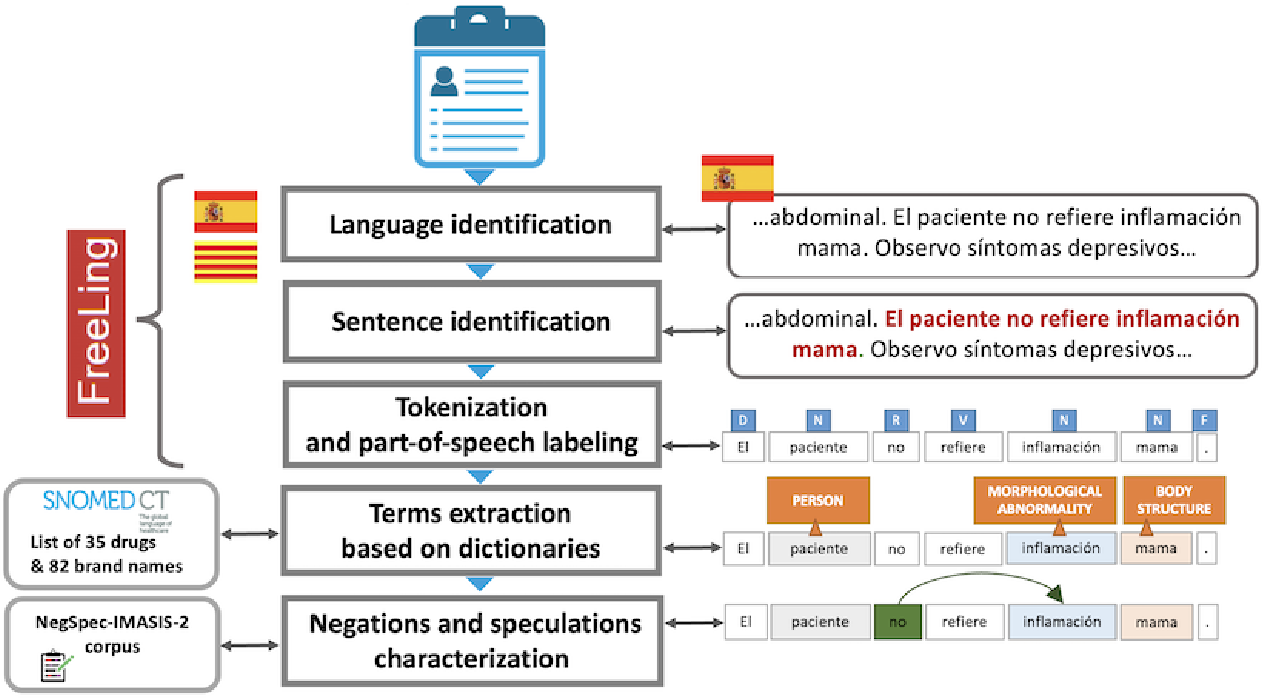
Figure 1. Flow diagram of the study process.



To get thorough information describing the occurrence of depressive disorders among patients with breast and colorectal cancers, we used a combination of different sources of clinical information present in the EHR. The included sources are the occurrence of ICD-9-CM diagnosis codes registered and related to depressive disorders (Multimedia Appendix 1) and the text mining of clinical notes by means of NLP tools to detect mentions of (1) terms and expressions that are commonly used to describe depressive disorders (based on Systematized Nomenclature of Medicine Clinical Terms [SNOMED CT] related to depressive disorders) [35] and (2) drugs used for the treatment of depression (Multimedia Appendix 2).

We analyzed the textual content of the 272,575 clinical notes from the visits of the 4238 patients with the considered cancers. The text of each clinical note was processed by means of the FreeLing [36] open-source language analysis framework, and the following text analysis steps were performed (see Figure 2).

Figure 2. The different text mining tools used and applied for the clinical annotations analysis.



- Language identification: The FreeLing language analyzer determined, for each clinical note, the language used (Spanish or Catalan). All subsequent NLP analyses performed were language-specific.
- Tokenization and part-of-speech tagging: The text of each clinical note was divided into tokens (substrings with assigned and identified meaning), and the part of speech of each token was identified (determiner, preposition, conjunction, punctuation, verb, adjective, pronoun, adverb, and name).
- Terms detection: In the text of each clinical note, mentions of the following types of terms were identified: (1) names of the active substances of the 35 antidepressants and their corresponding 82 brand names used in Spain; and (2) SNOMED CT with depressive disorders–related terms, including the lexicalizations of the 139 concepts classified under the concept “trastorno depresivo (trastorno)” (depressive disorder [disorder] in Spanish; SNOMED CT ID 35489007). We searched for mentions of antidepressant active substances and their commercial drug names over the whole textual content of clinical notes. For this purpose, we exploited the Elasticsearch search and analytics tool [37]. This search engine, apart from substantially speeding up the search for relevant mentions in the huge collections of clinical notes, allowed us to properly match the variations of the considered terms with respect to misspellings that are frequent in free-text clinical notes.
- Negation characterization: A negation detection algorithm tailored to the Spanish and Catalan languages was applied to the clinical notes for both SNOMED CT depressive disorders terms and antidepressant active substance and brand names to exclude the negated occurrences of these terms from our study. This detection was performed using a negation detection algorithm implemented as a token sequence tagger, relying on Conditional Random Fields. For this purpose, a corpus of 949 sentences (572 in Spanish and 277 in Catalan) extracted from clinical notes were manually annotated, detecting for each sentence the negation marker and the related negation span (ie, the portion of the text of the sentence that is actually negated). This corpus has been used to train a Conditional Random Fields sequence tagger that is able to automatically identify negation markers and related spans inside the text of clinical notes in Spanish and Catalan.

When needed, the names of antidepressant active substances as well as the names of depressive disorders–related terms from SNOMED CT were manually translated into Spanish and Catalan by a bilingual psychologist, since the textual content of the clinical notes analyzed in our study includes both languages.

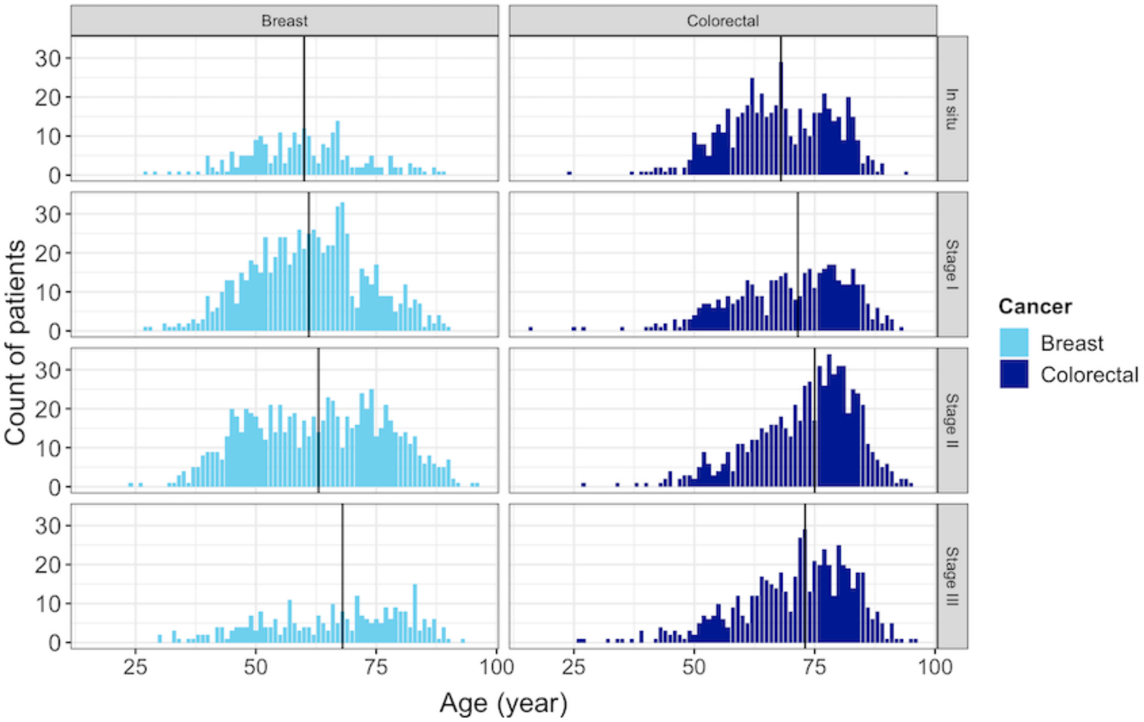
Ethics Approval

The study was approved by the Hospital del Mar Research Ethics Committee (Comitè Ètic d'Investigació Clínica del Parc de Salut Mar; 2016/7130/I) and performed according to the Declaration of Helsinki, the General Data Protection Regulation (EU 2016/679), and the Spanish Law (3/2018) for data protection. All data were anonymized and treated with maximal confidentiality and respect according to good clinical practice guidelines.

Results

The number of patients with cancer included in our study was 4238. There were 2032 women with breast cancer with a mean age of 62.3 (SD 13.2) years, and there were 2206 patients with colorectal cancer with a mean age of 70.5 (SD 11.4) years, including 1277 (57.9%) men and 929 (42.1%) women with significant differences in the ages of both groups of patients with these cancers (*P*<.001). The distribution of age by stages of both cancers is shown in Figure 3. The median age increases gradually according to the stage of the cancer, and it is higher in patients with colorectal cancer. The median age changed from 60 years in the "in situ" stage to 68 years in stage III for breast cancer and from 68 years in the "in situ" stage to 73 years in stage III for colorectal cancer.

Figure 3. Distribution of age by the stages of breast and colorectal cancers. The median age is shown as a vertical line.



The total number of patients with depression based on the use of ICD-9-CM, antidepressants drug mentions, SNOMED CT concepts related to depressive disorders, or the combination of these 3 methods was 1269. The percentage of patients diagnosed with depressive disorders increased after cancer diagnosis, with significant differences across all the types of cancer considered (*P*=.004) and the stages of cancer (*P*<.001). In Table 1, the distribution of patients according to the type of cancer, stage, and depression after the date of diagnosis of cancer based on ICD-9-CM codes is shown.

The increase in the number of patients with depression observed was a trend that we found separately in the ICD-9-CM codes, mentions of antidepressant drugs, and mentions of the set of SNOMED CT depression concepts. In the tables below, we show the number of patients with depression before and after the diagnosis of cancer using 3 different methods to detect them: the ICD-9-CM depression codes, antidepressant drug mentions, and SNOMED CT concepts related to "trastorno depresivo," and the combination of the 3 methods.

Considering exclusively the ICD-9-CM codes of depressive disorders and excluding patients diagnosed with depression in visits both before and after the date of cancer diagnosis (n=164), of the 4074 remaining patients, 16.3% (n=664) were diagnosed with depression, and 86.6% (575/664) were diagnosed after the cancer diagnosis date (see Table 2). The total number of patients with depression increased significantly after the date of cancer diagnosis (McNemar test: χ^2_1=354.25; *P*<.001).

Considering the diagnosis of depression based on antidepressant drug mentions and excluding patients diagnosed with depression in visits both before and after the date of diagnosis cancer (n=68), of the 4170 remaining patients, 15% (n=624) were diagnosed with depression, and 91% (568/624) were diagnosed after the cancer diagnosis date (see Table 3). The total number of patients with depression increased significantly after the diagnosis date of cancer (McNemar test: χ^2_1=418.46: *P*<.001).

Of the 824 antidepressant mentions, the most frequent were citalopram (n=274, 33.3%), escitalopram (n=174, 21.1%), amitriptyline (n=125, 15.2%), trazodone (n=64, 7.8%), venlafaxine (n=57, 6.9%), paroxetine (n=37, 4.5%), desvenlafaxine (n=22, 2.7%), fluoxetine (n=22, 2.7%), and bupropion (n=21, 2.5%).

Considering the mentions of SNOMED CT depression concepts and excluding patients diagnosed with depression in visits both before and after the date of cancer diagnosis (n=20), of the 4218 remaining patients, 379 (89%, N=426) patients with depression were diagnosed after the data of cancer diagnosis—222 (94.5%) out of 235 for breast cancer and 157 (82.2%) out of 191 for colorectal cancer (see Table 4). The total number of patients with depression increased significantly after the diagnosis date of cancer (McNemar test: χ^2_1=257.19; *P*<.001).

Table 1. Distribution of patients according to the type of cancer, stage, and diagnosis of depression based on ICD-9-CM (International Classification of Diseases, Ninth Revision, Clinical Modification) codification.

Cancer type, cancer stage	Number of patients, n/N (%)	Depression (ICD-9-CM) after cancer diagnosis, n/N (%)
Breast		
In situ	234/2032 (11.5)	40/234 (17.1)
Stage I	739/2032 (36.4)	152/739 (20.6)
Stage II	781/2032 (38.4)	166/781 (21.3)
Stage III	278/2032 (13.7)	82/278 (29.5)
All stages	2032/2032 (100)	440/2032 (21.7)
Colorectal		
In situ	544/2206 (24.7)	48/544 (8.8)
Stage I	438/2206 (19.9)	61/438 (13.9)
Stage II	656/2206 (29.7)	94/656 (14.3)
Stage III	568/2206 (25.7)	96/568 (16.9)
All stages	2206/2206 (100)	299/2206 (13.6)
Total	4238/4238 (100)	739/4238 (17.4)

Table 2. Number of patients characterized by ICD-9-CM (International Classification of Diseases, Ninth Revision, Clinical Modification) depression diagnosis codes before and after the cancer diagnosis date.

Cancer type	Before cancer diagnosis date, n/N (%)	After cancer diagnosis date, n/N (%)	Patients with depression, n/N (%)	Patients without depression, n/N (%)
Breast	39/398 (9.8)	359/398 (90.2)	398/1951 (20.4)	1553/1951 (79.6)
Colorectal	50/266 (18.8)	216/266 (81.2)	266/2123 (12.5)	1857/2123 (84.5)
Total	89/664 (13.4)	575/664 (86.6)	664/4074 (16.3)	3410/4074 (83.7)

Table 3. Number of patients with antidepressant drug mentions before and after the cancer diagnosis date.

Cancer type	Before cancer diagnosis date, n/N (%)	After cancer diagnosis date, n/N (%)	Patients with depression, n/N (%)	Patients without depression, n/N (%)
Breast	27/352 (7.7)	325/352 (92.3)	352/2009 (17.5)	1657/2009 (82.5)
Colorectal	29/272 (10.7)	243/272 (89.3)	272/2161 (12.6)	1889/2161 (87.4)
Total	56/624 (9)	568/624 (91)	624/4170 (15)	3546/4170 (85)

Table 4. Number of patients with mentions of SNOMED CT (Systematized Nomenclature of Medicine Clinical Terms) concepts related to “trastorno depresivo” (depressive disorder in Spanish) before and after the cancer diagnosis date.

Cancer type	Before cancer diagnosis date, n/N (%)	After cancer diagnosis date, n/N (%)	Patients with depression, n/N (%)	Patients without depression, n/N (%)
Breast	13/235 (5.5)	222/235 (94.5)	235/2021 (11.6)	1786/2021 (88.4)
Colorectal	34/191 (17.8)	157/191 (82.2)	191/2197 (8.7)	2006/2197 (91.3)
Total	47/426 (11)	379/426 (89)	426/4218 (10)	3792/4218 (90)

When we considered the previous 3 selection criteria together (ICD-9 codes, drug mentions, and SNOMED CT concepts) to detect patients with a diagnosis of depression and excluded the patients with a depression diagnosis both before and after cancer diagnosis date (n=248), of a total of 1021 patients, 920 (90.1%) were diagnosed after the cancer diagnosis date—533 (92.5%) out of 576 for breast cancer and 387 (87%) out of 445 for colorectal cancer (see Table 5).

Of the total 4238 individuals, we identified 1269 (30%) characterized by 1 or more diagnoses of depression by analyzing their clinical histories (both ICD-9-CM codes and clinical notes, including drug mentions and SNOMED CT concepts detection). The identification of a diagnosis of depression in 441 (34.8%) patients out of 1269 has been performed by relying exclusively on the analysis of clinical notes using text mining (drugs and SNOMED CT concepts detection)—such patients would have not been considered as having been diagnosed with depression by relying on ICD-9-CM clinical codes. If we consider patients with breast cancer, the diagnosis of depression has been performed by relying exclusively on text mining in 30.6% (211/690) of the patients; this percentage is 39.7% (230/579) when we consider patients with colorectal cancer. Consequently, thanks to the analysis of clinical notes, we detected a considerably larger number (828/1269, 65.2%) of patients diagnosed with depression, with 34.8% (441/1269) more individuals using text mining (drugs or SNOMED CT concept mentions), by relying on ICD-9-CM codes in combination or not with drugs or SNOMED CT concepts mentions (see Table 6).

Finally, we tried to determine if there was a relationship between the onset of depression and receiving chemotherapy. Of the 2032 patients with breast cancer, 907 (44.6%) received chemotherapy and 1125 (55.4%) did not. Of the 2206 patients with colorectal cancer, 564 (25.6%) received chemotherapy and 1642 (74.4%) did not. The number of patients with depression who received chemotherapy was higher than those who did not receive chemotherapy, with significant differences (*P*<.001).

Table 5. Number of patients with ICD-9-CM (International Classification of Diseases, Ninth Revision, Clinical Modification) codes of depressive disorders, a mention of antidepressant drugs, or a mention of one of the sets of 139 SNOMED CT (Systematized Nomenclature of Medicine Clinical Terms) concepts subsumed by the concept "trastorno depresivo" (depressive disorder in Spanish), before and after the cancer diagnosis date.

Cancer type	ICD-9-CM codes or mentions of drugs and SNOMED CT concepts before cancer diagnosis date, n/N (%)	ICD-9-CM codes or mentions of drugs and SNOMED CT concepts after cancer diagnosis date, n/N (%)	ICD-9-CM codes or mentions of drugs and SNOMED CT concepts, n/N (%)	No ICD-9-CM codes or mentions of drugs and SNOMED CT, concepts, n/N (%)
Breast	43/576 (7.5)	533/576 (92.5)	576/1918 (30)	1342/1918 (70)
Colorectal	58/445 (13)	387/445 (87)	445/2072 (21.5)	1627/2072 (78.5)
Total	101/1021 (9.9)	920/1021 (90.1)	1021/3990 (25.6)	2969/3990 (74.4)

Table 6. Number of patients with ICD-9-CM (International Classification of Diseases, Ninth Revision, Clinical Modification) codes with or without mentions of drugs or SNOMED CT (Systematized Nomenclature of Medicine Clinical Terms) concepts.

Cancer type	ICD-9-CM codes without mentions of drugs or SNOMED CT concepts, n/N (%)	ICD-9-CM codes with mentions of drugs or SNOMED CT concepts, n/N (%)
Breast	479/690 (69.4)	211/690 (30.6)
Colorectal	349/579 (60.3)	230/579 (39.7)
Total	828/1269 (65.2)	441/1269 (34.8)

Discussion

Principal Findings

The detection of depressive disorders in patients with cancer is a key element in the management of these patients, which can impact the treatment outcomes of cancer [6]. In this study, we analyzed the relationship between depression and cancer diagnosis, particularly in breast and colorectal cancers. We considered the diagnosis of depression based on both structured information encoded by ICD-9-CM codes and extracted information from free-text clinical notes, using text mining and NLP tools for the mentions of antidepressant drugs and SNOMED CT concepts related to the concept "trastorno depresivo" (depressive disorder in Spanish). We identified a significantly higher number of patients with depression after the diagnosis of cancer, in both breast and colorectal cancers, thus highlighting the importance of such comorbidity in patients with these conditions [9]. The proportion of patients with depression increased with the progression of the cancer stage and when receiving chemotherapy. In addition, this trend was maintained when we detected patients with depression using the different sources of information that are available in the EHR, including structured data and free-text clinical notes in which antidepressants and depressive symptoms are mentioned. Nevertheless, our study demonstrates that the diagnosis of depression detected by medical doctors is not always registered using codifications (ie, ICD-9-CM codes), but it is often mentioned exclusively in free text in clinical notes where it can be indirectly detected based on the mentions of depressive symptoms or antidepressant drugs [38]. The detection of information related to depression from unstructured EHR data identified individuals among the patients included in the study who were missed based only on the information from encoded data.

The use of unstructured data for the identification of conditions such as depression, as well as other diseases and comorbidities [26], should be considered as a source of information that can contribute to the management of complex diseases such as cancer and depression. Using NLP methods to detect patients with conditions that are previously encoded can improve the codification process and follow-up of these patients. In addition, the use of NLP to detect symptoms and comorbidities from free text in the EHR can contribute to the characterization of diseases or predict response to treatment [39-41].

The value of relying on these 2 types of clinical information—structured and unstructured—has been analyzed in other conditions such as geriatric syndrome [26], different mental illnesses [42], and psychiatric phenotyping [43], helping in the identification of additional clinical information not registered using codifications, although the extraction of this data is challenging and resource intensive.

Limitations

This study has some limitations. It is not uncommon that if the main cause of admission of a patient is a complication of cancer, other secondary diagnoses such as depression are not included in the medical discharge report, and for this reason, these diagnoses can be underrecorded. However, specific words and expressions used by medical doctors to mention depression-related symptoms in clinical notes may not have been included among the terms used in this study. We based our analyses of clinical notes exclusively on the terminology encoded in SNOMED CT to capture mentions of depressive disorders, and therefore, our terminology could underestimate the number of patients with depression. In this regard, free text can be further explored to identify other expressions and terms used by clinicians to describe depression symptoms [26]. Finally, the mentions of antidepressant drugs could not always be associated with a diagnosis of depression but rather with other mental disorders in which these drugs are prescribed.

Conclusions

This study demonstrated that the use of NLP for extracting and processing unstructured clinical information, which is present in free-text clinical notes in the EHR, in combination with encoded diagnosis can contribute to the identification of relevant clinical data—in this case, the detection of depressive disorders in patients with breast and colorectal cancers. This study shows the possibility of combining structured and unstructured data included in the EHR, providing new opportunities to better understand and manage complex diseases and their comorbidities, such as cancer and depression, to the benefit of these patients. In future works, we intend to extract information from the EHR using NLP in combination with machine learning methods and apply prediction models to estimate different possible outcomes.

Acknowledgments

The Research Programme on Biomedical Informatics (GRIB) is a member of the Spanish National Bioinformatics Institute and funded by Instituto de Salud Carlos III and FEDER (PT17/0009/0014). The GRIB is also supported by the Agència de Gestió d'Ajuts Universitaris i de Recerca, Generalitat de Catalunya (2017 SGR 00519). This research was carried out under the framework of the project Creating medically-driven integrative bioinformatics applications focused on oncology, CNS disorders and their comorbidities (MedBioinformatics, H2020-EU; grant 634143); and partially funded by the Institute of Health Carlos III (project IMPaCT-Data; IMP/00019) and cofunded by the European Union, European Regional Development Fund ("A way to make Europe"); and the Clinical Knowledge Aggregation by Mining Medical Reports (CliKA-MinE; PI17/00230), which is funded by Institute of Health Carlos III and cofunded by the European Union.

Data Availability

The study involves the use of patients' medical data from the Hospital del Mar according to the General Data Protection Regulation. The data is not publicly available due to the ethical regulations under which the data is collected from our hospital database.

Authors' Contributions

The first draft was written jointly by AL, MAM, and FR. All the authors have read and agreed to the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

ICD-9-CM (International Classification of Diseases, Ninth Revision, Clinical Modification) diagnosis codes related to depressive disorders used in the study.

[DOCX File , 16 KB - cancer_v8i3e39003_app1.docx]

Multimedia Appendix 2

Names of the active substances of the 35 antidepressants and their corresponding 82 brand names used in Spain.

[DOCX File , 17 KB - cancer_v8i3e39003_app2.docx]

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Abbreviations

EHR: electronic health record
ICD-9-CM: International Classification of Diseases, Ninth Revision, Clinical Modification
NLP: natural language processing
SNOMED CT: Systematized Nomenclature of Medicine Clinical Terms

Edited by A Mavragani; submitted 26.04.22; peer-reviewed by A González, K Adapa; comments to author 03.06.22; revised version received 17.06.22; accepted 20.06.22; published 11.07.22.

Please cite as:
Leis A, Casadevall D, Albanell J, Posso M, Macià F, Castells X, Ramírez-Anguita JM, Martínez Roldán J, Furlong LI, Sanz F, Ronzano F, Mayer MA
Exploring the Association of Cancer and Depression in Electronic Health Records: Combining Encoded Diagnosis and Mining Free-Text Clinical Notes
JMIR Cancer 2022;8(3):e39003
URL: https://cancer.jmir.org/2022/3/e39003
doi:10.2196/39003
PMID:35816382

Original Paper

An Investigation of Virtual Reality Nature Experiences in Patients With Metastatic Breast Cancer: Secondary Analysis of a Randomized Controlled Trial

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Abstract

Background: Connection with nature has well-established physical and psychological benefits. However, women with metastatic breast cancer (MBC) are often unable to access nature because of physical limitations, psychological barriers, and treatment demands. Virtual reality (VR) nature experiences offer an alternative means of connecting with nature and may be of particular benefit to patients with cancer who are house- or hospital-bound.

Objective: This study aims to explore whether VR nature experiences are associated with physical and psychological benefits for women with MBC who are disconnected with nature.

Methods: This secondary analysis of a previous randomized controlled crossover trial recruited participants from the emailing lists of breast cancer support organizations. Participants were provided VR headsets for daily use in their homes for over 3 weeks. In the first week, participants used 1 of 2 VR nature experiences (*Ripple* or *Happy Place*) daily, followed by a 1-week washout period, before using the other VR experience every day for the final week. Outcomes assessed changes between baseline and postintervention scores in quality of life (EQ-5D-5L), pain (Brief Pain Inventory Short Form), fatigue (Functional Assessment of Chronic Illness Therapy-fatigue), depression (Depression, Anxiety, and Stress Scale-depression), anxiety (Depression, Anxiety, and Stress Scale-anxiety), and spiritual well-being (Functional Assessment of Chronic Illness Therapy- Spiritual Well-being) and investigated whether benefits were greater in participants who were not strongly connected with nature at baseline.

Results: A total of 38 women with MBC completed the VR interventions and were included in the analyses. Participants reported significantly less fatigue (P=.001), less depression (P<.001), and greater quality of life (P=.02) following the interventions than at baseline. Women with a weaker connection to nature reported greater fatigue (P=.03), depression (P=.006), and anxiety (P=.001), and poorer spirituality (P=.004) than their strongly connected counterparts. Only those with a weaker baseline connection with nature showed improvements in depression following the intervention (P=.03), with similar trends observed in fatigue (P=.07) and quality of life (P=.10).

Conclusions: This study provides preliminary evidence that feeling connected with nature is associated with better physical and psychological status in patients with MBC and that VR nature interventions might be beneficial for this clinical population. Future studies should focus on activities that encourage connection with nature (rather than simply exposure to nature) and investigate the aspects of VR nature interventions that have the greatest therapeutic potential.

Trial Registration: Australian New Zealand Clinical Trials Registry ACTRN12619001480178; https://tinyurl.com/et6z3vac

(JMIR Cancer 2022;8(3):e38300) doi:10.2196/38300

KEYWORDS

metastatic breast cancer; virtual reality; nature connectedness; intervention; quality of life

Introduction

Background

Metastatic breast cancer (MBC) is a terminal diagnosis that occurs when cancer cells spread from the breast to the lymph nodes and more distant regions such as the bone, brain, liver, and lung [1]. The impact of metastatic disease and its associated treatments (chemotherapy, radiotherapy, surgery, etc) can be physically and psychologically demanding. Although less research has been conducted on the effects of MBC compared with early disease [2], a limited body of work has identified physical challenges including pain and fatigue [3] and psychological problems including anxiety [4], depression [5], and spiritual distress [6]. Problematic physical and psychological issues are associated with diminished quality of life [7]. Recent data indicate that the median survival time following a diagnosis of MBC across all ages is 25 months [8]. Maintaining quality of life is particularly important in the context of a shortened life span. Therefore, pragmatic interventions that support the physical and psychological well-being of women with MBC are needed. This work investigates whether virtual reality (VR) nature experiences might offer benefit in this context.

Connecting to nature has well-established therapeutic benefits. For instance, exercising in the countryside improves mood [9], gardening promotes stress recovery [10], and immersing oneself in nature through activities such as “forest bathing” offers benefits to both mind and body [11] and can promote feelings of awe, wonder, and spiritual well-being [11,12]. Notably, studies have shown that exposure to specific elements of nature (eg, auditory and visual cues) can also be beneficial. Sounds of nature such as flowing water and birdsong are associated with improved stress recovery in healthy volunteers [13] and in clinical populations undergoing medical procedures [14]. Likewise, viewing images of natural landscapes during exercise is associated with improved mood and reduced blood pressure [15]. Specifically, qualitative work has proposed that connection with nature provides an enriching experience in which patients with cancer can source strength and meaning [16]. The concept of connection with nature has been assessed in a variety of ways, including the 21-item “nature relatedness scale” [17], the 14-item “connectedness to nature scale” [18], and the single item “inclusion of nature with self scale” [19]. The latter is not only brief but also appears particularly associated with well-being [20,21].

Exposure to nature through virtual means may offer proximal benefit where real-world exposure is not feasible. A VR experience is one in which an individual is immersed in, and interacts with, a computer-generated environment using a headset that displays visual and auditory stimuli that simultaneously obstructs the views and sounds of what is happening in the real-world context [22,23]. VR experiences can be wide-ranging, and nature-based experiences seem to have therapeutic potential. Experimental work has demonstrated that virtual exposure to nature offers more benefits than virtual urban environments [24]. A recent review noted the therapeutic benefits of VR nature experiences in psychiatric and medical care [25]. Notably, a study found that a VR nature video offered equivalent benefits to immersion in an actual real-world nature setting [26]. Thus, virtual experiences of nature offer promise in contexts in which people may be unable to connect directly with real-world nature.

Women with MBC face barriers to getting outdoors. The physical limitations of advanced cancer can reduce mobility [27-29], psychological issues such as low mood or demoralization can reduce the motivation to venture outside [30,31], and treatment demands can keep people tied to urban environments [32,33]. Thus, connecting with nature can be difficult for several reasons. Of relevance, research in the general population demonstrates a dose response such that the less time a person spends outdoors and the less vegetation in their neighborhood, the greater the psychological difficulties, even when controlling for sociodemographic factors [34]. Thus, connecting with nature through virtual means may be beneficial for women with MBC who are not currently connected with nature.

Although VR interventions have been studied during cancer treatment as a form of distraction [35,36] and nature-inspired VR experiences have been used specifically with patients undergoing chemotherapy [37], VR nature experience has never been investigated as an intervention in a patient’s own home. Home-based interventions play a role in addressing disparities in the uptake, adherence, and accessibility of psychological interventions for women with MBC [38]. Interventions that have the flexibility to be self-directed and delivered in a person’s home seem well suited to address such disparities.

This Study

This study presents a secondary analysis of a randomized controlled trial comparing 2 VR nature interventions in women with MBC. Primary analyses, including a detailed discussion of the differences between the 2 interventions, are presented elsewhere [39]. The focus of this work was to assess whether VR nature experiences might be of greater benefit to women with MBC who are disconnected with nature than those who are connected with nature. We hypothesized that daily use of VR nature interventions in women with MBC would improve quality of life, reduce physical symptoms (pain and fatigue), and improve psychological well-being (depression, anxiety, and spiritual well-being) and that benefits would be moderated by baseline connection with nature. That is, we hypothesized that women who did not initially feel connected with nature would have worse quality of life, physical symptoms, and psychological well-being at baseline and would benefit more from VR exposure to nature than women who were initially highly connected with nature.

Methods

Research Design

This study reports secondary analyses from a randomized controlled crossover design in which participants were randomized to a different order of exposure to 2 VR nature experiences. A detailed discussion of the methods used in the original study has been published previously [39].

Ethics Approval

This study was approved by the Health and Disability Ethics Committees (19/NTB/146) and registered on the Australian New Zealand Clinical Trials Registry (ACTRN12619001480178). Written informed consent was obtained from the participants, and all procedures were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and the Declaration of Helsinki 1975, as revised in 2000.

Participants

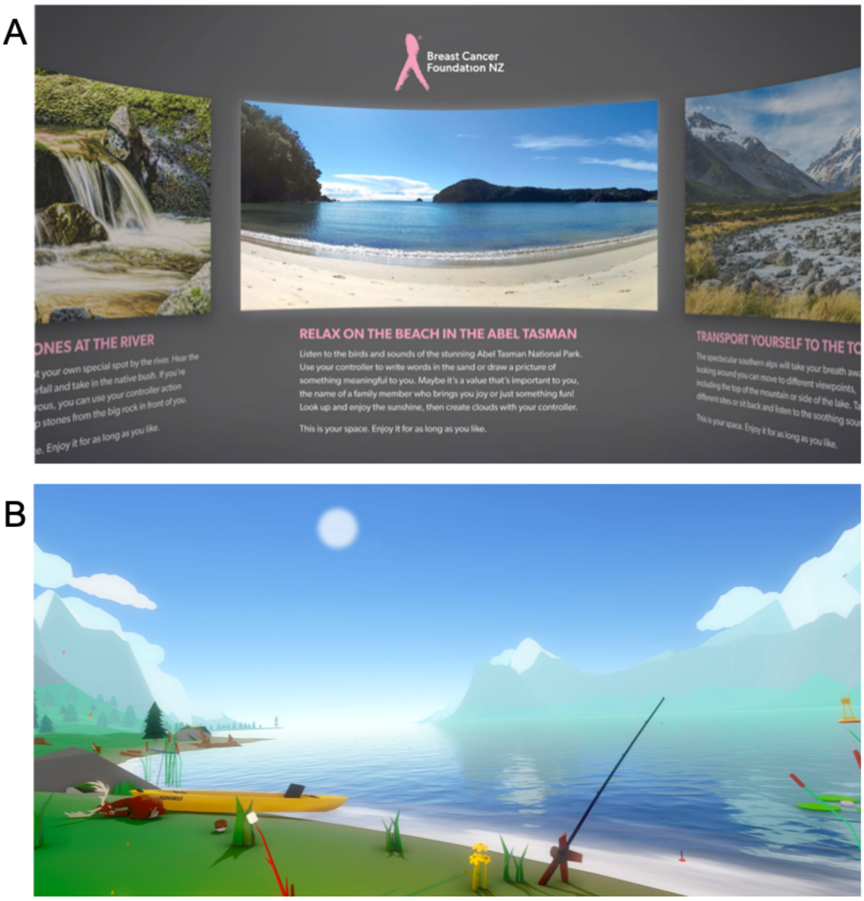
Participants were recruited between October 2019 and March 2020 by advertising flyers sent to the emailing lists of 2 breast cancer support organizations. A total of 46 participants contacted the researchers and were assessed for eligibility. Women who could read and write English were included if they had a self-reported MBC diagnosis and (1) had experienced pain, fatigue or anxiety in the week before recruitment and (2) were able and willing to use a VR headset for at least 10 minutes a day for the study duration. Exclusion criteria were the presence of any visual, hearing, or cognitive impairments or face, head, or neck discomfort that would preclude them from wearing the VR headset.

VR Equipment

Participants were sent VR equipment and instructions via courier after obtaining study information and informed consent. The equipment included a Pico Goblin VR headset, remote control, headphones, charger and cable, batteries, screen-cleaning cloth, and a logbook to record daily use. The participants also received 4 envelopes with instructions to open them weekly, in a specified order. Each headset had 2 VR experiences installed: a real-world nature experience—*Ripple* and an animated experience—*Happy Place* (Figure 1 [40,41]).

Ripple is a real-world nature VR experience developed by Mixt Studio [40] and commissioned for the study by the Breast Cancer Foundation New Zealand based on feedback from qualitative work with patients with MBC. In this virtual experience, the sounds and images of three 360° nature environments are presented: (1) a view of different perspectives of a mountaintop, (2) a stacking stones activity by a waterfall, and (3) writing in the sand at a beach. The other VR experience was *Happy Place*, an animated nature VR experience developed by Hjärtat [41]. This experience involves a camping scene where participants can explore a campsite, listen to a guided relaxation exercise, and complete various activities such as roasting a marshmallow over a campfire or blowing bubbles.

Figure 1. Images from Ripple (A) [40] and Happy Place (B) [41].



RELAX ON THE BEACH IN THE ABEL TASMAN

Listen to the birds and sounds of the stunning Abel Tasman National Park. Use your controller to write words in the sand or draw a pricture of something meaningful to you. Maybe it's a value that's important to you, the name of a family member who brings you joy or just something fun! Look up and enjoy the sunshine, then create clouds with your controller.

This is your space. Enjoy it for as long as you like.

Procedure

After providing informed consent, participants completed baseline measures before being block randomized via REDCap (Research Electronic Data Capture; Vanderbilt University) by age (<50 years vs ≥50 years) to the order of exposure to each of the VR experiences. In one condition, participants used Ripple for 7 days, had a 7-day washout period, and then used the Happy Place for 7 days. The timings were the same in the other condition, but the order of exposure to the VR experiences was reversed. Participants were blinded to randomization and were instructed to use the headset for a minimum of 10 minutes per day during the periods of VR use. Primary analyses revealed no order effects or differences among the VR experiences [39]; therefore, these are not further reported in this work.

Measures

Demographic and clinical information was collected at baseline, including age, ethnicity, education, relationship status, years since diagnosis, and current cancer treatment.

Baseline connectedness to nature was assessed using the Inclusion of Nature in the Self (INS) [19] measure. This single item presents a series of 7 diagrams with 2 circles that increasingly overlap; one circle represents the self and the other represents nature. Participants are asked to "mark the picture that best describes how close you have felt to nature in the past week," with ratings ranging from 1 (circles do not overlap) to 7 (circles overlap entirely). Higher numbers represent a stronger self-perceived connection with nature. Given the aim of this work to assess whether VR exposure might differentially benefit women who were not initially connected with nature, we dichotomized scores at the point where there was potential to improve a person's connection with nature, that is, where there was ≤50% overlap between the circles. Thus, scores between 1 and 5 were categorized as "weaker connection with nature" and 6 and 7 as "stronger connection with nature." Given the lack of precedence in categorizing the INS into weak and strong connections with nature, we ran alternative models splitting the INS at other points as sensitivity analyses to evaluate this choice of cutoff on the results. As such, we also dichotomized the scores as weak (1-4) and strong (5-7), and then trichotomized the scores as weak (1-3), medium (4-5), and strong (6-7).

Quality of life was assessed using the EQ-5D-5L index score [42], which measures 5 dimensions of well-being: mobility, self-care, usual activities, pain or discomfort, and anxiety or depression. Participants chose from a 5-point Likert scale (1="no problems" to 5="unable to/extreme problems"). An external calculator based on the United Kingdom value set provided a value for the quality of life [43]. The EQ-5D-5L has shown good construct validity and reliability in patients with cancer [44]. Internal reliability was adequate for this study, both at baseline (Cronbach α=.82) and after the intervention (Cronbach α=.68).

Fatigue was measured using the Functional Assessment of Chronic Illness Therapy-fatigue (FACIT-fatigue [45]) scale. The scale assesses overall fatigue and its influence on daily activities and functioning in the past week and includes 13 items such as tiredness, weakness, and lack of energy. Participants rated the items on a 4-point Likert scale from 0 ("not at all") to 4 ("very much"). The total fatigue score ranged from 0 to 52, with higher scores representing higher fatigue levels. In this study, FACIT-fatigue showed good internal reliability at baseline (Cronbach α=.91) and after the intervention (Cronbach α=.91).

The Brief Pain Inventory Short Form (BPI-SF [46]) measured *pain* over the past week. The first item asks participants to choose "yes" or "no" to whether they experienced pain other than everyday pain such as minor headaches. A total of 5 items measured pain levels in the past week, ranging from 0 ("no pain") to 100 ("pain as bad as you can imagine"). The final 7 items assessed the level of interference of pain on well-being domains such as mood and sleep from 0 ("does not interfere") to 100 ("completely interferes"). Excellent internal consistency has been demonstrated among patients with cancer [47]. This was similarly observed in this study: baseline Cronbach α=.93 and postintervention Cronbach α=.93.

Depression and *anxiety* were measured using the Depression, Anxiety, and Stress Scale Short Form (DASS-21) [48]. The DASS-21 is a 21-item measure that assesses anxiety, depression, and stress symptoms. Severity scores were calculated for each subscale, with higher scores indicating a greater severity. Each subscale has cutoff scores from "normal" to "extremely severe." The DASS-21 has shown good internal consistency among patients with cancer (Cronbach α=.74−.91 [49]). In this study, the Depression, Anxiety, and Stress Scale (DASS)-depression subscale demonstrated excellent internal reliability before (Cronbach α=.94) and after intervention (Cronbach α=.89). Initial analyses of the DASS-anxiety subscale revealed poor postintervention reliability. However, given that one of the items measured mouth dryness, a common treatment side effect experienced by 40% of patients with advanced cancer [50], we removed this item and the reliability of the scale subsequently improved to an acceptable level (baseline Cronbach α=.80; after the intervention Cronbach α=.73).

Spiritual well-being was assessed using the Functional Assessment of Chronic Illness Therapy-Spiritual Well-being (FACIT-Sp-12) scale [51]. The scale assesses 3 domains of spiritual well-being (faith, meaning, and peace) and has 12 items rated on a 5-point Likert scale, ranging from 0 ("not at all") to 4 ("very much"). A total of 2 items were reverse scored, and the sum of the items provided a total score that ranged from 0 to 48. Higher scores indicate greater spiritual well-being. Good internal reliability (Cronbach α=.81-.91) [51] and good factorial validity (r=0.7) have been shown among patients with cancer [52]. The measure demonstrated good internal reliability in this study at baseline (Cronbach α=.90) and after the intervention (Cronbach α=.94).

Statistical Analyses

Data were analyzed using SPSS Statistics (version 26; IBM Corp). Descriptive statistics were conducted using numbers and percentages for categorical variables and means and SDs or medians and IQRs for continuous measures. The normality of all continuous outcome measures was assessed visually using the Shapiro-Wilk test. Square root transformation improved the normality of the DASS-depression and DASS-anxiety scales, and the EQ-5D-5L index improved when squared. The transformed data for these measures were used for all analyses. Linear mixed-effects models assessed whether baseline connection to nature (INS) was associated with quality of life (EQ-5D-5L), physical symptoms (FACIT-fatigue and BPI-SF), and psychological well-being (DASS-depression, DASS-anxiety and FACIT-Sp-12) and whether improvements over time in these metrics differed between those who had a weaker connection and those who had a stronger connection with nature at baseline. Time, baseline connection to nature, and the interaction between time and connection with nature were entered as fixed factors, with a random effect to account for repeated measures within the participants. Post hoc tests were used to compare the average change over time within the weaker and stronger baseline connection with nature groups, where there was an indication of a potential interaction (using a threshold of interaction *P* value of <.10). *P* values of <.05 were considered statistically significant. Adjustments for multiple testing were not performed because of the exploratory nature of this study.

Results

Overview

The participants in this study were all female (38/38, 100%), mostly New Zealand European (31/38, 82%), and had a median age of 51 years (Table 1). The majority did not work in paid employment (21/38, 55%) and were either married or living with a partner (22/38, 58%). The median time since cancer diagnosis was 5 years (compared with 2 years in the broader population with MBC [8]), and participants were currently undergoing a variety of cancer treatments at the time of study involvement. Most participants had a weaker compared with a stronger connection with nature at the baseline (29/38, 76%).

Table 1. Baseline characteristics of the sample (N=38).

Measure	Participants
Age (years), median (IQR)	51 (58-45)
Ethnicity, n (%)	
New Zealand European	31 (82)
New Zealand Maori	6 (16)
Pacific	1 (3)
Highest education, n (%)	
Secondary	16 (42)
Tertiary	15 (40)
Postgraduate	7 (18)
Employment status, n (%)	
Full-time	10 (26)
Part-time	7 (18)
Not working	21 (55)
Relationship status, n (%)	
Single	7 (18)
Divorced or separated or widowed	9 (24)
Married or cohabitating	22 (58)
Current cancer treatment, n (%)	
Chemotherapy only	8 (21)
Hormone therapy only	16 (42)
Hormone and target therapy	8 (21)
Radiation and hormone therapy	1 (3)
No current cancer treatment	5 (13)
Time since diagnosis (years), median (IQR)	5 (7)
Connection with nature, mean (SD)	3.95 (1.97)
Weaker (scores 1-5), n (%)	29 (76)
Stronger (scores 6-7), n (%)	9 (24)

Assessment of Baseline Connection With Nature

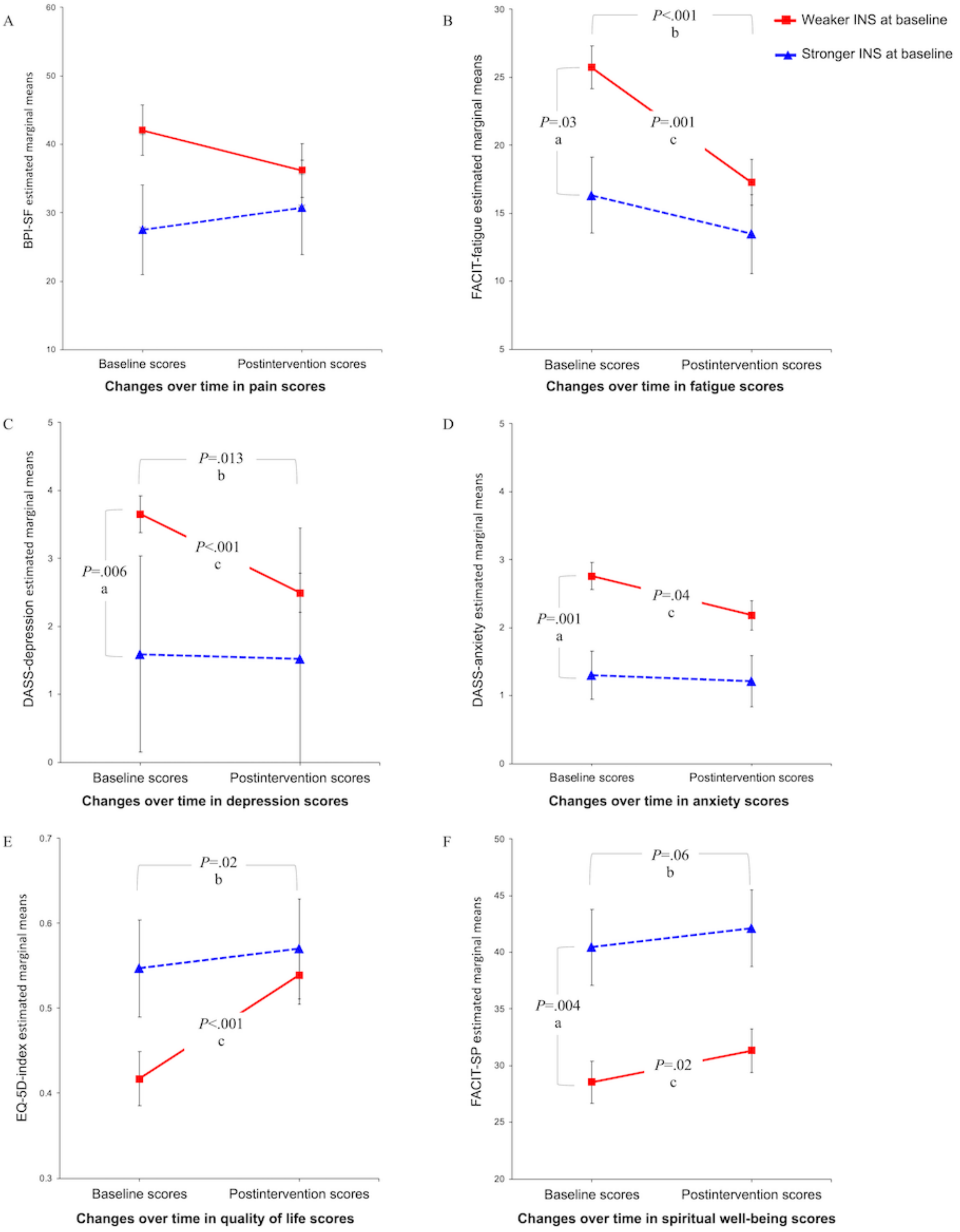
Overview

The linear mixed-effects models investigating the role of connection with nature indicated that the group with a weaker (cf stronger) connection with nature at baseline had poorer functioning on several metrics (fatigue, depression, anxiety, and spirituality; Table 2 and Figure 2). There was only one significant interaction between connection with nature and time, indicating that initial differences in depression among groups became less marked after the intervention, although a similar trend was observed in fatigue and quality of life scores. The results are discussed in more detail in further sections.

Table 2. Comparison of outcome measurements for time, baseline Inclusion of Nature in the Self (INS), and the interaction between time and baseline INS.

Measure and comparison	Estimated marginal mean difference (95% CI)	*P* value
Brief Pain Inventory Short Form-pain		
Post- vs preintervention scores	1.31 (−6.55 to 9.17)	.74
Weak vs strong baseline INS	9.97 (−3.61 to 23.54)	.15
Time x weak baseline INS	−5.88 (−13.69 to 1.93)	.14
Time x strong baseline INS	3.27 (−10.38 to 16.91)	.63
Functional Assessment of Chronic Illness Therapy-fatigue		
Post- vs preintervention scores	5.66 (2.59 to 8.73)	.001
Weak vs strong baseline INS	6.60 (0.66 to 12.53)	.03
Time x weak baseline INS	−8.46 (−11.51 to −5.41)	<.001
Time x strong baseline INS	−2.86 (−8.18 to 2.46)	.28
Depression, Anxiety, and Stress Scale-depression		
Post- vs preintervention scores	0.62 (0.14 to 1.09)	.01
Weak vs strong baseline INS	1.52 (0.47 to 2.57)	.01
Time x weak baseline INS	−1.16 (−1.64 to −0.68)	<.001
Time x strong baseline INS	−0.07 (−0.90 to 0.76)	.86
Depression, Anxiety, and Stress Scale-anxiety		
Post- vs preintervention scores	0.33 (−0.21 to 0.87)	.23
Weak vs strong baseline INS	1.21 (0.55 to 1.87)	.001
Time x weak baseline INS	−0.57 (−1.11 to −0.04)	.04
Time x strong baseline INS	−0.09 (−1.03 to 0.86)	.85
EQ-5D-5L		
Post- vs preintervention scores	−0.07 (−0.13 to −0.01)	.02
Weak vs strong baseline INS	−0.08 (−0.20 to 0.04)	.19
Time x weak baseline INS	0.12 (0.06 to 0.18)	<.001
Time x strong baseline INS	0.02 (−0.08 to 0.13)	.66
Functional Assessment of Chronic Illness Therapy-Spiritual Well-being		
Post- vs preintervention scores	−2.24 (−4.58 to 0.11)	.06
Weak vs strong baseline INS	−11.37 (−18.81 to −3.92)	.004
Time x weak baseline INS	2.76 (0.42 to 5.10)	.02
Time x strong baseline INS	1.71 (−2.36 to 5.77)	.40

Figure 2. Mean scores of outcome measures over time by baseline connection with nature with SE bars. (A) Significant difference between weaker and stronger INS at baseline indicated in B, D, and F; (B) significant improvement over time indicated in B, C, E and F; (C) significant improvement between baseline and postintervention scores in participants with weaker INS at baseline indicated in B, C, D, E, and F. BPI-SF: Brief Pain Inventory Short Form; DASS: Depression, Anxiety, and Stress Scale; FACIT: Functional Assessment of Chronic Illness Therapy; FACIT-Sp-12: Functional Assessment of Chronic Illness Therapy-Spiritual Well-being scale; INS: Inclusion of Nature in the Self.



Pain

Analyses of the effects of study involvement on pain indicated no main effects of time or baseline INS on the BPI-SF scores. Pain did not change over time ($F_{1,31.43}$=0.12; P=.74) and did not vary according to baseline connection with nature (baseline INS: $F_{1,34.88}$=2.22; P=.15), and there was no interaction effect between time and baseline INS ($F_{1,31.43}$=1.41; P=.25; Figure 2A).

Fatigue

There was an effect of baseline connection with nature ($F_{1,35.38}$=5.08; *P*=.03), in that women with weaker baseline INS scores had higher fatigue (mean 21.50, SE 1.43) than those with stronger INS scores (mean 14.90, SE 2.55). There was a main effect of time on fatigue (FACIT-Fatigue scores: $F_{1,31.45}$=14.16; *P*=.001) where postintervention fatigue (mean 15.37, SE 1.68) was significantly lower than baseline fatigue (mean 21.03, SE 1.61; Figure 2B). However, the interaction between time and connection with nature indicated a trend ($F_{1,31.45}$=3.45; *P*=.07), with post hoc tests revealing that fatigue levels only improved in women with weaker INS scores at baseline (FACIT-fatigue scores: baseline mean 25.72, SE 1.57; postintervention scores: mean 17.27, SE 1.67; *P*<.001). The FACIT-fatigue scores did not change in participants with a stronger baseline connection with nature (baseline mean 16.33, SE 2.81; postintervention mean 13.47, SE 2.92; *P*=.28).

Depression

There was a significant interaction between time and connection with nature on depression scores (DASS-depression: $F_{1,31.44}$=5.35; *P*=.03 with cancer; Figure 2C). Only those with a weaker connection with nature at baseline had significant improvements in depression over time (weaker INS: baseline mean 3.65, SE 0.27; postintervention mean 2.49, SE 0.29; *P*<.001). In contrast, those with a stronger baseline connection with nature showed no difference over time (stronger INS: baseline mean 1.59, SE 0.48; postintervention mean 1.52, SE 0.50; *P*=.86). There was also an effect of baseline connection with nature ($F_{1,35.82}$=8.55; *P*=.006) in that women with a weaker baseline connection with nature had greater depression (mean 3.07, SE 0.25) than those with a stronger connection to nature (mean 1.55, SE 0.45).

Anxiety

There was no overall effect of time on anxiety (DASS-anxiety: $F_{1,33.01}$=1.53; *P*=.23); however, there was an effect of baseline connection with nature ($F_{1,34.39}$=13.93; *P*=.001), where women with a weaker baseline connection to nature had significantly higher anxiety (mean 2.47, SE 0.16) than those with a stronger connection with nature (mean 1.26, SE 0.28; Figure 2D). The interaction between time and connection with nature was not significant ($F_{1,33.01}$=0.82; *P*=.37).

Quality of Life

There was a main effect of time on quality of life (EQ-5D-5L index scores: $F_{1,31.07}$=6.12; *P*=.02) such that quality of life after the intervention (mean 0.55, SE 0.03) was significantly greater than that at baseline (mean 0.48, SE 0.03). There was no effect of the baseline connection with nature on quality of life ($F_{1,35.19}$=1.83; *P*=.19; Figure 2E), and the interaction between time and connection with nature indicated a nonsignificant trend ($F_{1,31.07}$=2.87; *P*=.10). However, post hoc tests revealed that only participants with a weaker INS at baseline experienced improvements in quality of life over time (weaker INS: baseline mean 0.42, SE 0.03; postintervention mean 0.54, SE 0.03; *P*<.001 and stronger INS: baseline mean 0.55, SE 0.06; postintervention mean 0.57, SE 0.06; *P*=.66).

Spirituality

The effect of time on spirituality also indicated a trend but was not significant (FACIT-Sp-12: $F_{1,30.78}$=3.78; *P*=.06). However, there was an effect of baseline connection with nature ($F_{1,35.99}$=9.58; *P*=.004) where women with a stronger baseline connection with nature (mean 41.30, SE 3.21) had significantly greater spirituality than those with a weaker connection with nature (mean 29.93, SE 1.79; Figure 2F). There was no interaction between time and connection with nature ($F_{1,30.78}$=0.21; *P*=.65).

Sensitivity Analyses

We evaluated the impact of splitting the INS at other points based on the aforementioned results. First, we dichotomized the scores as weak (1-4; 23/38, 61%) and strong (5-7; 15/38, 39%) and then trichotomized the scores as weak (1-3; 16/38, 42%), medium (4-5; 13/38, 34%), and strong (6-7; 9/38, 24%). The results of these models were essentially unchanged, except for the *P* values for the interaction of time and INS on depression, quality of life, and fatigue, which increased above the threshold of *P*<.10. Although post hoc tests in these instances remained consistent with the aforementioned results and continued to be strongly statistically significant (ie, *P*<.001), the statistical justification to report on these tests was diminished without the interaction effect.

Discussion

Principal Findings

This study investigated whether VR nature interventions might benefit women with MBC who are disconnected with nature. Primary analyses of this intervention found no differences in outcomes between the 2 VR nature experiences [33]; hence, this study focused on whether these interventions might provide differential benefit to women who were not strongly connected with nature at baseline. In line with the primary report [39], time effects revealed that participants reported significantly less fatigue, less depression, and a greater quality of life following the interventions compared with baseline. The difference in spirituality across time indicated a trend for improvement, although it did not meet the threshold for significance. Of note, our analyses revealed 2 key findings specific to our research focus on the connection with nature. First, our results demonstrated differences in well-being between those who had a weaker connection and those who had a stronger connection with nature, that is, women with a weaker connection with nature reported greater fatigue, depression, anxiety, and poorer spirituality than their strongly connected counterparts. Second, we also found evidence of a potential moderating effect between connection with nature and time on depression; only those with a weaker baseline connection with nature at baseline had improvements in depression following the intervention. Although similar patterns were observed for fatigue and quality of life, these effects did not reach the threshold for significance. In the following sections, we discuss the implications of these findings and consider how this report may inform future research in this area.

Interpretation and Clinical Implications

This report extends primary analyses demonstrating the benefits of VR nature experiences [39] by indicating that patients with MBC, who are disconnected with nature have poorer well-being according to physical (fatigue) and psychological (depression, anxiety, and spirituality) metrics compared with women who are well connected with nature. In addition, although the effect was small (*P*=.03), our VR nature intervention was associated with improvements in depression among women who were disconnected with nature. The trend that these VR nature experiences might also be helpful for quality of life and fatigue in this population requires further investigation. Thus, the first contribution to the literature of this report lies in demonstrating a positive cross-sectional relationship between connection with nature and well-being in patients with MBC. Compared with those already strongly connected with nature, patients with MBC, with a relatively weaker connection reported poorer physical status (greater fatigue, although no differences in pain) and psychological function (greater depression and anxiety and poorer spiritual well-being). These results indicate that feeling connected with nature seems to matter in this population much like it does in other groups [53].

It is worth emphasizing that we focused on “connection” with nature (ie, asking participants how “close” they felt with nature) rather than “time” spent in nature. Recent work has demonstrated that it is not time spent in nature per se that is the critical factor for well-being. Instead, it is feeling connected or engaged with nature that is a key predictor in explaining variance in mental health and well-being [54]. Thus, activities that encourage engagement or connection are likely beneficial. It is also important to note that our study design limits the conclusions on the direction of the nature–well-being relationship. It is possible that rather than disconnection with nature leading to poorer physical and psychological status in patients with MBC, the reverse might be true, such that poorer mental or physical health inhibits connection with nature. We suspect that the relationship is bidirectional, much like the exercise–well-being relationship [55]; that is, connection with nature positively affects well-being, and positive well-being makes a person more likely to connect with nature. These findings have important implications for supporting women with MBC. Further investigation into the direction and nature of this relationship is warranted, including the extent to which feelings of *dis*connectedness are stable over time (ie, trait dispositions) versus fluctuate in response to short-term (ie, state) situations.

The second contribution of this work lies in demonstrating that a nature-based intervention might provide particular benefits to women who are disconnected with nature. Consistent with well-established evidence that describes how exposure to natural environments benefits groups who typically have infrequent contact with nature (eg, urban dwellers) [56-58], this report reveals that the participants in our study most likely to benefit were those who initially felt disconnected with nature. A burgeoning body of work has established that green spaces and activities such as forest bathing can provide both psychological benefits (stress reduction and mood improvement [56]) and physiological benefits, including reductions in blood pressure and heart rate [59,60] and improvements in immune function [61,62]. Benefits such as these are relevant to populations with cancer, where disease trajectories and quality of life might be improved through enhanced physiological and psychological functions. Although the benefits revealed in this study were limited to improvements in depression, similar patterns were observed in fatigue and quality of life, and these areas appear worthy of future attention. This work extends previous literature that has primarily focused on urban dwellers by indicating that a clinical population who is disconnected with nature owing to constraints that are either medical (eg, cancer) and psychological (eg, depression) might also benefit.

Finally, our findings suggest that *virtual* exposure to nature may be sufficient to generate benefits. Virtual experiences may be important in contexts in which patients with cancer are tied to urban settings that provide their treatment or indoors because of physical or psychological constraints. Virtual exposure to nature might provide benefits that align with work in other clinical contexts demonstrating benefits for pain management, stroke rehabilitation, and distraction during cancer treatment [25]. As noted earlier, research has demonstrated that a virtual replication of a nature experience provides almost identical benefits (physiological arousal, mood, and restorativeness) to the real-world experience [26]. Furthermore, following from the earlier point that connection rather than time in nature matters most, VR interventions appear particularly well placed to offer interactive activities designed to foster connectedness and active engagement with nature. Therefore, rather than simply providing an opportunity to observe (ie, be a bystander), virtual nature-based activities that encourage engagement may be helpful. Furthermore, interactive experiences may not need to be lengthy in a “quality over quantity”–type approach, and investigation of this possibility is warranted.

Our findings have important clinical implications for patients with MBC, a population that is often overlooked. Numerous studies have reported that the psychological and physical needs of patients with advanced cancer are frequently unmet [63,64]. Simple, scalable interventions such as VR nature experiences seem worthy of future attention. VR interventions designed to stimulate feelings of connectedness with nature appear to have merits, and brief interventions may be sufficient. In the context of scarce resources and fierce competition for the health care dollar, these preliminary findings provide a general indication of where resources could be effectively targeted. VR interventions are relatively affordable and can be implemented in a person’s own home as well as in hospital or hospice care, making this an approach worthy of further consideration.

Limitations and Suggestions for Future Research

Although this report is the first to provide evidence that a VR nature experience might be of particular benefit to women with MBC, who are disconnected from nature, this work is not without its limitations. First, it is worth emphasizing that this was a preliminary study with only a small number of participants (N=38), and as such, the study was only powered to identify large effects. The group with a higher connection to nature at baseline was small (9/38, 24%), and despite sensitivity analyses to determine the best way to categorize data, the statistical power to detect interaction effects was limited. Therefore, the results of this study should be interpreted as preliminary findings that require further investigation in other studies. Although our confidence in the merits of this intervention is bolstered by the fact that participants were compliant, enjoyed their experiences, and were generally open to the idea of using VR again [39], future work should recruit larger samples that will provide insight into the physical and psychological aspects of well-being most likely to be improved through an intervention of this kind.

In addition, as noted, this report outlines secondary analyses that did not assess the differences between the 2 VR experiences. Although it seems likely that different kinds of VR nature experiences might offer different types of benefits, primary analyses found no differences between the 2 interventions presented in this study [39]. Notably, there were numerous stylistic and content differences between the 2 VR experiences, and our design precludes comments on which of these elements might have been the most therapeutically potent. For instance, one experience used the real-life footage of nature scenes (Ripple), whereas the other was an animated experience (Happy Place). The latter included a greater number of interactive activities and thus, probably offered greater opportunities for distraction, but the former might have been more meditative. Furthermore, an alternative explanation for our findings is that those who perceived themselves as more connected to nature (ie, with higher INS scores) rejected the VR representations as oversimplifications of real nature compared with those with lower INS scores who were more satisfied with the simplistic representations of nature. Understanding how various characteristics of a VR nature intervention might influence outcomes and how people with varying degrees of self-perceived connection of nature seem worthy of investigation. Future studies could standardize aspects of the experience across conditions to assess, for instance, how the *sounds* of nature compare with the *sights* of nature, how *animated* footage compares with *real-world* photography, or how *guided relaxation* compares with *self-directed* experiences (to name a few). These are opportunities for future research to inform the development of targeted interventions.

Finally, this work is limited in that we did not include a control group, nor did we compare nature experience to a different kind of experience (eg, a gaming experience); thus, we cannot claim that the intervention or exposure to nature specifically caused benefits. However, some confidence that this might be the case is drawn from other evidence that VR nature experiences trump other virtual experiences [24] and our own participant feedback describing the therapeutic benefits of the experience, "Since starting the experiment I have had more energy, lasted full days at work, could still function when I got home, my memory is better ... it's the best I've felt since before starting treatment" [39]. Confirming the causality of benefits with regard to VR interventions or the potency of nature-based activities requires further study. It might also be that an interactive VR nature experience that can be shared with children or grandchildren might offer incremental benefits given the well-established benefits of social interaction [65]. Accordingly, future studies should assess social support as a possible confounding or moderating factor. Finally, our findings may demonstrate the power of interventions to improve outcomes by providing support, attention, and care to vulnerable groups. Women with MBC certainly need psychosocial support, and it is possible that any intervention that provides focused attention would have led to benefits.

Conclusions

This report is the first to provide preliminary evidence that feeling connected with nature is associated with better physical and psychological status in patients with MBC and that VR nature interventions might be of particular benefit for this clinical population. These findings have implications for the development of future interventions so that groups can be targeted not only where the need is most significant but also where benefits are most likely to be gained. For example, nature connectedness interventions could be developed for people who avoid venturing outdoors owing to clinically significant anxiety or depression. Such studies should focus on activities that encourage connection (rather simply exposure) with nature and investigate the aspects of VR nature interventions that have the greatest therapeutic potential.

Acknowledgments

This work was supported by the Breast Cancer Foundation New Zealand (grant 3719356).

Authors' Contributions

All authors were involved in the study conception and design. SC and AA were involved in the acquisition of data. SC, AC, and LR were involved in the analysis and interpretation of data. All authors were involved in manuscript writing and have read and approved the final manuscript.

Conflicts of Interest

AG is employed by the funder of this study (Breast Cancer Foundation New Zealand), which commissioned the development of one of the virtual reality interventions tested in this work (Ripple). LR received a grant from the Breast Cancer Foundation NZ to conduct this study.

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Abbreviations

BPI-SF: Brief Pain Inventory Short Form
DASS: Depression, Anxiety, and Stress Scale
DASS-21: Depression, Anxiety, and Stress Scale Short Form
FACIT: Functional Assessment of Chronic Illness Therapy
FACIT-Sp-12: Functional Assessment of Chronic Illness Therapy-Spiritual Well-being
INS: Inclusion of Nature in the Self
MBC: metastatic breast cancer
REDCap: Research Electronic Data Capture
VR: virtual reality

Edited by A Mavragani; submitted 04.04.22; peer-reviewed by Z Dai, L Powers Tomasso; comments to author 14.05.22; revised version received 24.05.22; accepted 11.06.22; published 22.07.22.

Please cite as:
Chin S, Cavadino A, Akroyd A, Tennant G, Dobson R, Gautier A, Reynolds L
An Investigation of Virtual Reality Nature Experiences in Patients With Metastatic Breast Cancer: Secondary Analysis of a Randomized Controlled Trial
JMIR Cancer 2022;8(3):e38300
URL: https://cancer.jmir.org/2022/3/e38300
doi:10.2196/38300
PMID:35867398

Original Paper

Association Between Patient Portal Use and Perceived Patient-Centered Communication Among Adults With Cancer: Cross-sectional Survey Study

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Abstract

Background: Patient-centered communication (PCC) plays a vital role in effective cancer management and care. Patient portals are increasingly available to patients and hold potential as a valuable tool to facilitate PCC. However, whether more frequent use of patient portals is associated with increased perceived PCC and which mechanisms might mediate this relationship have not been fully studied.

Objective: The goal of this study was to investigate the association between the frequency of access of patient portals and perceived PCC in patients diagnosed with cancer. We further sought to examine whether this association was mediated by patients' self-efficacy in health information–seeking.

Methods: We used data from the Health Information National Trend Survey 5 (HINTS 5) cycle 3 (2019) and cycle 4 (2020). This analysis includes 1222 individuals who self-reported having a current or past diagnosis of cancer. Perceived PCC was measured with a 7-item HINTS 5–derived scale and classified as low, medium, or high. Patient portal use was measured by a single item assessing the frequency of use. Self-efficacy about health information–seeking was assessed with a 1-item measure assessing confidence in obtaining health information. We used adjusted multinomial logistic regression models to estimate relative risk ratios (RRRs)/effect sizes of the association between patient portal use and perceived PCC. Mediation by health information self-efficacy was investigated using the Baron and Kenny and Karlson-Holm-Breen methods.

Results: A total of 54.5% of the sample reported that they had not accessed their patient portals in the past 12 months, 12.6% accessed it 1 to 2 times, 24.8% accessed it 3 to 9 times, and 8.2% accessed it 10 or more times. Overall, the frequency of accessing the patient portal was marginally associated (P=.06) with perceived PCC in an adjusted multinominal logistic regression model. Patients who accessed their patient portal 10 or more times in the previous 12 months were almost 4 times more likely (RRR 3.8, 95% CI 1.6-9.0) to report high perceived PCC. In mediation analysis, the association between patient portal use and perceived PCC was attenuated adjusting for health information–seeking self-efficacy, but those with the most frequent patient portal use (10 or more times in the previous 12 months) were still almost 2.5 times more likely to report high perceived PCC (RRR 2.4, 95% CI 1.1-5.6) compared to those with no portal use.

Conclusions: Increased frequency of patient portal use was associated with higher PCC, and an individual's health information–seeking self-efficacy partially mediated this association. These findings emphasize the importance of encouraging patients and providers to use patient portals to assist in patient-centeredness of cancer care. Interventions to promote the adoption and use of patient portals could incorporate strategies to improve health information self-efficacy.

(JMIR Cancer 2022;8(3):e34745) doi:10.2196/34745

KEYWORDS

health information technology; informatics; cancer care; patient-centered communication; patient portal; patient communication; cancer; oncology; health information; information seeking; patient-centered care; patient perception

Introduction

Approximately 17 million people in the United States are living with cancer [1]. Cancer, in many forms, is considered a chronic disease [2]. Living with cancer imposes significant disease management demands and carries substantial psychological, financial, and physical burdens [3]. Patients undergoing active treatment and survivors needing continued cancer surveillance and management deserve high-quality patient-centered care rooted in respect for patients' dignity and clear communication [4,5]. There has been a strong and growing emphasis in policy and practice on patient-centered care since the Institute of Medicine released a consensus report in 2013 that provided a blueprint for it [6].

Patient-centered care comprises multiple factors, and patient-centered communication (PCC) is an essential aspect [7,8]. PCC is a communication style that seeks to understand and account for the patient's concerns, needs, feelings, and psychosocial and cultural context [9,10]. PCC increases patient satisfaction in chronic disease management, especially in cancer care [5,9-13]. However, PCC is challenging and time-consuming in practice [14] and can benefit from patient-facing digital health tools that can aid in effective communication within the time restraints of busy oncology settings [11]. Patient portals are potentially one such tool. They enable patients to view their medical records, communicate via secure messaging with their care teams, access lab results, renew prescriptions, request appointments, and pay their medical bills [15,16]. Even though patient portals have been documented to improve patient engagement, increase PCC, advance health care quality, and improve psychosocial outcomes in medical care [17-19], their optimal use in cancer care delivery has not yet been achieved [20-22].

Much research promoting PCC in cancer care has focused on assessing and improving clinicians' skills and training. Less work, however, has been done on patient-specific characteristics such as a patient's ability to seek information [23]. One specific factor impacting the quality of care received in cancer care is the patient's perceived self-efficacy [24]. Perceived self-efficacy is one's confidence to exercise control over one's functioning and execute actions that will lead to a specific outcome [25]. It influences the adoption and maintenance of health-promoting behaviors [23,26]. Self-efficacy related to one's ability to take care of one's health has shown a positive association in earlier studies with PCC [27], including in a study of patients diagnosed with cancer [28]. Moreover, self-efficacy has been shown to mediate the association between PCC and emotional distress in patients diagnosed with cancer [29].

Health information self-efficacy is a personal belief that one can take action to get the information if they need it regarding a health concern [30]. Patients diagnosed with cancer have an increased need for information-seeking due to the level of health care decisions they need to make [31]. Providers remain the most trusted form of knowledge in cancer information-seeking [32-34]. Health informatics tools such as patient portals have become additional channels by which patients communicate with their providers and access their medical records [35,36]. Patients with increased health information self-efficacy may be better positioned to engage with their clinical team through patient portals, potentially leading to better rapport and better perceived patient-centeredness of communication. However, this has yet to be empirically studied.

The purpose of this study was to assess the association between the frequency of access to patient portals and perceived PCC in a national sample of individuals who have had a diagnosis of cancer. We further sought to determine whether self-efficacy related to information-seeking mediated the relationship between frequency of access to patient portals and PCC. We hypothesized that greater frequency of portal access would be associated with high PCC and that health information self-efficacy mediates the relationship between portal use frequency and PCC.

Methods

Data Source

Data examined for this study were from the Health Information National Trends Survey (HINTS). HINTS is a cross-sectional survey that the National Cancer Institute has regularly administered since 2004. HINTS aims to assess how people access and use health information, how people use information technology to manage health and health information, and the degree to which people are engaged in healthy behaviors [37]. The population from which HINTS samples is civilian, noninstitutionalized adults aged 18 years and above living in the United States. Similar to prior HINTS cycles, the sampling frame consisted of drawing on a database of participant addresses used by the Marketing System Group to provide random samples of addresses [38].

This study combines the third and fourth data collection cycles for HINTS 5. HINTS 5 cycle 3 was conducted from January 22 to April 30, 2019, and it consisted of data from 3500 respondents using a mailed survey. The response rate for the mailed survey was 30.2%. During HINTS 5 cycle 3, a web pilot test was run alongside the self-administered mailed version from January 29 to May 7, 2019. The web pilot comprised 2046 additional respondents. The web-based pilot included an experiment testing the effectiveness of offering a $10 Amazon gift card for responding via the web. Web pilot respondents who were offered the bonus incentive had a slightly higher response rate (31.5%) compared to the control group (29.6%), who did not receive the Amazon gift card [38]. We used both mail-in and online responses for HINTS 5 cycle 3. To use the combined sample, we tested for the differences in both versions for our outcome variable by mode and found no difference. The data collection for HINTS 5 cycle 4 was conducted from February 24, 2020, to June 15, 2020, using self-administered mail-in surveys only. A total of 3865 surveys were collected. The overall response rate for HINTS 5 cycle 4 was 32.6% [39]. Of the 9411 HINTS 5 participants in cycles 3 and 4, 1482 self-reported a diagnosis of cancer, the population of interest for this study. Of these individuals, 260 were excluded due to missing data, resulting in a final analytic sample of 1222.

Ethics Approval

This study qualified for exempt status from the Committee for the Protection of Human Subjects at the University of Massachusetts Chan Medical School.

Measures

Use of Patient Portals

Use of patient portals was measured by the question: How many times did you access your online medical record in the last 12 months? We categorized this as no use, 1 to 2 times, 3 to 9 times, and 10 or more times during the last 12 months. Online medical records are accessed with the help of patient portal secure log-ins [40-42], and patient portal is a more familiar term [16]; hence we used the term patient portal in this paper for this measure.

Perceived PCC

Perceived PCC was assessed with 7 items. Participants asking about communication with all health professionals were asked to assess the frequency with which their providers engaged in the following behaviors in the past 12 months: Give you the chance to ask all the health-related questions you had? Give the attention you need to your feelings and emotions? Involve you in decisions about your health care as much as you wanted? Make sure you understood the things you needed to do to take care of your health? Explain things in a way you could understand? Spend enough time with you? Help you deal with feelings of uncertainty about your health or health care? All items were measured on a 4-point Likert scale ranging from always (1) to never (4).

To create the PCC score, items were reverse coded so that higher numbers reflected higher levels of communication. The mean of all 7 items is transformed to a linear scale ranging from 1 to 100 [11]. The PCC score for individuals in our study was highly skewed with a great number of individuals at the top of the scale toward higher communication. As such, we broke the scale into 3 categories: low PCC (<25th percentile, mean 51.7, SE 2.0, range 0-66.7); moderate PCC (25th-50th percentile, mean 78.2, SE 0.7, range 71.4-85.7), and high PCC (≥50th percentile, mean 97.9, SE .3, range 86.7-100).

Health Information–Seeking Self-efficacy

The mediating variable was health information–seeking self-efficacy. We hypothesized that it mediated the relationship between frequency of portal use and perceived PCC. Self-efficacy in seeking health information was measured using 1 item used in previous studies [43,44]. In cycle 3, this item was worded as such: Overall, how confident are you that you could get advice or information about health or medical topics if you needed it? This question was worded differently in cycle 4: Overall, how confident are you that you could get advice or information about cancer if you needed it? In both cycles, the answer choices used a Likert scale ranging from 1 to 5, from completely confident (1) to not confident at all (5). We treated them as the same question in our analyses as our sample consisted of only patients with a diagnosis of cancer. Because of small cell sizes, response choices were dichotomized to somewhat/a little/not at all confident versus completely/very confident and conceptualized as highly confident versus not highly confident. This dichotomization is similar to that used in a previous study using this variable [45].

Other Variables

Our analysis is adjusted for gender (male, female), age (<55 years, 55 to 64 years, 65 to 74 years, 75 years and older), race/ethnicity (non-Hispanic White, non-Hispanic Black, Hispanic, non-Hispanic Asian/other), income level (<\$35,000, \$35,000-\$99,999, ≥\$100,000), education level (less than high school, high school graduate, some college, college graduate or more), and health insurance status (private, Medicare, Medicaid, or dual coverage). Previous research has shown that these variables have an impact on access and use of patient portals [20,46,47]. In this analysis, we also accounted for time since diagnosis of cancer (less than 1 year, 2 to 5 years, 6 to 10 years, ≥11 years) as it can also impact a patient's information-seeking needs [48].

Statistical Analysis

All analyses used Taylor series variance estimation with HINTS sampling weights to produce nationally representative estimates as suggested in HINTS methodology guides [38,39]. Characteristics of the sample were described using weighted percentages. Multivariable multinomial logistic regression models estimated relative risk ratios (RRRs)/effect sizes and 95% confidence intervals comparing high and moderate perceived PCC versus low perceived PCC. We tested 2 regression models, one without health information self-efficacy and one with it. Models were adjusted for gender, age, race/ethnicity, income, education, type of health insurance, time since diagnosis, and HINTS cycle. The role of self-efficacy as a mediator of the association between frequency of access to patient portals with PCC was first investigated using the Baron and Kenny method [49,50]. A formal mediation analysis using the Karlson-Holm-Breen method was then conducted to estimate and interpret total direct and indirect effects for nonlinear probability modes [51]. All analyses were conducted using Stata 14 (StataCorp LLC).

Results

Sample Description

The analytic sample with complete data responses included 1222 respondents, 661 from HINTS 5 cycle 3 and 561 from HINTS 5 cycle 4. As shown in Table 1, about half (49.1%) of the sample was younger than 65 years and male (45.4%). A majority (77.0%) were non-Hispanic White, 41.2% reported less than $35,000 in household income, and approximately 70% attended college. Consistent with our categorization scheme, approximately one-quarter of respondents were categorized as low (26.5%) or moderate (24.5%) on the PCC scale and slightly less than half (49.0%) were categorized as high. About half (54.49%) had not accessed their patient portal in the past 12 months. In this sample, the greatest proportion of those with no portal use were females (55.5%), aged 75 years and older (71.7%), non-Hispanic Black (77.1%), <$35,000 per year in income (64.9%), with less than high school education (76.5%). Almost two-thirds (62.6%) of the sample reported high levels of health information–seeking self-efficacy.

Table 1. Characteristics and differences in portal use among respondents with a self-reported cancer diagnosis in the Health Information National Trends Survey cycles 3 and 4 (n=1222 weighted percentages)[a].

Characteristic	Total sample, %	Portal use in the past 12 months, %				
		No use	1-2 times	3-9 times	≥10 times	*P* value
Gender	—[b]	—	—	—	—	.31
Male	45.4	50.9	17.2	23.5	8.4	—
Female	54.6	55.5	9.8	26.3	8.3	—
Age group (years)	—	—	—	—	—	<.001
<55	26.5	52.0	11.5	29.7	6.9	—
55-64	22.6	41.1	15.6	25.6	17.8	—
65-74	24.0	49.6	17.5	25.6	7.3	—
≥75	26.9	71.7	5.1	20.2	2.9	—
Race/ethnicity	—	—	—	—	—	.02
Non-Hispanic White	77.0	46.5	16.0	27.1	10.4	—
Non-Hispanic Black	7.4	77.1	7.7	8.7	6.5	—
Hispanic	10.8	66.2	6.8	25.7	1.4	—
Non-Hispanic Asian/other	4.9	54.1	8.5	34.2	3.2	—
Income level ($)	—	—	—	—	—	.03
<35,000	41.2	64.9	7.9	18.8	8.5	—
35,000-99,999	39.7	49.9	15.1	27.5	7.5	—
>100,00	19.1	41.6	17.5	32.0	9.0	—
Highest level of education	—	—	—	—	—	<.001
Less than high school	7.9	76.5	1.2	21.9	0.4	—
High school graduate	22.2	61.6	10.3	21.7	6.5	—
Some college	42.6	58.6	10.5	21.5	9.4	—
College graduate or higher	27.3	34.1	21.6	34.2	10.2	—
Health insurance	—	—	—	—	—	.17
Private (employer or purchased on own)	56.3	50.1	15.8	25.5	8.7	—
Medicare and privately purchased insurance	8.8	55.0	11.2	28.8	5.1	—
Medicare	25.0	62.0	8.2	24.7	5.1	—
Medicaid	7.9	54.0	8.8	15.7	21.5	—
Other/IHS[c]/VA[d]/Tricare	2.0	82.3	4.3	13.4	0	—
Time since diagnosis (year)	—	—	—	—	—	.21
<1	15.9	48.8	12.3	25.0	13.9	—
2-5	21.2	47.9	11.7	24.8	15.5	—
6-10	15.5	60.9	10.2	21.6	7.3	—
≥11	47.4	53.5	13.5	28.8	4.2	—
Patient-centered communication score	—	—	—	—	—	.19
Low (<25th percentile)	26.5	61.2	15.0	20.5	3.4	—
Moderate (25th-50th percentile)	24.5	53.0	10.6	29.5	7.1	—
High (≥50th percentile)	49.1	51.7	12.2	24.8	11.3	—
Health information–seeking self-efficacy	—	—	—	—	—	.006
Somewhat/a little/not at all	37.4	63.0	13.0	20.7	3.3	—

Characteristic	Total sample, %	Portal use in the past 12 months, %				
		No use	1-2 times	3-9 times	≥10 times	*P* value
Completely/very	62.6	48.8	12.5	27.6	11.1	—

[a] All analyses used Taylor Series variance estimation with Health Information National Trends Survey sampling weights to produce nationally representative estimates.

[b] Not applicable.

[c] IHS: Indian Health Service.

[d] VA: Veterans Affairs.

Multivariable Multinomial Model

Results of the multinomial model assessing the association between frequency of portal use and perceived PCC are presented in the middle column of Table 2. In the overall multivariable multinomial model, the frequency of access to the patient portal was marginally associated (*P*=.06) with PCC. Patients who accessed their patient portal only 1 or 2 times were equally as likely to have moderate PCC versus low PCC (RRR 0.99, 95% CI 0.42-2.34) than those who did not access it. Those who accessed the patient portal 3 to 9 times had more than twice the odds of moderate versus low PCC (RRR 2.22, 95% CI 1.01-4.86) than those who never accessed it. Those who accessed the patient portal 10 or more times were almost 3 times as likely to have moderate PCC versus low PCC (RRR 2.91, 95% CI 0.89-9.49) than those who did not access it. With respect to comparisons between respondents with high PCC versus low PCC, those who accessed the patient portal 1 or 2 times were 14% more likely than those who did not access it to have high versus low PCC (RRR 1.14, 95% CI 0.49-2.64). Those who accessed it 3 to 9 times had a 67% increase in the odds of high PCC versus low PCC (RRR 1.67, 95% CI 0.88-3.16). Last, those who accessed their record 10 or more times were almost 4 times more likely to have high PCC versus low (RRR 3.63, 95% CI 1.58-8.34).

Table 2. Results of adjusted multinomial logistic regression models measuring the association of frequency of online access to patient portals with perceived patient-centered communication score[a].

Characteristic	Without adjustment for health information–seeking self-efficacy			With adjustment for health information–seeking self-efficacy		
	Moderate vs low PCC[b], RRR[c] (95% CI)	High vs low PCC, RRR (95% CI)	*P* value	Moderate vs low PCC, RRR (95% CI)	High vs low PCC, RRR (95% CI)	*P* value
Frequency of patient portal access	—[d]	—	.06	—	—	.25
None	—	—	—	—	—	—
1-2 times	0.99 (0.42-2.34)	1.14 (0.49-2.64)	—	0.94 (0.39-2.23)	0.94 (0.38-2.32)	—
3-9 times	2.22 (1.01-4.86)	1.67 (0.88-3.16)	—	2.01 (0.91-4.48)	1.31 (0.67-2.56)	—
≥10 times	2.91 (0.89-9.49)	3.63 (1.58-8.34)	—	2.49 (0.78-8.02)	2.32 (1.03-5.23)	—
Health information–seeking self-efficacy	—	—	—	—	—	<.001
Somewhat/a little/not at all	—	—	—	1.78 (0.97-3.26)	4.57 (2.57-8.12)	—
Completely/very high	—	—	—	1.78 (0.97-3.26)	4.57 (2.57-8.12)	—

[a] All analyses adjust for gender, age, race/ethnicity, income level, education level, health insurance status, and time since diagnosis.

[b] PCC: patient-centered communication.

[c] RRR: relative risk ratio.

[d] Not applicable.

Mediation Analyses

The 4-step Baron and Kenny method was first used to investigate the role of health information–seeking self-efficacy as a mediator of the association between frequency of patient portal use and PCC [52]. In multinomial logistic models, we found the frequency of patient portal use overall was marginally associated with PCC (step 1, column 1 of Table 2, *P*=.06). Of note, those who accessed their portal 10 or more times (compared to those who did not access it) were more likely to have high PCC versus low PCC (RRR 3.63, 95% CI 1.58-8.34). We also found that the frequency of patient portal use was significantly associated with health information–seeking self-efficacy (step 2, column 2 of Table 2, *P*<.001). Health information–seeking self-efficacy was also associated with PCC. Individuals with high self-efficacy were more likely to report high PCC compared to those with low self-efficacy (step 3, column 3 of Table 3; RRR 4.57, 95% CI 1.03-5.23). When adjusting for health information self-efficacy, the *P* value for the association of frequency of portal use and PCC was no longer marginally significant (step 4, column 3 of Table 2, *P*=.25). The association between portal use of 10 or more times (compared to none) was also attenuated but remained statistically significant, with those reporting high use more likely to report high PCC (RRR 2.23, 95% CI 1.03-5.23).

These findings led to a more formal mediation analysis using the Karlson-Holm-Breen method, presented in Table 3. This analysis revealed that all levels of patient portal use showed a decreased association with PCC when controlled for health information–seeking self-efficacy. The full results are presented in Table 3. In the Karlson-Holm-Breen analysis, for those who accessed the patient portal 10 or more times, the odds of having high PCC versus low PCC were almost 4 times greater than those who did not access the portal (95% CI 1.63-9.59). After controlling for health information–seeking self-efficacy, that effect decreased to 2.3 times (95% CI 0.94-5.72). A total of 43% of the association between portal use and PCC was due to health information–seeking self-efficacy.

Table 3. Mediation results of communication scores using the Karlson-Holm-Breen method.

Characteristic	Odds ratio (95% CI)	Confounding ratio	Mediated proportion (indirect/total)
Frequency of patient portal access: moderate compared with lowest scores			
None	—[a]	—	—
1-2 times	—	–0.25	1.07
Total effect	1.02 (0.43-2.43)	—	—
Direct effect	0.94 (0.39-2.23)	—	—
Indirect effect	1.09 (0.92-1.28)	—	—
3-9 times	—	1.15	0.5
Total effect	2.23 (1.08-4.63)	—	—
Direct effect	2.01 (0.97-4.16)	—	—
Indirect effect	1.11 (0.93-1.33)	—	—
≥10 times	—	1.22	0.4
Total effect	3.05 (1.02-9.10)	—	—
Direct effect	2.49 (0.82-7.55)	—	—
Indirect effect	1.22 (0.95-1.58)	—	—
Frequency of patient portal access: highest compared with lowest scores			
None	—	—	—
1-2 times	—	–2.63	1.06
Total effect	1.17 (0.49-2.81)	—	—
Direct effect	0.94 (0.39-2.28)	—	—
Indirect effect	1.24 (0.85-1.81)	—	—
3-9 times	—	2	0.76
Total effect	1.73 (0.89-3.33)	—	—
Direct effect	1.31 (0.68-2.54)	—	—
Indirect effect	1.31 (0.89-1.93)	—	—
≥10 times	—	1.63	0.43
Total effect	3.95 (1.63-9.59)	—	—
Direct effect	2.32 (0.94-5.72)	—	—
Indirect effect	1.70 (1.11-2.60)	—	—

[a] Not applicable.

Discussion

Principal Findings

This study examined the association between the frequency of patient portal use and perceived PCC in patients diagnosed with cancer. We also investigated health information–seeking self-efficacy as a mediator of this association. Our findings indicated that the frequent levels of patient portal use (≥10 times in the past year) may be correlated with high levels of PCC. We also found that this association was partially mediated by health information–seeking self-efficacy.

In cancer care delivery, patient portal use has been increasing [20]. Patients report having more self-advocacy by feeling more involved and informed in their care when they access information through patient portals. The use of portals allowed them to reach their providers in a timely manner and enhanced their participation in their in-person consultations [21]. Our findings suggest that frequency of portal use may have an important role to play in improving PCC with their providers. These findings further support the small body of literature that has demonstrated that patient portals positively impact patient communication with their providers in cancer care delivery [21,53-55].

The provider's role is critical in establishing PCC, and patient portals are intended to enhance, not replace, patient-provider face-to-face interactions [54,56]. Prior work has demonstrated that such use cannot always replace the human approach needed for establishing PCC for everyone [55,57,58]. The portal use would facilitate patient-provider communication between visits and may better prepare patients with information for in-person visits. As patient portals become more widely used in all medical settings, cancer care providers, particularly given the complexity of cancer and its treatment [54], will need to become more engaged with how patients view their medical information. It will be beneficial to consider the portal within the framework of patient-centered care by valuing patient communication preferences [21]. However, these efforts will require health systems to enable the providers to have the time and reimbursement ability to allow for safe and effective integration of patient portal–related tasks in their daily workflow [59].

Although there was a strong association between high use of patient portals and PCC in this study, only a small proportion of the included sample were frequent users of patient portals, and more than half of the sample reported no patient portal use. The greatest proportion of those with no portal use were females, participants in the 75 years and older age group, non-Hispanic Black participants, in households with <$35,000 per year in income, and participants who reported to have had less than a high school education (76.5%). Our findings are consistent with prior research on these sociodemographic differences except for gender, where males were reported to be less likely to use patient portals in previous studies [60,61]. A future study will be fruitful in addressing low access to patient portals in oncology-specific populations focused on patient preferences, type, and stage of their cancer, along with their patient portal accessibility and other sociodemographic characteristics.

Our analysis further confirms that a significant digital divide persists in actively getting patients to engage with patient portals, as previously reported [62,63]. Patient portal technology may create or exacerbate health equity concerns by not addressing the divide that social determinants of health play in its access and use [64,65]. One promising action to reduce such disparities in portal use is to aim for universal access to health information technology tools and to become aware of users' health literacy levels and preferred ways of communicating with the providers [66]. While provider encouragement is one of the factors associated with increased access and use of patient portals [67-70], referrals vary by patient race, socioeconomic status, and providers' personal beliefs about the benefits of patient portal use, contributing significantly to access disparities [22,71]. Targeting providers with additional patient portal referral training could be an effective strategy for increasing patient portal adoption among cancer patients, as demonstrated in studies of other patient populations [72-74].

This analysis also demonstrated that health information–seeking self-efficacy partially mediates the association between patient portal use and PCC. Hence, our findings suggest that enhancing self-efficacy in portal use is an important intervention target. It is increasingly emphasized to incorporate user perspectives in health information technology designs [75]. Numerous ventures have incorporated patient-centered approaches in patient portal use [72,73]. One approach to accomplishing this in cancer care is to design portals according to the needs of patients with different kinds of cancers, as portal enrollment by cancer sites varies [76]. Research shows that the digital divide is not caused only by a lack of devices and knowledge but also by a lack of fit between digital tools and people's experiences [66]. Hence, there remains a need to improve portals to increase confidence in user usability, including among underresourced populations and in populations that experience poor self-reported health, where portal use is reported to be beneficial [77-79]. For example, features such as OpenNotes, which allow patients to access provider notes via portals, have shown promise in increasing feelings in patients of being informed and in control of their care, thus increasing trust in clinicians [57,77-80]. Oncology patients who face a greater information burden have shown enthusiasm for reading their clinicians' notes [22]. Another approach to increase patient portal use in cancer care is promoting interventions targeting portal awareness and supporting patients accessing their notes.

It is crucial to consider that enhancing portal use is not only dependent on increasing competencies such as knowledge and skills but also on aligning with patient needs and live experiences. To meet these needs, user input is required in designing patient portals in specific populations dealing with distinct health care needs [81]. For example, our analysis indicated that the percentage of nonusers climbed as the ages rose: 41.1% for those aged 55 to 64 years, 49.6% for those aged 65 to 74 years, and 71.7% for those aged 70 years and older. Therefore, more studies should involve adults over 65 years to determine their patient portal design needs to increase usability. Contrary to the conventional belief that adults 65 years and older may not want to use patient portals, this age group may vary in their use based on their age cohort. It is essential in cancer care, where the burden of cancer is higher in older adults. Health care researchers focused on patient portal design and implementation will need to use community-engaged research strategies to conduct studies that will include the users and find out from them directly what will make portals helpful and attractive for them. Efforts will need to be directed toward minimizing biases in the recruitment of such studies based on age, gender, race/ethnicity, socioeconomic status, and education. Multiple studies may be needed to truly understand the needs of communities and disease populations where portals are intended to be available for users [56]. Developers of patient portals can also use some approaches used by health apps that offer user-centric interface design [82].

Limitations

Limitations of our study include the use of self-reported data and the cross-sectional design. There is the possibility of recall bias in the frequency and use of patient portals, and the design precludes causal inference. Specifically, we cannot infer whether increased portal use causes increased PCC and vice versa [35]. We elected to examine portal use as an independent variable because of the population under consideration and other evidence suggesting the contributing role of patient accessible online records on PCC [19]. Our adjustment for confounders was limited to variables available in the HINTS data set. It is possible that unmeasured confounding affected our results. We also could not assess the type of cancer the individuals had or for what purposes individuals were accessing portals in this analysis due to small cell sizes. For example, scheduling an appointment is much different than checking for labs or communicating with a provider. It will also be challenging to address through patient portals any emotional concerns of the patient that require face-to-face direct communication. The wording of the health information self-efficacy survey item differed slightly between HINTS cycles. Based on similar distributions across cycles and our selection of the sample with only patients diagnosed with cancer, the 2 similarly worded variables were merged into a single variable. However, the 2 items may measure different dimensions of medical health information self-efficacy.

Concerning the generalizability of this study, HINTS weights only reflect certain demographic characteristics of the US population and do not take into consideration other factors that may influence individuals electing to participate in the study, which hypothetically could include factors such as greater motivation related to health and health-related constructs. The study sample includes a mix of patients with recent (<15% diagnosed less than a year ago) and distant (approximately 50% diagnosed ≥11 years ago) cancer diagnoses. Hence our results are not generalizable to more recently diagnosed patients. We also combined non-Hispanic Asians/others as our numbers in each category were too low to keep separate. Hence we could not point toward any differences based on race or ethnicity. Likewise, we were unable to compare our sample to a similar national sample of cancer survivors with respect to sociodemographic profile as these data do not exist. Last, we used the term patient portals in this paper as it is a more widely known term and most online records can be accessed via secure patient portal sign-ins. However, online medical records and patient portals could refer to different types of systems, and we cannot ascertain to which the participants were referring.

Conclusion

In summary, PCC is a vital part of quality cancer care. Findings from this national survey suggest that increased frequency of patient portal use is associated with higher PCC and that an individual’s health information–seeking self-efficacy partially mediates this association. While the results of this study need to be replicated in future longitudinal studies, these findings suggest that interventions to encourage the adoption and use of patient portals could incorporate strategies to improve health information self-efficacy and lead to improved PCC.

Acknowledgments

MZ is supported by grant T32 CA172009 from the National Cancer Institute (NCI). DA is supported by the grant KL2TR001455 from the National Center for Advancing Translational Sciences of the National Institutes of Health (NIH). SCL, RSS, EA, MIF, and JMF are supported by grant 1K12HK138049-01 from the National Heart, Lung, and Blood Institute. The contents are solely the responsibility of the authors and do not necessarily represent the official views of the NIH, NCI, US Department of Veterans Affairs, or the US Government. The authors are thankful to the NCI Health Information National Trends Survey (HINTS) investigators for their commitment to data collection and making it publicly available, and NCI HINTS participants for their participation in this research.

Conflicts of Interest

None declared.

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Abbreviations

HINTS: Health Information National Trends Survey
NCI: National Cancer Institute
NIH: National Institutes of Health
PCC: patient-centered communication
RRR: relative risk ratio

Edited by A Mavragani; submitted 19.11.21; peer-reviewed by J Benjamins, J Alpert, R Moser; comments to author 24.01.22; revised version received 12.06.22; accepted 14.07.22; published 09.08.22.

Please cite as:
Zaidi M, Amante DJ, Anderson E, Ito Fukunaga M, Faro JM, Frisard C, Sadasivam RS, Lemon SC
Association Between Patient Portal Use and Perceived Patient-Centered Communication Among Adults With Cancer: Cross-sectional Survey Study
JMIR Cancer 2022;8(3):e34745
URL: https://cancer.jmir.org/2022/3/e34745
doi:10.2196/34745
PMID:35943789

Original Paper

Deploying the Behavioral and Environmental Sensing and Intervention for Cancer Smart Health System to Support Patients and Family Caregivers in Managing Pain: Feasibility and Acceptability Study

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Abstract

Background: Distressing cancer pain remains a serious symptom management issue for patients and family caregivers, particularly within home settings. Technology can support home-based cancer symptom management but must consider the experience of patients and family caregivers, as well as the broader environmental context.

Objective: This study aimed to test the feasibility and acceptability of a smart health sensing system—Behavioral and Environmental Sensing and Intervention for Cancer (BESI-C)—that was designed to support the monitoring and management of cancer pain in the home setting.

Methods: Dyads of patients with cancer and their primary family caregivers were recruited from an outpatient palliative care clinic at an academic medical center. BESI-C was deployed in each dyad home for approximately 2 weeks. Data were collected via environmental sensors to assess the home context (eg, light and temperature); Bluetooth beacons to help localize dyad positions; and smart watches worn by both patients and caregivers, equipped with heart rate monitors, accelerometers, and a custom app to deliver ecological momentary assessments (EMAs). EMAs enabled dyads to record and characterize pain events from both their own and their partners' perspectives. Sensor data streams were integrated to describe and explore the context of cancer pain events. Feasibility was assessed both technically and procedurally. Acceptability was assessed using postdeployment surveys and structured interviews with participants.

Results: Overall, 5 deployments (n=10 participants; 5 patient and family caregiver dyads) were completed, and 283 unique pain events were recorded. Using our "BESI-C Performance Scoring Instrument," the overall technical feasibility score for deployments was 86.4 out of 100. Procedural feasibility challenges included the rurality of dyads, smart watch battery life and EMA reliability, and the length of time required for deployment installation. Postdeployment acceptability Likert surveys (1=strongly disagree; 5=strongly agree) found that dyads disagreed that BESI-C was a burden (1.7 out of 5) or compromised their privacy (1.9 out of

5) and agreed that the system collected helpful information to better manage cancer pain (4.6 out of 5). Participants also expressed an interest in seeing their own individual data (4.4 out of 5) and strongly agreed that it is important that data collected by BESI-C are shared with their respective partners (4.8 out of 5) and health care providers (4.8 out of 5). Qualitative feedback from participants suggested that BESI-C positively improved patient-caregiver communication regarding pain management. Importantly, we demonstrated proof of concept that seriously ill patients with cancer and their caregivers will mark pain events in real time using a smart watch.

Conclusions: It is feasible to deploy BESI-C, and dyads find the system acceptable. By leveraging human-centered design and the integration of heterogenous environmental, physiological, and behavioral data, the BESI-C system offers an innovative approach to monitor cancer pain, mitigate the escalation of pain and distress, and improve symptom management self-efficacy.

International Registered Report Identifier (IRRID): RR2-10.2196/16178

(JMIR Cancer 2022;8(3):e36879) doi:10.2196/36879

KEYWORDS

mobile health; mHealth; smart health; cancer; pain; palliative care; family caregiver; remote monitoring; feasibility and acceptability; rural

Introduction

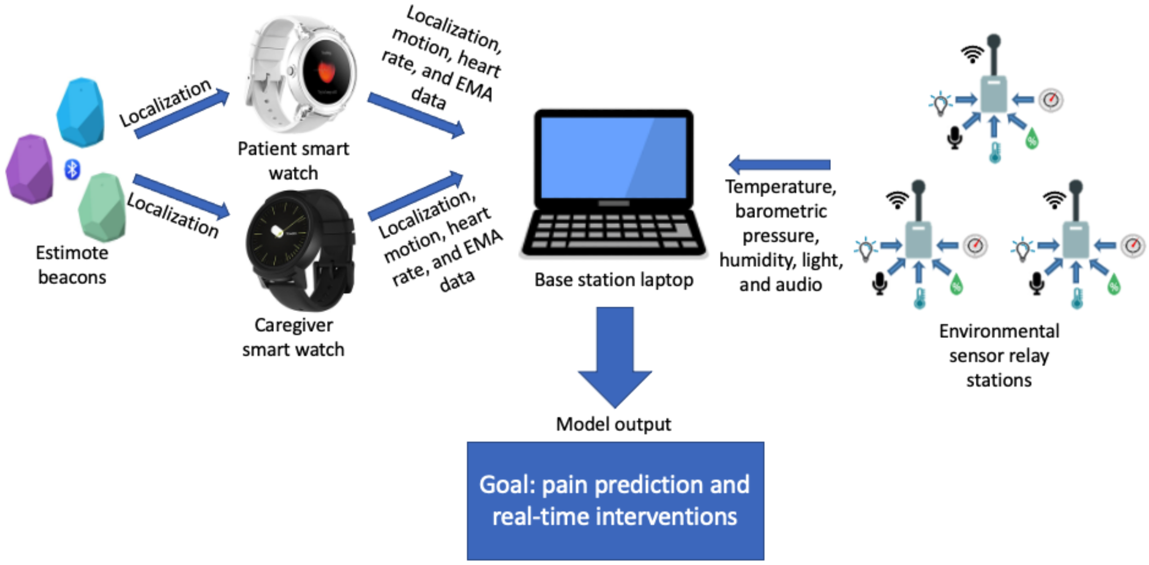
Background

Pain is a pervasive problem in advanced-stage cancer, occurring in almost 100% of patients [1] and undertreated in most (close to 70% of patients [2]). Complicating this reality is the fact that most cancer symptom management occurs in the home setting, often requiring significant support and help from family caregivers, who may be ill-prepared to take on this role [3,4]. The distress experienced by family caregivers in helping manage symptoms, especially difficult cancer pain, is well documented [5-10], as is the multitude of negative physical and emotional sequelae of poorly managed pain [11-13]. Ensuring equitable access to pain management requires innovative approaches that capitalize on low-burden home-based technologies that can support both patients and family caregivers. One critical lesson from the COVID-19 pandemic is the importance and great potential of remotely providing quality health care [14]. Sensing systems that can effectively monitor and prevent escalation of difficult symptoms at home, such as cancer pain, provide a powerful opportunity to reduce patient and caregiver distress, as well as unwanted emergency room visits and hospitalizations [15-23].

Objectives

This study aimed to address the need for improved cancer pain management and represents a multiphase, interdisciplinary effort to design and test an in-home smart health remote monitoring system known as the Behavioral and Environmental Sensing and Intervention for Cancer (BESI-C). Our research has a particular focus on supporting the pain management needs of patients with advanced cancer and their family caregivers in rural settings, a population with well-documented disparities and challenges related to symptom management [24-27]. The overall research protocol [28] and user-centered design process [29] for BESI-C have been reported in detail elsewhere. Briefly, BESI-C is an end-to-end sensing system that consists of (1) physical components (smart watches, environmental sensors, and localization beacons) deployed in patient homes to gather physiological, behavioral, and contextual data regarding pain events from the perspective of both patients and family caregivers and (2) an approach for data analytics (Figure 1). The long-term clinical goal of BESI-C is to successfully predict pain episodes and deliver real-time tailored interventions to reduce distress and enhance self-efficacy in managing pain for both patients and caregivers, as well as sharing relevant data with stakeholders to inform personalized care management decisions. The broader aim of BESI-C is to reduce cancer health disparities by increasing equitable access to quality and compassionate cancer pain management. This manuscript presents the results of feasibility and acceptability testing of BESI-C and offers “lessons learned” for others engaged in similar digital health research.

Figure 1. BESI-C system architecture used for feasibility and acceptability testing.



Methods

Overall Study Design

This descriptive study assessed the feasibility and acceptability of the BESI-C system. Feasibility was operationalized *procedurally* as (1) logistic barriers related to in-home deployment (eg, structural constraints within the dyad home related to placing environmental sensors) and (2) participant recruitment and attrition rates and *technically* as (3) the fidelity of data capture, recorded as a composite score after each deployment. Acceptability was operationalized as dyad perceptions and receptivity to BESI-C and assessed at the time of removal of BESI-C from a dyad's home by (1) a Likert-style survey and (2) structured interview questions asking about general experiences with the system.

Ethics Approval

Ethics approval was granted by the University of Virginia Health Sciences Institutional Review Board (HSR IRB 21017), and all participants provided informed consent before data collection. The participants were shown prototypes or pictures of the BESI-C system during the informed consent process to better understand the project.

Setting

Patients and family caregivers were recruited from an outpatient palliative care clinic at an academic medical center in the southeastern United States. BESI-C was deployed in patient and caregiver homes living in Central Virginia between April 2019 and December 2019 (before the COVID-19 pandemic).

Sample

Our goal was to recruit patients and family caregivers coping with difficult cancer-related pain in a home setting. Therefore, we used a purposive sampling technique [30], and patient inclusion criteria included: (1) a diagnosis of locally advanced or metastatic malignancy, (2) currently taking prescribed opioid medications (eg, morphine type medications) for cancer-related pain, (3) scores of ≥6 on National Institutes of Health PROMIS (Patient-Reported Outcomes Measurement Information System) Cancer Pain Interference measures (a composite score assessed at each palliative care clinic visit to identify patients experiencing difficult pain) [31,32] or the standard 0 to 10 pain numeric rating scale, and (4) a primary informal (nonpaid; family, defined broadly) caregiver who helps manage their care and symptoms at home. Both patients and caregivers were aged ≥18 years, English speaking, and did not have cognitive or visual deficits or mental health issues that would preclude their ability to participate in the study. We excluded patients and caregivers who did not live in a private residence (eg, assisted living facility or nursing home), as we needed the ability to set up BESI-C without interfering with facility protocols or regulations. Palliative care clinicians helped screen and confirm the clinical eligibility of potential study participants.

Data Collection Procedures

After patients and caregivers provided informed consent, basic clinical and demographic data were collected, and a time was scheduled to deploy BESI-C in their homes. A team consisting of clinicians (1 nurse faculty and 1 nursing student) and technicians (1-2 engineering students) traveled to participant homes to set up the BESI-C system and provide education regarding system use. The first author (VL) maintained a detailed audit log to record procedural and technical challenges related to each deployment.

Participants were asked to maintain and use the BESI-C system in their homes for 10 to 14 days. During deployment, remote system monitoring was performed by our technical team (using the software platform TeamViewer), and participants had a study phone number to call if they had problems or questions. All data streams were deidentified and labeled only by the study ID number. Our team also provided brief, periodic check-ins every 3 to 4 days via telephone calls or text (depending on dyad preference) or as needed, if technical issues arose. Both patients and caregivers were asked to keep a ground truth daily log during deployment to record key events that may influence pain or functionality of the system (eg, prolonged power outage, hospital admission, or injury or fall).

During deployment, streaming data were passively collected from the smart watches worn by both patients and caregivers (heart rate and motion), environmental sensors (ambient noise, humidity, barometric pressure, light, and temperature data), and Bluetooth beacons (to help localize dyad positions within the home and in relation to each other). Active data (ie, requiring user engagement) were collected from ecological momentary assessments (EMAs) delivered via smart watches, including on-demand EMAs that allowed patients and caregivers to record and describe patient pain events from their own perspective when they occurred, as well as 30-minute follow-up pain reassessment EMAs (7 items). The smart watches also generated a daily scheduled EMA survey (12 items) to assess other factors over the past 24 hours that can influence pain, such as self-reported sleep quality and mood. EMAs were purposely designed to be fast and easy to complete and used simple Likert scale (0-10) or categorical response options (eg, “not at all,” “a little,” “fairly,” or “very”). Details of EMA data collection are the focus of a subsequent publication.

At the conclusion of the deployment, our team returned to the participants’ home, removed the equipment, and assessed the patient and caregiver experience with BESI-C by a structured interview and a Likert-style survey administered to both the patient and the family caregiver. Responses were captured verbally and recorded by pen-and-paper by study team members for deployments 1 to 4 and via an iPad (Apple Inc) for deployment 5. All participants were asked 13 Likert-style survey questions designed to assess their opinions regarding perceptions of system helpfulness (n=1), burden and privacy concerns (n=3), data sharing preferences (n=3), ease of using smart watches to mark and describe pain events (n=3), concerns regarding environmental sensors (n=1), and perceived impact of the system on cancer pain management and communication with their partner (n=2). Optional free-text responses within the survey allowed participants to expand on their answers or provide suggestions regarding system components. Structured interview questions (added after deployment 1, as we realized that more context was needed for some of the Likert scale survey items) provided additional opportunities for participants to discuss their experiences with the system. As the goal of this study was to understand the feasibility and acceptability of very specific features of our system architecture to guide future work, we opted to create a customized survey and interview guide [33], informed conceptually by other mobile health and technology evaluation tools, such as the System Usability Scale [34] and Mobile App Rating Scale [35]. The dyads received a US $50 gift card as compensation for their time.

Data Analysis Procedures

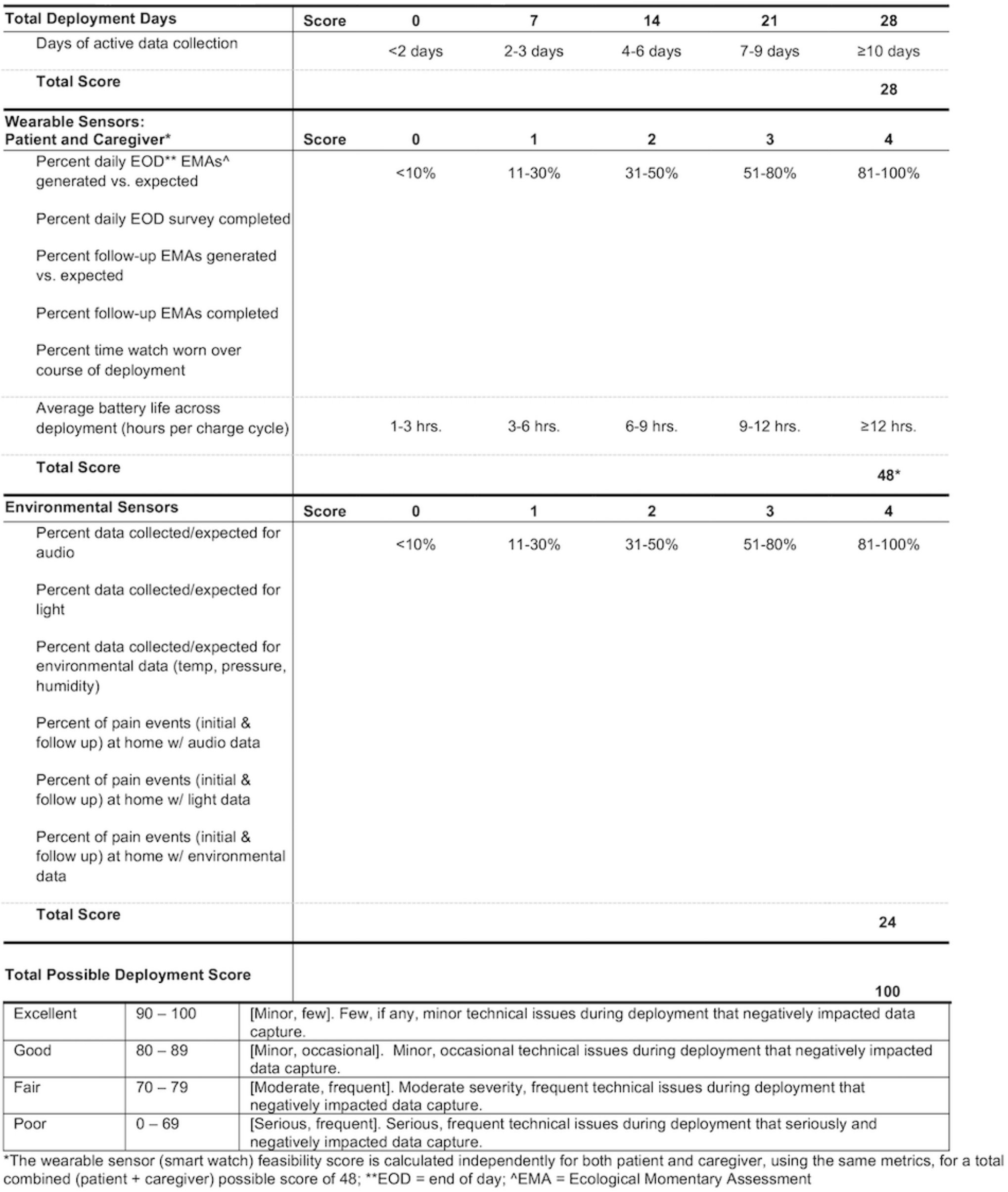
Survey and Interview Data

Postdeployment survey and structured interview data collected from patients and caregivers were verified and entered into Qualtrics for data management and storage. Quantitative responses were exported to SPSS (version 26.0; IBM Corporation), and basic descriptive statistics were run, including frequency counts and percentages for demographic data and individual and category means for Likert scale items. Independent sample *t* tests (2-tailed) were performed across all individual and category variables to assess statistically significant differences (Cronbach α=.05) between patient and caregiver mean scores. Likert scale survey items in which the respondent selected the option “don’t know” were omitted from analysis. Textual data (open-text survey and structured interview responses) were exported into Microsoft Word and organized into clusters using a basic descriptive content analysis approach that mapped to the questions asked (eg, all responses to a particular question were grouped together and reviewed for patterns). Our goal with the analysis of open-ended responses was not to conduct a qualitative analysis with a high level of abstraction, but instead, consistent with a descriptive approach, to stay close to our data and concretely understand participant responses [36].

Calculating Data Fidelity

We created a BESI-C Performance Scoring Instrument (Figure 2) to quantify the fidelity of data capture for each deployment. Conceptually, this tool was inspired by symptom assessment tools commonly used in clinical practice to better understand the health and functioning of individuals, such as the Memorial Symptom Assessment Scale [37] or the Eastern Cooperative Oncology Group (ECOG) Performance Status Scale [38]. Relatedly, the goal of our BESI-C Scoring Instrument was to understand the “health and functioning” of the BESI-C system. The BESI-C Performance Scoring Instrument is organized by the key components of the system architecture with corresponding feasibility parameters established by team consensus for poor or missing (score of 0), fair (score of 1), average (score of 2), good (score of 3), or excellent (score of 4) outcomes, with the highest possible score of 100. The following four categories were captured: (1) days of active data collection, (2) EMA reliability and data input from the patient’s smart watch, (3) EMA reliability and data input from the caregiver’s smart watch, and (4) reliability and data input from environmental sensors. The “total deployment days” category, which included 1 key metric, was weighted appropriately to ensure it was equally considered along with other category feasibility metrics. Our goal was to collect data between 10 and 14 days for each deployment. Specific details and examples of how each metric was calculated are included in Multimedia Appendix 1.

Figure 2. Template for the “BESI-C Performance Scoring Instrument” to assess technical feasibility of the system. EMA: ecological momentary assessment; EOD: end of day.



Total Deployment Days	**Score**	**0**	**7**	**14**	**21**	**28**
Days of active data collection		<2 days	2-3 days	4-6 days	7-9 days	≥10 days
Total Score						**28**
Wearable Sensors: Patient and Caregiver*	**Score**	**0**	**1**	**2**	**3**	**4**
Percent daily EOD** EMAs^ generated vs. expected		<10%	11-30%	31-50%	51-80%	81-100%
Percent daily EOD survey completed						
Percent follow-up EMAs generated vs. expected						
Percent follow-up EMAs completed						
Percent time watch worn over course of deployment						
Average battery life across deployment (hours per charge cycle)		1-3 hrs.	3-6 hrs.	6-9 hrs.	9-12 hrs.	≥12 hrs.
Total Score						**48***
Environmental Sensors	**Score**	**0**	**1**	**2**	**3**	**4**
Percent data collected/expected for audio		<10%	11-30%	31-50%	51-80%	81-100%
Percent data collected/expected for light						
Percent data collected/expected for environmental data (temp, pressure, humidity)						
Percent of pain events (initial & follow up) at home w/ audio data						
Percent of pain events (initial & follow up) at home w/ light data						
Percent of pain events (initial & follow up) at home w/ environmental data						
Total Score						**24**
Total Possible Deployment Score						**100**

Excellent	90 – 100	[Minor, few]. Few, if any, minor technical issues during deployment that negatively impacted data capture.
Good	80 – 89	[Minor, occasional]. Minor, occasional technical issues during deployment that negatively impacted data capture.
Fair	70 – 79	[Moderate, frequent]. Moderate severity, frequent technical issues during deployment that negatively impacted data capture.
Poor	0 – 69	[Serious, frequent]. Serious, frequent technical issues during deployment that seriously and negatively impacted data capture.

*The wearable sensor (smart watch) feasibility score is calculated independently for both patient and caregiver, using the same metrics, for a total combined (patient + caregiver) possible score of 48; **EOD = end of day; ^EMA = Ecological Momentary Assessment

Results

Sample Characteristics

A total of 10 individuals (5 dyads of patients and their primary family caregivers) completed BESI-C feasibility and acceptability deployments (Table 1). Overall, most participants were aged between 55 and 74 years (8/10, 80%), female (6/10, 60%), and living in a rural setting (8/10, 80%). A total of 60% (6/10) of the participants identified as White; 40% (4/10) identified as Black or African American. All caregivers, except 1, were female (4/5, 80%), and all were spouses of the patients (5/5, 100%). A total of 3 out of 5 (60%) patients were diagnosed with head and neck cancer, whereas the others included colorectal (1/5, 20%) and lung (1/5, 20%) cancers. The average baseline numeric patient pain score [39] was 6.8 out of 10. A total of 3 out of 5 (3/5, 60%) patients self-reported their ECOG performance score [38] as 1, “symptomatic and ambulatory”; one patient (1/5, 20%) self-reported an ECOG score of 2, “ambulatory 50% of the time, some help needed”; one patient (1/5, 20%) did not self-report an ECOG score.

Table 1. Demographic characteristics of patient and caregiver sample.

Demographic variable	Total (N=10), n (%)	Patients (n=5), n (%)	Caregivers (n=5), n (%)
Age band (years)			
45-54	1 (10)	1 (20)	0 (0)
55-64	4 (40)	2 (40)	2 (40)
65-74	4 (40)	2 (40)	2 (40)
75-84	1 (10)	0 (0)	1 (20)
Rural[a]	8 (80)	4 (80)	4 (80)
Sex			
Female	6 (60)	2 (40)	4 (80)
Male	4 (40)	3 (60)	1 (20)
Race			
Black or African American	4 (40)	2 (40)	2 (40)
White	6 (60)	3 (60)	3 (60)
Ethnicity			
Latino or Hispanic	0 (0)	0 (0)	0 (0)
Non-Latino or non-Hispanic	10 (100)	5 (100)	5 (100)
Highest education level			
Less than high school	1 (10)	1 (20)	0 (0)
High school graduate	2 (20)	0 (0)	2 (40)
Some college	5 (50)	3 (60)	2 (40)
Professional or graduate degree	2 (20)	1 (20)	1 (20)
Current employment			
Full-time	3 (30)	2 (40)	1 (20)
Retired	6 (60)	2 (40)	4 (80)
Other	1 (10)	1 (20)	0 (0)
Relationship with patient: spouse	N/A[b]	N/A	5 (100)
Primary cancer diagnosis			
Head and neck	N/A	3 (60)	N/A
Colorectal	N/A	1 (20)	N/A
Lung	N/A	1 (20)	N/A

[a] Rural as identified by Centers for Medicaid and Medicare Services; Rural Health Information Hub [40].

[b] N/A: not applicable.

Feasibility

Logistical and Technical Deployment Challenges

Logistic deployment barriers included the rural location of dyads, which involved challenges coordinating time-intensive trips to dyad homes along with internet stability issues and the length of time it took to set up the system, which varied according to the size of the home and other unanticipated factors. For example, in some homes, limited or poorly situated electrical outlets to plug in environmental sensors created challenges and added time to system installation. Table 2 summarizes the key logistic and technical barriers that occurred at the time of installation, during deployment, and at the time of system removal or teardown, along with subsequent iterative system changes or improvements.

Table 2. Summary of key technical and procedural deployment challenges and resulting iterative changes.

Deployment number	Total days of active data collection	Technical and procedural deployment challenges	How system and deployment procedures were changed or improved and lessons learned
1. Install: 190 min; teardown: 35 min	12	• Lengthy installation time (due in part to smart watches not properly paired with base station; teaching took 45 min). • Unable to remotely monitor smart watches due to bug in code logic; this required 2 members of engineering team to make additional trip to dyad home to fix. • Inconsistent delivery of EMAs[a] on caregiver smart watch. • Patient stopped wearing smart watch in final days of deployment due to a fall.	• Created standardized predeployment protocol checklists for both engineers and nurses to streamline deployment installation (eg, asking better dyad screening questions about size of home; developed environmental sensor placement protocol). • Cross-trained nurse team members to help engineers place environmental sensors to expedite installation process. • Established time goal of 1 h for installation; 30 min for teardown. • Revised structure of daily EMAs; decreased smart watch touchscreen sensitivity; added a "do not disturb/sleep" option on smart watch app. • Created a "ground truth" daily log for patients and caregivers to record important events that may occur during deployment (such as a fall or injury).
2. Install: 75 min; teardown: 38 min	9	• Patient reported they had stable internet, but this was not the case when we arrived in home. Mobile hot spot was set up. • Smart watch battery life lasting 6-7 h (vs desired 10-12 h); patient smart watch had to be factory reset due to running out of power, which resulted in loss of data. • EMAs not generating or coming at wrong time; smart watches not displaying correct date or time; base station went offline and did not connect properly to hot spot. • Smart watches "locking" after deployment resulting in difficulty offloading collected data. • Patient consented to study alone in clinic; caregiver unaware of pending deployment until study team arrived at dyad home.	• Ask more detailed questions about internet and cellular service before in-home visit; be prepared to set up mobile hot spot if needed. • Allow more time during installation for participants to practice using app and answering EMAs. • Investigation regarding battery life undertaken. • Avoid plugging in base station to switch-controlled electrical outlet. • Implemented automatic data download script to download smart watch data when they are charging to prevent any data loss. • Enhanced predeployment testing. • Changed recruitment and consenting processes to ensure caregiver aware of scheduled deployment.
3. Install: 95 min; teardown: 45 min	12	• Environmental sensors would not stick to wood paneling with standard 3M strips. • Participant confusion regarding EMAs; did not feel like they could answer some questions properly. • Issues with button press activation of EMAs due to patient neuropathy (numbness in fingers). • Battery life of smart watches still problematic, lasting 4-5 h. • Smart watches displaying correct data/time, but daily EMAs behaving inconsistently, not coming at all or generating at wrong time.	• Ensure other measures are available to adhere environmental sensors to walls, such as sticky putty. • Added "unsure" option to relevant EMAs. • Changed all EMAs to "touch to wake" or screen tap. • Refined sampling times for heart rate and accelerometer and operating system settings to optimize battery life. • Changed daily EMA to be manually available between 5 PM to midnight with a reminder sent at 8:30 PM.
4. Install: 75 min; teardown: 47 min	14	• Continued issues with daily EMAs not generating at correct times and smart watch battery life. • Caregiver did not understand she should continue to wear the smart watch even if she is not physically with patient. • Smart watch time going out of sync after battery dies. • Safety concerns for study team related to unsecured firearms in dyad home.	• System lock turned on to help with time sync issues with smart watches; code changed to help with processing power and accelerometer efficiency. • Smart watch wearing instructions revised. • Began deploying an Android smart phone to help sync the time and date on the smart watch when the smart watch battery dies. • Created home-safety protocol for team.

Deployment number	Total days of active data collection	Technical and procedural deployment challenges	How system and deployment procedures were changed or improved and lessons learned
5. Install: 100 min; teardown: 100 min[b]	15	• Blue light on environmental sensor in bedroom kept patient awake at night. • One Bluetooth beacon that was placed on top of refrigerator fell into the freezer. • One environmental sensor lost connectivity to the system and was not able to be put back online. • Patient smart watch not seen with remote monitoring; possibly due to system lock out turned off (to help with time sync issue and prevent smart watch from powering down) or from bug in code; follow-up EMAs not consistently being generated; random buzzes; long lag time with "touch-to-wake" feature of smart watch. • New operating system update of the smart watches came with battery consumption reduction mode called "doze mode"; this interfered with EMAs being generated.	• Ensure tape is placed over environmental sensors to prevent sleep disturbance. • Caution with placement of Bluetooth beacons. • Adding redundant environmental sensors in monitored rooms to ensure adequate data capture. • Code changed to ensure smart watches do not go into "doze mode" and to address other inconsistencies with EMA delivery.

[a] EMA: ecological momentary assessment.

[b] Increased teardown time primarily due to particularly social or talkative dyad; also, iPads for survey data collection took longer to use with this deployment.

Fidelity of Data Capture

Table 3 summarizes the composite BESI-C performance scores for all the 5 deployments. Full deployment BESI-C Scoring Instruments for all 5 deployments are included in Multimedia Appendix 1. The overall performance deployment score across all categories and for all 5 deployments was 86.4 out of 100. The first deployment had the lowest overall total score (77 out of 100), with improvements in total performance scores for later deployments (89 out of 100, 89 out of 100, 89 out of 100, and 88 out of 100, respectively). The environmental or room sensors had the most consistent performance (24 out of 24 for each deployment). One deployment did not achieve a full score for the number of days of active data collection (deployment 2, score of 21 out of 28). Performance variability was greatest with smart watches, with a caregiver smart watch average score across all deployments of 16.4 out of 24, and a patient smart watch average score across all deployments of 19.4 out of 24.

Table 3. Behavioral and Environmental Sensing and Intervention for Cancer Performance Scoring Instrument composite scores for pilot deployments.

Category	Deployment 1, score	Deployment 2, score	Deployment 3, score	Deployment 4, score	Deployment 5, score	Category average, score
Total deployment days	28/28	21/28	28/28	28/28	28/28	26.6/28
Smart watch: patient	15/24	21/24	20/24	19/24	19/24	19.4/24
Smart watch: caregiver	10/24	20/24	17/24	18/24	17/24	16.4/24
Environmental or room sensors	24/24	24/24	24/24	24/24	24/24	24/24
Total deployment score	77/100	89/100	89/100	89/100	88/100	86.4/100

Participant Recruitment and Attrition

Participant recruitment was significantly disrupted by the COVID-19 pandemic (which required the complete cessation of recruitment after our fifth deployment; we had planned for 15). Screening for eligibility was complicated by inherent limitations within the electronic health record, which made it difficult to verify key eligibility criteria such as caregiver status. A total of 2 dyads signed consent but withdrew before deployment; one due to being too busy; the other dyad was lost to follow-up and unable to be contacted. In all, 80% (4/5) of dyads who signed the consent form and had the system installed completed the minimum (10 days) target length of data collection. One dyad (1/5, 20%) only completed 9 days of data collection, but this was due to technical failures that truncated data input versus voluntary attrition.

Acceptability

Postdeployment Assessments: Quantitative

Postdeployment Likert surveys demonstrated that, overall, patients and caregivers perceived the BESI-C system to be helpful and low burden (Table 4). Specifically, on a scale of 1 (strongly disagree) to 5 (strongly agree), dyads agreed that BESI-C collected helpful data to better manage cancer pain (4.6 out of 5) and that it was easy to answer EMAs on the smart watch (4.3 out of 5) and remember to mark pain events in real time (4.4 out of 5) and expressed a willingness to answer more EMAs on the smart watch (4 out of 5). Completion times for initial and follow-up pain EMAs across all deployments were generally <1 minute (Figure 3), with slightly longer completion times for the daily end-of-day EMA, which was expected because this EMA survey included more questions. Overall, 283 unique initial pain events were reported, along with 106 follow-up pain reassessment EMAs. A total of 63 daily surveys were completed (Table 5). Further details of EMA results are the focus of a subsequent publication. Dyads disagreed that the system was a burden to themselves (1.5 out of 5) or their partner (1.7 out of 5) or violated their privacy (1.9 out of 5). Overall, dyads expressed a strong interest in data sharing (4.7 out of 5), with patients and caregivers equally agreeing about their desire to see their own data (4.4 out of 5), and even more strongly agreeing on the importance of sharing data with their respective partners (4.8 out of 5) and health care providers (4.8 out of 5). Interestingly, caregivers disagreed more strongly about the unobtrusiveness of the environmental sensors (3.4 out of 5) than patients (4.8 out of 5). Dyads disagreed that the BESI-C changed pain medication use (overall and patients: 2.2 out of 5; caregivers: 2.3 out of 5). Caregivers (4.4 out of 5) agreed more strongly than patients (2.6 out of 5) that recording pain events increased their awareness of pain. No statistically significant differences were found between the patient and caregiver responses (Cronbach α=.05).

Within Table 4, missing values are due to the patient or caregiver selected the response “do not know” or declined to answer (one patient, 1/5, 20% did not self-report an ECOG score).

Table 4. Comparison of postdeployment Likert survey mean scores by overall sample, patients, and caregivers (1=strongly disagree; 5=strongly agree).

Question asked of participant	Total (N=10)	Patients (n=5)	Caregivers (n=5)
Overall perceptions: I think BESI-C[a] can collect helpful information to better manage cancer pain, mean (SD); n	4.6 (0.52); 10	4.6 (0.55); 5	4.6 (0.55); 5
System burden, category mean (SD)	1.7 (0.51)	1.7 (0.43)	1.7 (0.43)
BESI-C system was a burden for me, mean (SD); n	1.5 (0.71); 10	1.4 (0.55); 5	1.6 (0.89); 5
BESI-C system was a burden for my partner, mean (SD); n	1.7 (0.71); 9	1.8 (0.50); 4	1.6 (0.89); 5
BESI-C system made me concerned about privacy, mean (SD); n	1.9 (0.99); 10	2 (0.71); 5	1.8 (1.30); 5
Data sharing preferences, category mean (SD)	4.7 (0.44)	4.7 (0.47)	4.7 (0.47)
I want to see the information collected by BESI-C about my experience, mean (SD); n	4.4 (0.84); 10	4.4 (0.89); 5	4.4 (0.89); 5
I think it is important to share information collected by BESI-C with my partner, mean (SD); n	4.8 (0.42); 10	4.8 (0.45); 5	4.8 0.45); 5
I think it is important to share information collected by BESI-C with health care providers, mean (SD); n	4.8 (0.44); 9	4.8 (0.45); 5	4.8 (0.50); 4
Environmental sensors (I mostly forgot about the room sensors after the first day), mean (SD); n	4.1 (0.99); 10	4.8 (0.45); 5	3.4 (0.89); 5
Smart watch or EMAs[b], category mean (SD)	4.2 (0.57)	4.5 (0.38)	4.0 (0.67)
It was easy to answer questions on the smart watch, mean (SD); n	4.3 (0.82); 10	4.6 (0.55); 5	4.0 (1.00); 5
Remembering to mark pain events in the moment was easy, mean (SD); n	4.4 (0.70); 10	4.6 (0.55); 5	4.2 (0.84); 5
I would be willing to answer more questions on the smart watch, mean (SD); n	4 (0.94); 10	4.2 (0.84); 5	3.8 (1.10); 5
Pain, category mean (SD)	2.9 (1.04)	2.4 (1.04)	3.4 (0.71)
BESI-C changed the way I or the patient normally takes their pain medication, mean (SD); n	2.2 (1.48); 9	2.2 (1.64); 5	2.3 (1.50); 4
Recording pain events made me more aware of the pain I or the patient was feeling, mean (SD); n	3.5 (1.51); 10	2.6 (1.52); 5	4.4 (0.89); 5

[a] BESI-C: Behavioral and Environmental Sensing and Intervention for Cancer.

[b] EMA: ecological momentary assessment.

Figure 3. Average ecological momentary assessment (EMA) completion times per deployment and overall. EMAs recorded as taking >5 minutes to complete (n=28) were considered incomplete EMAs or outliers and were omitted from analysis. "PT initial" and "CG initial" refer to the first pain event the EMA recorded. "PT follow-up" and "CG follow-up" refer to the 30-minute pain reassessment EMA. "PT end of day" and "CG end of day" refer to the end-of-day summary survey EMA. CG: caregiver; D: deployment; PT: patient.

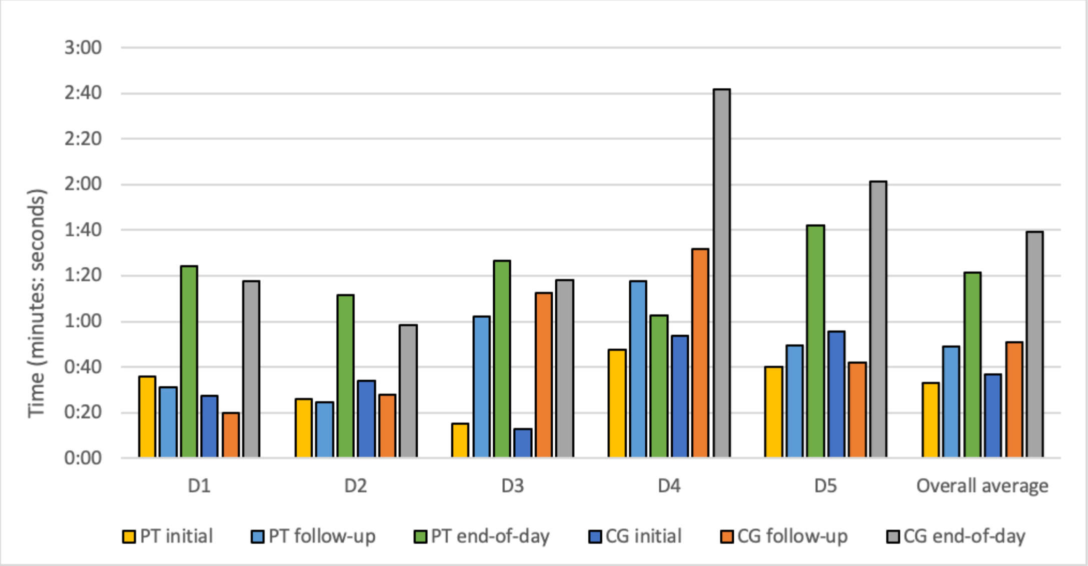


Table 5. Total number of completed ecological momentary assessments (EMAs) per deployment by patient and caregiver.

	Deployment 1		Deployment 2		Deployment 3		Deployment 4		Deployment 5		Total, N
	Pt[a]	CG[b]	Pt	CG	Pt	CG	Pt	CG	Pt	CG	
Initial pain EMA	49	15	42	18	24	15	30	21	53	16	283
Follow-up pain EMA[c]	25	5	15	7	19	9	15	3	5	3	106
End-of-day EMA	5	4	6	4	10	6	6	3	12	7	63
Total	79	24	63	29	53	30	51	28	70	26	452

[a] Pt: patient.

[b] CG: caregiver.

[c] Pain reassessment EMAs generated 30 minutes after an initial pain EMA, if participant reported that the patient took pain medication.

Postdeployment Assessments: Qualitative

Write-in or free-text survey items revealed that participants found the BESI-C system beneficial, particularly in relation to dyadic communication. Questions inquiring about specific hardware components of the system architecture (smart watches, environmental sensors, base stations or laptops, and localization beacons) yielded minimal or no comments or suggestions. Most of the feedback from the participants involved the smart watch interface and its functionality. A caregiver expressed concern regarding how environmental sensors may be perceived by visitors to the home ("is the government spying on us?") Both caregivers and patients acknowledged some frustration with the technical challenges with the smart watches, including battery life, occasional lag in the touch-to-wake screen tap feature, and inconsistency with EMA delivery. A caregiver expressed the desire for greater flexibility in describing unusual events that may influence pain.

Structured interviews allowed participants to more fully contextualize or expand upon their survey responses, and dyads largely reiterated perceptions documented in the free-text survey items, particularly related to technical inconsistencies with smart watch functioning. Despite technical glitches with the smart watch app interface, when asked, "about what percentage of the time did you wear the smart watch in a 24-hr period?" 40% (4/10) of the participants said 100% of the time, 30% (3/10) said 75% of the time, and 10% (1/10) said 85% of the time; this question was added after deployment 3, and so only answered by participants of deployments 4 and 5. A participant was particularly averse to wearing the smart watch as he explained, "he doesn't wear a watch in general" and expressed a dislike for jewelry. Participants also expressed a desire for clearer instructions about wearing the smart watch and an interest in having the smart watch capture distress from symptoms other than pain, such as nausea. Because of the high degree of similarity in responses to free-text survey items and structured interview questions, qualitative feedback was integrated and is summarized in Table 6.

Table 6. Summary of postdeployment qualitative responses related to Behavioral and Environmental Sensing and Intervention for Cancer (BESI-C).

Question	Pt[a]	CG[b]
What was your general or overall impression of having BESI-C in your home?	• "Just need to work out watch problems." [Pt 1] • "It was a painless event. Didn't know it was there. Did like the way it followed up [about the pain] with the follow up-EMA." [Pt 2] • "The technical aspect was frustrating and inconsistent. Hard rating the pain since I was trying to stay ahead of the pain." [Pt 3] • "Didn't bother us a bit." [Pt 4] • "Positive. Did not pay any attention to the equipment at all...This will be a great asset to patient dealing with pain. It makes you more aware of how important it is to manage pain properly and on a timely basis..." [Pt 5]	• "Just needs to work more consistently." [CG 1] • "[Privacy concerns] got better over time... we adjusted." [CG 2] • "An interesting study and easy to use"; "equipment was inconsistent" (caregiver notes that they did not wear the smart watch to sleep). [CG 3] • "Some days would work well, sometimes not. It's not obvious when she's in pain. When she was taking a pill I would guess she'd be in pain." [CG 3] • "Battery life [was an issue]." [CG 4] • "Didn't even know [environmental] sensors were here." [CG 4] • "I think it can help a lot of people out there who cannot get to a doctor when they're really hurting and sick. Think you have a great invention here!" [CG 5]
What did you like about having BESI-C in your home? What did you dislike about having BESI-C in your home?	• "Made me pay attention to what I was feeling and if my caregiver felt it." [Pt 3] • "Helped me communicate with [my partner] more; Felt like I was able to tell [my partner] I was in pain, not hiding it and not waiting to take pain medication." [Pt 5] • "Disliked watch. I don't like wearing jewelry. Don't wear a watch in general." [Pt 4] • "Lag time in watch turning on was frustrating. Watch went back to black screen before you could answer." [Pt 5]	• "It was easy, took little time out of the day." [CG 3] • "If it can help someone, I'm glad to do it." [CG 4] • "The watch didn't bother me. [But] I had to remember to wear the watch. It wasn't clear if I had to wear it if I wasn't with [patient]." [CG 4]
What could be changed to make the BESI-C system better?	• "Accuracy with watch date/time; end of day surveys." [Pt 2] • "Work to improve watch lag time." [Pt 5]	• "Longer charge on watch." [CG 2] • "Include nausea. [Pt] was having nausea and I was distressed but that wasn't because she was in pain." [CG 3] • "Clearer instructions when to wear watches. When we were apart, wasn't sure how to answer the questions." [CG 4]
Did having BESI-C in your home impact or change how you communicated or interacted with your partner about pain? If so, how?	• "We discussed pain more." [Pt 2] • "She asked more specific questions about my pain." [Pt 4] • "The system helped me take my medication on a more consistent basis before the pain built up to an intolerable level...`Before the BESI-C system I wouldn't always communicate my pain with my caregiver in trying to prevent him from worrying. The system made me aware by not communicating I was doing the [opposite]." [Pt 5]	• "I was paying more attention to the small things—like does she go sit down and rest? Raised awareness on pain management and how she looks and acts." [CG 3] • "This is a good way to communicate...It made her [patient] more aware to take the pain medication at the right time so the pain did not build up and get worse and she could tolerate it better." [CG 5]

You had the BESI-C system in your home for (10-14) days. Would you be willing to have BESI-C in your home for longer? Why or why not?	• Yes
	  • "The feeling of being monitored may be of benefit to me or others." [Pt 2]
	  • "I want the equipment to be tweaked. I want to be able to explain things under unusual event. BESI-C makes sense to me, helps piece things together." [Pt 3]
	• No
	  • "It was enough time. Found [ground truth] log annoying. Should be less repetitious—just note what has changed or unusual. Not so many reminders on watch." [Pt 5]
		• Yes
		  • "Sure. It was easy, didn't take much time. Interesting in the beginning. Wanted to help in research. I liked the 'level of distress' question." [CG 3]
		  • "If it's helping us or others, then yes." [CG 4]
		• No
		  • "People were asking about what the sensors were for, asking us 'is the government watching us?'" [CG 2]

[a] Pt: patient.

[b] CG: caregiver.

Discussion

Summary of Findings and Potential Impact

In this study, we demonstrated the acceptability and feasibility of deploying a smart health system, BESI-C, in the homes of adults with advanced cancer, to collect holistic and heterogenous sensing data from patients, caregivers, and the home environment. Importantly, our findings suggest an innovative approach to supporting home-based symptom self-management for cancer pain, promoting patient and caregiver self-efficacy, and strengthening the relationship between caregivers and care recipients—all critical and persistent gaps in oncology care [41,42]. More specifically, our research contributes to advancing the science of remote oncology care [43-47] and extends current efforts to leverage technology to monitor and manage cancer pain [48-51] by providing data that can inform future interventions. For example, by monitoring environmental and contextual factors in the home that may influence pain, BESI-C could prompt a patient or caregiver to implement a low-burden, high-impact environmental modification to reduce pain, such as adjusting the room temperature. In addition, BESI-C concurrently incorporates the perspective of *both* the patient and the family caregiver via smart watches programmed with a custom app to collect participant-reported EMA data, as well as passive physiological data. This is critically important, as a holistic understanding of the family caregiver experience in the context of the patient experience is essential for designing effective cancer interventions [3,52]. Integrating data from BESI-C to develop a comprehensive understanding of cancer pain experience at home facilitates the design of multidimensional interventions that can be tailored to the patient, caregiver, dyad, or home itself. The BESI-C approach offers unique benefits for rural populations who may live far from cancer care centers and may reduce disparities related to access to quality cancer pain care. In addition, the BESI-C system can provide critical support to clinicians by providing holistic, longitudinal data related to the pain experience at home (versus relying on a cross-section of recollection by patients or caregivers when they present for an outpatient clinic visit). Below, we discuss the implications of our findings and specific lessons learned related to acceptability and feasibility.

Acceptability

We found that patients and caregivers coping with serious, advanced cancer *will* mark pain events in real time using a smart watch and that they find this activity meaningful and not overly burdensome. This is a noteworthy finding given the severity of illness experienced by palliative care patient populations, which can make data collection extremely difficult or impossible [53-55]. We believe this underscores and confirms the value patients and caregivers place on meaningful self-reported outcomes [44,56,57] and validates other work seeking to use EMAs to collect data about cancer pain [48]. We also believe that participants' acceptance of answering EMAs about pain in real time was enhanced by our intentional choice to use smart watches versus a mobile phone app. Although mobile smartphones are ubiquitous, we wanted an even more direct and straightforward way (ie, a device "attached" to the person) for participants to record difficult symptoms in real time; our results confirm that the smart watch is an effective method for this type of symptom data collection. We did have a patient who was uniquely averse to wearing a smart watch, and future iterations of the system architecture could potentially offer a smartphone mobile app option for such patients. Our work in this area makes important contributions related to the use of smart watches for remote health monitoring by collecting both continuous physiological data as well as EMA data from actual patients with cancer [58-60].

We also learned that once participants became accustomed to the smart watch interface (which usually took only a couple of practice rounds), they were able to answer the EMAs very quickly, generally in <30 seconds. Postdeployment assessments also revealed that the participants were willing to answer additional EMAs. This was helpful information, as we purposely designed the EMAs for this study to be as streamlined and brief as possible to enhance adherence and reduce participant burden; this required making difficult choices about questions to include and ones to omit. Confirmation that we had latitude to add questions increased our confidence to add EMAs to the next iteration of our smart watch app, such as important questions about the use of nonpharmacological measures taken to reduce pain and other co-occurring symptoms, such as fatigue. Importantly, we also confirmed that patients and caregivers not only want to share collected data with their health care providers but that they wish to see their own data and for their partners to see their data. This is an important finding, as prior work has demonstrated challenges in ensuring health care providers understand and act upon patient-reported outcome data [61]. Given this reality, we concur with Villegas et al [48] and suggest that a more effective (or at least equally important) strategy is to focus on how remote monitoring data can inform real-time intervention strategies delivered directly to patients and caregivers for more empowered symptom self-management. We hypothesize that different "buckets" of data exist, and who needs access to these data—when, and how, and in what ways—will vary, temporally and by end user. For example, there are likely data most relevant to the patient themselves, data best mutually shared between patients and family caregivers, data helpful for the caregiver only, data best shared between health care providers and family caregivers, and data most helpful to health care providers. A key element of future work will be to explore more robustly how, when, and to whom to present relevant data visualizations and how they can best inform interventions.

Another interesting finding is that BESI-C may influence dyadic communication related to cancer pain management and medication use. Unfortunately, we were unable to interpret the direction of these Likert scale survey items (eg, caregivers, 4.4 out of 5, agreed more strongly than patients, 2.6 out of 5, that "recording pain events increased awareness of pain"—but whether this was considered positive or negative by the participant is unclear; these items have since been revised for future work). Qualitative responses, however, were able to shed light on these ambiguous quantitative results. In the postdeployment interviews, both patients and caregivers discussed that BESI-C made them more attuned to their partner's experience and created more awareness of pain in a way that facilitated earlier, more proactive symptom management and enhanced communication. Navigating challenging cancer symptoms is an immensely stressful experience for patients and caregivers, and the potential for BESI-C to lessen distress by improving interpersonal communication is exciting.

Importantly, we also learned to provide clearer instructions regarding marking pain events on smart watches. With our first deployments, we purposely did not provide overly specific instructions regarding how and when participants should mark pain events. This created confusion for some participants, who were unsure when exactly they were supposed to mark pain events and what exactly constituted a "cancer-related pain event," particularly if the patient experienced some level of constant, baseline pain (which is normative for many patients with cancer). In response to this, we became clearer that our on-demand EMAs were best designed to capture "breakthrough pain"—pain that increases or "breaks through" a patient's baseline level of pain, which is notoriously difficult to assess and manage owing to its short duration, intensity, and unpredictable nature [18,48,62,63]. Once we had a better understanding of this, we revised our instructions to participants and explained, "Tap the screen on the smart watch to report an episode of cancer pain. You can consider a pain event as one in which the pain has increased from what it was previously and that you feel requires attention. Mark the pain event as close to when it occurs as possible. You do not need to report pain clearly unrelated to cancer (eg, stubbing a toe)." Recognizing the BESI-C's role in addressing breakthrough pain, and being more explicit about it, was an important realization for our team, as controlling breakthrough pain is considered a key element of comprehensive cancer pain management [64]. In addition, we also emphasize that there are no "right or wrong" answers and added an "unsure" option to relevant EMA questions. A related issue was the temporal uncertainty of patients taking medication for a pain event. In other words, did they mark a pain event and *then* take pain medication, and if so, how much later? Or did they take pain medication and *then* mark a pain event afterward? We ultimately dealt with this thorny problem by revising our reassessment pain EMAs to retrospectively ask participants what was done to manage the pain and approximately what time the patient took their medication, if applicable.

We also found that participants, overall, accepted passive environmental monitoring and did not feel this compromised their privacy. However, it remains critical for researchers working in this field to be aware of, and sensitive to, concerns regarding environmental monitoring that may be particularly relevant for participant groups where long-standing systemic and structural factors have resulted in negative and discriminatory experiences related to such types of surveillance. Transparent informed consent, easy ways for participants to opt out (such as simply unplugging devices), and flexible monitoring protocols (eg, ones that can pivot to only active, user-initiated vs passive, environmental monitoring if needed or requested) are essential to ensure that systems such as BESI-C are culturally sensitive.

Feasibility

Technical Feasibility: Fidelity of Data Capture; System Performance Scores

Our "BESI-C Performance Scoring Instrument" proved to be a helpful tool to assess holistic system functioning, while being able to identify trends regarding individual system components. To our knowledge, this is the first document created to monitor technology health modeled after clinical assessment tools.We suggest that this type of scoring sheet be adapted for other complex sensing systems or remote health monitoring systems to provide team members with a concise, clear, and quantifiable snapshot of system performance and a way to compare functioning and ensure a positive trajectory over time.

It is encouraging that the BESI-C overall composite performance scores increased over time, with a clear increase after our first deployment. Our scoring instrument confirmed that our environmental sensors had the most stable data-capture fidelity. This was not surprising, as this technology evolved from a previous, well-established project designed to monitor agitation in home-based patients with dementia and had more prior testing [65-67]. The primary concern regarding environmental sensors is aesthetics. Subsequent iterations resulted in a drastic reduction in size and a more streamlined design of our custom environmental relays without compromising the technical performance.

In contrast, the BESI-C smart watch app (the newest aspect of the system) proved to be less reliable, with inconsistent delivery of EMAs and challenges with battery life (our goal was 14 hours to increase the chance for 24 hours of continuous smart watch data, but we maxed out around 7 hours) and losing synchronization with the correct date and time. Unreliability of the smart watch app likely resulted in underreporting of pain events and contributed to other missing data. A key reason for these challenges with the smart watch app was automatic Android operating system updates, which affected system stability, a known challenge when using off-the-shelf commercial products [68]. On the basis of a review of our performance scores, after these 5 deployments, we migrated to a cloud services system to improve our ability to securely off-load and store data in real time.

A key technical lesson learned during these initial deployments was related to the importance of periodic code reviews and putting best practices in place regarding the software coding procedures. With each deployment, we learned new information regarding data capture that required iterative changes. However, the clinical team often underestimated the complexity or length of time needed to make, implement, and test these changes. Technical challenges reinforced the importance of clear, frequent, and transparent interdisciplinary communication as well as the importance of streamlining deployment procedures with this particularly sick and fragile patient population.

Procedural Feasibility: Deployment Processes; Participant Recruitment

Despite the known challenges of participant recruitment for palliative care–related research [53,55,69], we were able to successfully recruit 5 dyads (and expect this positive momentum would have continued if the COVID-19 pandemic had not interfered). Demographic trends must be interpreted cautiously given the sample size. However, we recruited patients with diverse cancer diagnoses, the majority with head and neck cancer, consistent with the high rates of tobacco use in our cancer center catchment area [70,71]. We also demonstrated the ability to recruit patients from groups at high risk of inadequate symptom management, including Black or African American and rural patients. This is important, as the most significant overarching goal of this research is to reduce cancer health disparities by increasing equitable access to quality cancer pain management.

Our study was complicated by the need for informed consent from both the patient and family caregiver. At times, this presented logistic challenges. For example, the patient's family caregiver was not always physically present in the clinic when the study was discussed and the patient signed consent (this has become even more of a challenge with the COVID-19 pandemic and visitor restrictions). This resulted in one instance where the (consented) patient repeatedly assured the study team that he had discussed the study with his caregiver, who agreed to participate and would sign the informed consent form at home. However, when we arrived at the dyad home, our team quickly ascertained that the patient had not discussed the study with his wife. After careful discussion and emphasizing voluntary participation, the caregiver agreed, consented, and the deployment proceeded smoothly. After this experience, we made significant changes to our consenting procedures to ensure that if the caregiver is not with the patient at the time of the clinic visit, the caregiver is contacted before deployment, and interest in participating is directly confirmed by a study team member. We also learned the importance of deploying BESI-C as soon as possible after obtaining informed consent. Reducing time delays between consent and deployment proved essential to mitigate attrition and accommodate the dynamic clinical status of patients who are seriously ill.

Another primary recruitment challenge included screening potentially eligible clinic patients, as some key study criteria were not easily verifiable within the electronic health records. For example, it was difficult to determine whether the patient had a full-time family caregiver. We found that the most accurate (but not necessarily most efficient) way to identify potentially eligible patients was to discuss the daily clinic list face-to-face with the patient's primary palliative care provider, who was more familiar with the nuances of the patient's social context and clinical trajectory. Ultimately, we met our prestudy identified goal of 80% of enrolled dyads completing the full deployment (4 out of 5 completed the full deployment). We also set a prestudy goal of 50% of eligible dyads to enroll, but this proved difficult to accurately assess and reinforce the importance of having a stronger infrastructure in place for tracking participant screening, eligibility, enrollment, and reasons for not enrolling, such as with a REDCap (Research Electronic Data Capture; Vanderbilt University) database and a dedicated clinical research coordinator who could be physically present in clinic full-time to discuss the study with all eligible and interested participants.

Recruitment was also severely disrupted by the COVID-19 pandemic, which put a temporary halt on all human subject research and had a particularly negative impact on our research, which involved small research teams entering participant homes. We initially intended to recruit 15 dyads but were only able to complete 5 deployments before the COVID-19 restrictions were enacted. During this hiatus, we pivoted and completely redesigned our system to be contactless and allow for self-installation. This was a significant undertaking, from both the clinical and engineering sides of the project, but has resulted in a more scalable, streamlined system architecture (the "BESI Box" [72]) for future deployments (Figure 4). The "BESI Box" allows us to ship or drop off the system at participant homes and they can set it up themselves with remote support as needed.

With each deployment, our team became better and faster at setting up and removing the BESI-C system in participant homes. We also learned important lessons regarding the inherent challenges of in-home research. Specifically, we recognized the importance of explicit protocols for identifying and promptly responding to unexpected safety issues at home. For example, during a deployment, it was discovered that the participant home had multiple unsecured firearms whose locations interfered with sensor placement. This was detected by the engineering team members during the installation of environmental sensors in bedrooms and other living spaces but not by the nurse team members who remained in the living room teaching the caregiver about the smart watch app. Consequently, this critical information was not shared with the entire team until the return car ride. On the basis of this experience the team decided on an illogical but nonthreatening "safety phrase" (eg, "the server is down") that would alert team members a huddle was immediately needed to reassess safety in the home.

Figure 4. The “BESI Box” to facilitate “contactless” deployments.

Limitations

The primary limitation of this study is the sample size, which reduces generalizability and the ability to detect statistical significance in our analysis of survey responses. However, our sample size is consistent with the scope of feasibility and acceptability studies that deploy complex remote health monitoring technology with actual patients [58,67,73] and addresses an important gap in reducing cancer health disparities in rural populations. It is also important to interpret our sample size in the context of the COVID-19 global pandemic, which completely halted participant recruitment during the second half of the funding period. We also had a sample of particularly dedicated and altruistic participants (screened and referred by palliative care staff) committed to making a broader scientific contribution. In addition, patients and caregivers answered postdeployment surveys and structured interview questions individually, but verbally in the presence of each other (deployments 1-4). Deployment 5 participants recorded their responses on separate iPads, which likely reduced potential response bias. Finally, as this was a feasibility and acceptability study (and not an efficacy or intervention trial), it was not our goal to use the collected data to directly help or modify patient or caregiver pain or distress; however, this is a key goal for future work.

Conclusions

The BESI-C smart health remote monitoring system offers a holistic and innovative approach for monitoring and managing cancer pain in the home context. In this study, we successfully demonstrated the feasibility and acceptability of BESI-C using a sample of primarily rural patients with advanced cancer and their family caregivers. We also demonstrated the exciting possibilities of using heterogenous environmental, physiological, and behavioral sensing data to increase awareness and understanding of the cancer pain experience and promote enhanced communication among patients, caregivers, and health care providers. Future work will test the BESI-C in a larger and more diverse sample; continue to streamline system architecture; deploy a no-contact, self-installation system in response to the COVID-19 pandemic and to enhance scalability; explore how to best share data visualizations of collected data with key stakeholders; and design and deliver just-in-time personalized pain management interventions to patients and caregivers.

Acknowledgments

This research was funded by the American Cancer Society, Exploratory Pilot Projects in Palliative Care, PEP-19-042-01-PCSM, and the National Institutes of Health, National Institute of Nursing Research, NIH R01NR019639-01.

The authors wish to thank Penn Baumann, Susan Beck, Nadim El-Jaroudi, Kara Fitzgibbon, Bryan Lewis, Taylor Patrick, Sarah Ratcliffe, Amber Steen, and Caleb Williams.

Conflicts of Interest

The first (VL) and last (JL) authors have a pending patent application through the University of Virginia Licensing & Ventures Group related to the Behavioral and Environmental Sensing and Intervention for Cancer technology.

Multimedia Appendix 1
Details of the Behavioral and Environmental Sensing and Intervention for Cancer Scoring Instrument.
[DOCX File , 44 KB - cancer_v8i3e36879_app1.docx]

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Abbreviations

BESI-C: Behavioral and Environmental Sensing and Intervention for Cancer
ECOG: Eastern Cooperative Oncology Group
EMA: ecological momentary assessment
PROMIS: Patient-Reported Outcomes Measurement Information System
REDCap: Research Electronic Data Capture

Edited by A Mavragani; submitted 09.02.22; peer-reviewed by F Lehocki, J Vangara, I Olver; comments to author 23.05.22; revised version received 03.07.22; accepted 04.07.22; published 09.08.22.

Please cite as:
LeBaron V, Alam R, Bennett R, Blackhall L, Gordon K, Hayes J, Homdee N, Jones R, Lichti K, Martinez Y, Mohammadi S, Ogunjirin E, Patel N, Lach J
Deploying the Behavioral and Environmental Sensing and Intervention for Cancer Smart Health System to Support Patients and Family Caregivers in Managing Pain: Feasibility and Acceptability Study
JMIR Cancer 2022;8(3):e36879
URL: https://cancer.jmir.org/2022/3/e36879
doi:10.2196/36879
PMID:35943791

Original Paper

Creating and Implementing a Principal Investigator Tool Kit for Enhancing Accrual to Late Phase Clinical Trials: Development and Usability Study

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Abstract

Background: Accrual to oncology clinical trials remains a challenge, particularly during the COVID-19 pandemic. For late phase clinical trials funded by the National Cancer Institute, the development of these research protocols is a resource-intensive process; however, mechanisms to optimize patient accrual after trial activation are underdeveloped across the National Clinical Trial Network (NCTN). Low patient accrual can lead to the premature closure of clinical trials and can ultimately delay the availability of new, potentially life-saving therapies in oncology.

Objective: The purpose of this study is to formally create an easily implemented tool kit of resources for investigators of oncology clinical trials within the NCTN, specifically the NRG Oncology cooperative group, in order to optimize patient accrual.

Methods: NRG Oncology sought to formally develop a tool kit of resources to use at specific time points during the lifetime of NRG Oncology clinical trials. The tools are clearly described and involve the facilitation of engagement of the study principal investigator with the scientific and patient advocate community during the planning, activation, and accrual periods. Social media tools are also leveraged to enhance such engagement. The principal investigator (PI) tool kit was created in 2019 and thereafter piloted with the NRG Oncology/Alliance NRG-LU005 phase II or III trial in small-cell lung cancer. The PI tool kit was developed by the NRG Oncology Protocol Operations Management committee and was tested with the NRG/Alliance LU005 randomized trial within the NCTN.

Results: NRG Oncology/Alliance NRG-LU005 has seen robust enrollment, currently 127% of the projected accrual. Importantly, many of the tool kit elements are already being used in ongoing NRG Oncology trials, with 56% of active NRG trials using at least one element of the PI tool kit and all in-development trials offered the resource. This underscores the feasibility and potential benefits of deploying the PI tool kit across all NRG Oncology trials moving forward.

Conclusions: While clinical trial accrual can be challenging, the PI tool kit has been shown to augment accrual in a low-cost and easily implementable fashion. It could be widely and consistently deployed across the NCTN to improve accrual in oncology clinical trials.

Trial Registration: ClinicalTrials.gov NCT03811002; https://clinicaltrials.gov/ct2/show/NCT03811002

(JMIR Cancer 2022;8(3):e38514) doi:10.2196/38514

KEYWORDS

clinical trial accrual; social media tools; principal investigator; PI toolkit; oncology; clinical trial; tool; resources; patient; investigators; accrual; development; engagement; study; community; planning; activation; social media

Introduction

Approximately 2% of all patients with cancer participate in a clinical trial in the United States [1]. The reason behind this seemingly low number is complex and multifactorial [2]—likely a combination of clinical trials with overly restrictive inclusion criteria, lack of access to clinical trials in some environments, low health literacy around clinical trials, and perhaps a generalized feeling of wanting to move forward with standard cancer-directed therapies.

In lung cancer, recent clinical trials have led to an explosion in US Food and Drug Administration approvals of new therapeutic agents in the last several years, including immunotherapies and targeted therapies. The American Cancer Society recently reported the highest percentage drop in cancer mortality, which was felt to be primarily related to improvements in lung cancer therapies [3]. Recent data also show that overall survival for non–small-cell lung cancer has significantly improved, which is in close correlation with the approval of new targeted therapies [4]. Taken together, these advances would not have been possible without the patients who enrolled in clinical trials investigating these therapies. However, there are significant barriers to patient recruitment and retention in oncology clinical trials, including restrictive eligibility criteria, financial barriers, logistical concerns, and uncertainty around experimental treatment arms that can make it difficult for patients to enroll [5,6]. Slow patient accrual to clinical trials ultimately impairs development of new therapies for patients.

The National Cancer Institute (NCI) National Clinical Trials Network (NCTN) is composed of 5 cooperative groups, which are as follows: The Alliance for Clinical Trials in Oncology, Children's Oncology Group, The Eastern Cooperative Oncology Group-American College of Radiology Imaging Network (ECOG-ACRIN) cancer research group, NRG Oncology, and Southwest Oncology Group. It develops and conducts federally funded cancer trials across the United States and Canada [7,8]. Recent data evaluating the association of NCTN trials with guideline-based care and new drug indications found that nearly half of all phase-III Southwest Oncology Group trials were practice influential, meaning they either established the role of new cancer therapies or confirmed the benefits of standard of care therapies [9]. NCTN trials are critical to advancing cancer care, but many trials take years to complete accrual owing to lower-than-projected accrual rates.

To facilitate the goal of meeting projected clinical trial accrual, the NRG Oncology Protocol Operations Management (POM) Committee sought to develop, with input from the NRG Communications Committee, a tool kit for study principal investigators of newly activated NRG Oncology trials. Membership of these committees include physician leaders across various types of cancers who design and enroll patients on clinical trials. The physician membership includes a diverse array of people who practice in academia, the private sector, as well as underserved communities. Members also include patient advocates, statisticians, and administrative leaders with expertise in clinical trial design. The principal investigator (PI) tool kit was therefore developed with input from a wide array of stakeholders involved in clinical trial design, including patients themselves.

The goal of the PI tool kit is to harness communication-driven tools to message information about the trial stakeholders including patients, physicians, health care teams, advocacy groups, and oncology organizations. The tool kit works to create a patient-driven message, with a clinical trial patient advocate working with the principal investigator to cultivate a message that resonates with the patient community. This builds upon the concept of patient-centric clinical trials that involve patient input throughout the life cycle of the clinical trial [10]. Here, we describe the components of the PI tool kit, and present 18-month accrual data of the first NRG Oncology clinical trial to incorporate the PI tool kit: NRG/Alliance NRG-LU005 (registered with Clinical Trials.gov: NCT03811002). Importantly, the PI investigator tool kit is a newly created tool for clinical trial accrual, and this manuscript details a first pilot experience using the tool kit. Further studies using implementation science to integrate the PI tool kit into additional clinical trials are ongoing, albeit beyond the scope of this manuscript.

Methods

Tool Kit Development

In January 2019, NRG Oncology POM committee members, with input from the NRG Communications Committee, began developing the PI tool kit. It was developed based upon the cataloguing of best practices and was designed to be formulaic and easily broken down into discrete tasks to be performed at designated time points throughout the life cycle of the clinical trial. The tool kit tasks would be implemented by the overall study principal investigator with support from NRG Oncology operations staff. The study principal investigator is defined as the individual who has led the development of the clinical trial and who is responsible for the overall conduct of the clinical trial. The tool kit would use various awareness resources, communication tools, social media platforms (including Twitter), general oncology and disease-specific conferences, patient engagement websites, and disease-specific patient advocates. Patient advocates would partner with the study principal investigator to promote patient-centric messaging about the clinical trial and would be identified through the NRG Oncology patient advocacy committee.

The PI tool kit components as well as activation time points are detailed below. Of note, the PI tool kit focuses on methods to enhance patient recruitment and does not specifically address retention in clinical trials. Patient recruitment refers to the number of patients registered to participate in a clinical trial. The terms recruitment and accrual are used interchangeably. The PI tool kit is shown in Multimedia Appendix 1 and in the tables below.

Ethical Considerations

The PI tool kit uses social media and scientific communications tools to enhance clinical trial accrual. The principal investigator tool kit was piloted using the clinical trial NRG Oncology/Alliance LU005, which is an approved clinical trial through the National Cancer Institute’s central institutional review board (CIRB; IRB00000781).

Tools Used at Trial Activation

In the weeks to months leading up to study activation, a trial-specific Power Point slide deck is created that provides a succinct overview of the study, including the study rationale, patient population and inclusion or exclusion criteria, study schema, primary and secondary end points, expected accrual, and projected study length (Table 1). This is created by the protocol development team in the Operations and Statistics and Data Management Center offices, in collaboration with the study principal investigator. Upon completion and approval, it becomes available under “study documents” tab on the NCI’s Clinical Trials Support Unit (CTSU) website. A patient brochure is created for study sites to use as an educational tool for the trial. For select trials where resources are available, a study landing page is created on the NRG Oncology website for patients to easily engage with and obtain more information about the clinical trial and to identify possible involvement. The patient landing page and patient brochure development are assisted by the Communications Committee members. The patient landing website and brochure require CIRB approval and are available at both the NRG Oncology website and the CTSU protocol web page.

Upon study activation, an email communication is sent by the study principal investigators to the institutional NRG Oncology contact principal investigators (as well as to the institutional principal investigators for the study in question) to communicate that the new trial is activating and any specific information that may be of value to site principal investigators. The CIRB-approved patient brochure can also be sent with this email. The study principal investigator would also create a short 30- to 60-second video aimed at a patient audience, which describes the study patient population, study rationale, and study schema. This brief video script includes CIRB approval with the video initially shared on social media platforms such as Twitter by both the trial study principal investigator and NRG Oncology. Patient advocates are also encouraged to help develop this video to ensure the content is patient focused with clear messaging. NRG Oncology maintains an active Twitter account (“@NRGonc”) and Facebook page, both with a focus on engaging with the community and sharing information about cancer clinical trials. Lastly, the study principal investigator will conduct a study launch or kick-off session at the NRG semiannual meeting to educate clinical investigators and research staff on specific trial goals and requirements, as well as to stimulate overall study awareness.

Table 1. Principal Investigator (PI) tool kit—tools for study activation phase.

Tasks	Responsible party	Product or placement
Study overview slide set	Protocol Development or Communications Committee with Study Chair review	• CTSU[a] web page
Study landing page[b] for patients	Protocol Development or Communications Committee with Study Chair review	• NRG Oncology web page • CTSU web page
Patient brochure	Protocol Development or Communications Committee with Study Chair review	• NRG Oncology web page • CTSU web page
Introductory letter to targeted sites with high accrual on similar trials or potential for high accrual	Protocol Development or Study Chair	• Email from Study Chair
Patient-focused promotional video	Study Chair with or without patient advocate with support from Communications Committee	• Study chair Tweets and NRG Oncology retweets
Study launch session	Protocol Development or Communications Committee with Study Chair review	• NRG Oncology semiannual meeting

[a] CTSU: Clinical Trials Support Unit.

[b] Selected trials only.

Tools Used During Trial Accrual Period

A second series of tools are used during the accrual period. Throughout the duration of the clinical trial, updates will be given by the study principal investigator at NRG Oncology semiannual meetings during disease-specific sessions that occur every 6 months (Table 2). Study NCTN champions will provide study updates at the different network group meetings on a semiannual basis. The study principal investigators will submit a “Trial in Progress” abstract to appropriate professional society meetings including the American Society of Clinical Oncology (ASCO) annual meetings and pertinent disease- and modality-specific society meetings. The purpose of “Trial in Progress” abstracts is to raise awareness about the trial among other health care professionals with the goal of increasing the number of study sites that have the trial open and available for patients. The study principal investigator and trial leadership (including study cochairs or subinvestigators) will also be expected to use conference speaking opportunities to discuss the science around the clinical trial and promote awareness about the study design and eligible population. For trials with industry funding available, additional investigator sessions could be held with an industry collaborator at appropriate scientific meetings such as the American Society of Clinical Oncology or the American Society for Radiation Oncology. As these investigator sessions are an additional cost, they are only included for trials with industry funding.

Table 2. Principal investigator tool kit—tools for the accrual phase.

Tasks	Responsible party	Product or placement
Study updates[a]	Protocol Development or PI[b]	NRG Oncology semiannual meeting
Trials-in-progress abstract	Study Chair or NRG Oncology publications	Conference poster at ASCO[c] and disease-specific society meetings
Trial-related social media messages	Study Chair, Communications Committee, patient advocates, and other stakeholders	Monthly compilation of Twitter, Facebook, and other social media platform visibility
Mention trial in education sessions	Study Chair and NCTN[d] study champions	Relevant professional meetings
Investigator luncheon	Industry partner	Relevant professional meetings
Monitor accrual	Study Chair	Review month CTSU[e] reports

[a] Selected trials only.

[b] PI: principal investigator.

[c] ASCO: American Society of Clinical Oncology.

[d] NCTN: National Clinical Trials Network.

[e] CTSU: Clinical Trials Support Unit.

A vital component of the PI tool kit is the use of social media platforms such as Twitter. The study principal investigator with assistance from the Communications Committee members will be expected to engage with the scientific community through these platforms around the clinical trial and other scientific advances in the disease space that may be pertinent to the ongoing clinical trial. Public communication through social media about clinical trials is an important avenue to raise awareness of these trials with patients, caregivers, and patient advocacy groups, all of whom have a presence on social media platforms. Many patient-led disease-specific advocacy groups use social media platforms to engage with patient communities; through collaboration with an identified patient advocate, messaging about the importance and availability of clinical trials may be amplified within disease-specific communities [11,12]. Importantly, every trial should identify a patient advocate to collaborate with during the accrual period. This can be carried out through the NRG Oncology patient advocacy committee, which is a committee of patient advocates that works closely with NRG Oncology on all phases of clinical trial development.

During the trial accrual period, a critical monitoring tool to be used is monthly CTSU reports. These reports are sent to trial principal investigators. They outline the number of study sites that are approved to enroll study participants, as well as monthly and overall accrual reports (Multimedia Appendix 2).

Tools to Address Barriers to Accrual

The PI tool kit includes specific tools for trials that are not meeting accrual goals (Table 3). The first tool includes a process for identifying barriers to patient accrual. This information can be gleaned from site principal investigators during monthly NRG Oncology disease-specific meetings. These touch points with site principal investigators are crucial for an understanding of major reasons for screen failure or patients declining trial participation. After such barriers are identified, subsequent adjustments or trial amendments can be made that address specific issues (if required). It is crucial that the study principal investigator maintains a high level of bidirectional communication with site principal investigators and the disease group such that any barriers to accrual can be identified and addressed in a timely manner.

For trials that are not meeting accrual targets, a patient landing page can be created that is located within the NRG Oncology website to provide study information to health care teams and patients in a seamless way. Other tools include site surveys to reengage the study teams and surveys that assess the feasibility of opening the study at other sites that are not currently open to accrual. NCTN study champions should also be engaged when accrual is lacking and to continue to energize the NCTN community around trial accrual. Moreover, monthly webinars with the study principal investigator can be used to facilitate engagement with site principal investigators to further enhance accrual efforts. Such engagement can be performed with monthly protocol webinars for active study sites. Additionally, each NCTN group has an oversight committee, which monitors study accrual and can help address accrual issues with the study chair of underperforming trials. Within NRG Oncology, the POM committee reviews accrual data quarterly for all NRG trials and connects with study principal investigators as needed to offer support for improving accrual.

Table 3. Principal investigator tool kit—trials experiencing accrual barriers.

Tasks	Responsible party	Product or placement
Identify barriers to accrual and adapt	Study Chair or Protocol Development team	• Monthly site calls or amendments • Webinar
Engage community intermediaries	Study Chair with support of disease-specific committee and advocates	• Targeted communication about the trial
Regular contact with institutional PIs[a]	Study Chair with support from Protocol Development	• Monthly calls or webinars • In-person meetings
Consider study landing page (if not already available)	Protocol Development or Communications Committee with Study Chair review	• NRG Oncology web page • CTSU[b] web page
Use NCTN[c] champions (if not already available)	Study Chair with Protocol Development	• Sponsorship of trial at other NCTN groups
Conduct site surveys	Study Chair	• Assessment of feasibility of opening new sites or reengaging existing sites

[a] PIs: principal investigators.

[b] CTSU: Clinical Trials Support Unit.

[c] NCTN: National Clinical Trials Network.

Piloting the Study Principal Investigator Tool Kit

The NRG Oncology PI tool kit was developed in 2019, with the idea that the tool kit would be piloted by a trial selected by the POM committee. NRG Oncology/Alliance NRG-LU005 launched on May 28, 2019. The latter is a trial for limited-stage, small-cell lung cancer that is testing standard chemoradiation with or without atezolizumab. This is a phase II or III study with a target accrual of 506 patients. Historically, clinical trials in limited-stage, small-cell lung cancer have been difficult to complete [13], and it was felt that the PI tool kit would be a valuable resource to use at the outset of NRG Oncology/Alliance NRG-LU005. The PI tool kit was used at study launch and throughout study accrual, which was completed on June 30, 2022.

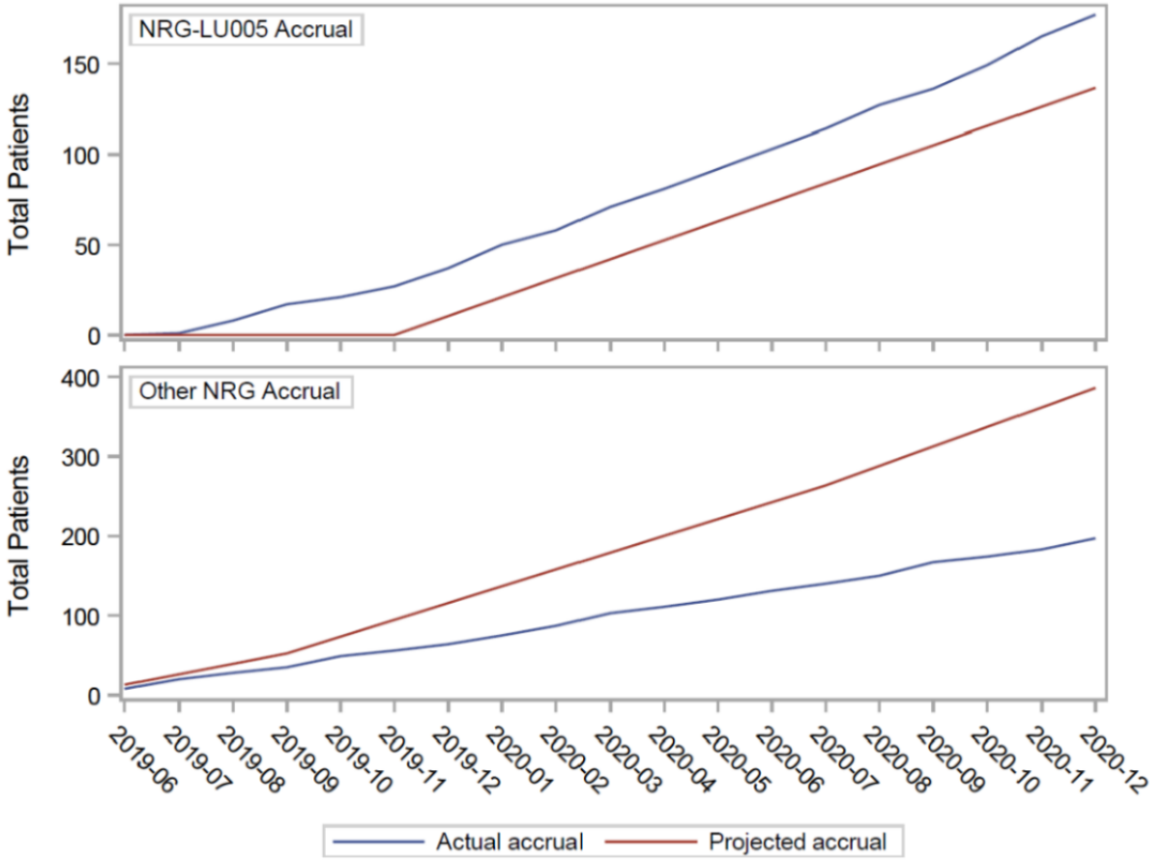
Results

NRG Oncology/Alliance NRG-LU005 has been accruing ahead of the projected schedule since the time of study launch. This has occurred despite the COVID-19, pandemic which began several months after the study launched (Figure 1). As of January 31, 2021, a total of 374 sites were approved for enrollment; 109 (29.1%) sites have accrued at least one patient, and 20 (5.3%) sites have accrued three patients or more. The trial was projected to accrue 10.5 patients per month; however, the accrual rate for the last 6 months has been 11.3 patients per month. As of October 2, 2021, total accrual was 127% of the projected accrual.

Compared with the rate of study accrual for Cancer and Leukemia Group B 30610, the prior NCTN study in limited-stage, small-cell lung cancer (activated on March 15, 2008), NRG Oncology/Alliance NRG-LU005 accrual, which used the PI tool kit intervention, was higher. The latter enrolled 48 patients during the first 9 months of activation, compared with 18 patients enrolled in Cancer and Leukemia Group B 30610 during the first 9 months of activation. These 2 trials enrolled the same patient population with very similar inclusion criteria, including newly diagnosed, limited-stage, small-cell lung cancer without prior treatment, with an Eastern Cooperative Group Performance Status of 0-2 [14]. Considering the accrual of NRG Oncology/Alliance NRG-LU005 relative to other NRG Oncology lung cancer phase II or III trials during the same period (June 2019 to December 2020), Figure 1 shows an accrual greater than what was projected for NRG Oncology/Alliance NRG-LU005, while other NRG Oncology lung cancer trials accrued at rates less than what was projected. Additionally, NRG Oncology/Alliance NRG-LU005 accrual was not negatively impacted by the COVID-19 pandemic relative to other NRG lung cancer trials, which did see reduced accrual with the onset of the pandemic in early 2020.

In terms of operationalizing the PI tool kit, NRG Oncology specifically assessed ongoing clinical trials for retroactive use of study PI tool kit elements. Out of the 71 active studies, 40 (56%) are currently using at least one element of the tool kit, with 29 studies (41%) using patient brochures, 24 (34%) with study training slides, 26 (37%) with social media cards, 9 (13%) with a study flyer, 6 (8%) with study newsletters, and 6 (8%) using study-specific webinars. Given the successful adoption of several PI tool kit elements in active studies and early feasibility of proactive tool kit use during NRG LU-005 activation, operationalizing the PI tool kit for all new NRG Oncology studies in development is not expected to be difficult or costly.

Figure 1. Accrual pace of NRG/Alliance LU005 (top panel) relative to other NRG Oncology lung cancer phase II or III trials (bottom panel).



Discussion

Principal Findings

Accrual to federally funded NCTN trials is critical to advance cancer care and to study novel treatments. Many trials within the NCTN portfolio fail to accrue as rapidly as projected, and this can ultimately lead to delayed knowledge of treatment effect or study closure as well as poor use of limited resources. Premature closure of federally funded clinical trials ultimately results in tax-payer dollars being used in an ineffective way. A study of National Cancer Institute Cancer Therapy Evaluation Program phase I-III trials between 2000 and 2007 showed that 81.5% of trials did not achieve projected accrual goals, and 37.2% failed to achieve the minimum projected accrual at study closure [15]. This study also showed that trials that accrue the first patient beyond 2 months from activation are significantly less likely to achieve accrual goals [15]. Another study of NCI cooperative group phase III trials activated from 2000 to 2007 demonstrated that the number of phase-III trials that did not reach their projected total accrual due to insufficient enrollment was estimated to be 22% for pediatric and adult trials combined and 26.7% for nonpediatric trials [16]. Targeted interventions designed to optimize accrual early, at the time of activation and throughout the duration of the trial, are urgently needed to answer our most pressing scientific questions in oncology. Particularly considering the COVID-19 pandemic, with reduced enrollment in clinical trials across the United States, methods to help investigators overcome accrual barriers and a road map of resources offer the potential to address trial accrual barriers in a timely manner.

The NRG Oncology PI tool kit was developed to take a multipronged approach in a style of a checklist with accrual-enhancing activities developed and performed by both NRG Oncology staff and the study principal investigator. The PI tool kit uses a variety of methods to leverage optimal engagement within the scientific and patient advocate community. Engagement with the patient and physician population that will participate in the trial serves as the cornerstone of the PI tool kit, and it is expected that the study principal investigator or physician champions have an active and professional Twitter presence. By creating a clear road map of activities to be performed at key time points during the study lifetime, the study team can most optimally engage and support trial accrual. The PI tool kit was designed to be used for any cancer disease site and could be readily adopted by other groups within the NCTN. The PI tool kit was piloted with NRG Oncology/Alliance NRG-LU005, and this trial has exceeded accrual goals despite the COVID-19 pandemic. NRG Oncology plans to use the PI tool kit for all future phase II and III trials that are activated. Notably, most of the tools in the tool kit are low-cost and can be implemented with a modest degree of infrastructure.

Comparison With Prior Work

Many of the interventions described in the tool kit use social media platforms for awareness and engagement. The role of social media in enhancing recruitment to clinical trials is an active area of investigation. Social media can be leveraged to engage with patients with cancer, including rare cancers, and facilitate patient knowledge of and enrollment to clinical trials

[17]. A recent review reported that preliminary data suggest that social media platforms can enhance patient participation in a cost-effective manner [18]. However, there are currently barriers to generating high-quality, evidence-based data, specifically assessing how social media platforms impact clinical trial accrual, primarily due the difficulties in capturing data. It has also been suggested that social media platforms such as Facebook and Twitter may also be tools that could improve recruitment of minority populations to clinical trials [19]. In an evaluation of recruitment methods to a randomized controlled study of Spanish-speaking smokers in the United States, Facebook was the most effective method of recruitment for enrolling Hispanic or Latinx smokers [20].

Limitations

One important caveat to the PI tool kit is that it primarily serves to amplify study accrual for well-designed clinical trials that are asking important scientific questions. The success in patient accrual seen in the first pilot trial (NRG Oncology/Alliance NRG-LU005) is also attributed to the excitement around immunotherapy in patients with small-cell lung cancer, given recent data showing a survival benefit when immunotherapy is combined with frontline chemotherapy in extensive-stage, small-cell lung cancer [21,22], which cannot be attributed to the PI tool kit alone.

While the NRG Oncology PI tool kit focuses primarily on tools that enhance engagement, there are certainly other tools that could be explored to improve accrual to clinical trials. The PI tool kit does not specifically address fundamental flaws in trial design that could negatively impact accrual. Additionally, it focuses on overall accrual and does not have any tools to enhance enrollment of patients from underrepresented groups and elderly patients, which is important for study applicability. Future efforts for NRG Oncology include the development of specific tools to enhance the accrual of diverse patient populations. Lastly, the PI tool kit is in the early phase of development, and as such, it has not been fully implemented into all NRG Oncology trials. Implementation science methodologies have not yet been used to fully integrate the tool kit into all clinical trials within our organization.

Conclusions

In conclusion, the NRG Oncology PI tool kit was created to enhance overall accrual efforts to NCI-sponsored clinical trials. With a focus on tools that will enhance engagement across the stakeholders in oncology care, the PI tool kit fills an unmet need and could be widely adopted across the NCTN.

Acknowledgments

This project was supported by grants U10CA180868 (NRG Oncology Operations) from the National Cancer Institute (NCI).

Data Availability

Research data are stored in an institutional repository and will be shared upon request from the corresponding author.

Authors' Contributions

SHS, KAH, MJM, NS, AT, and MWW contributed to conception and design; SHS, KAH, TBJ, RP, and AT conducted data collection and assembly; TJG, KAH, MJM, RP, AT, and MWW carried out data analysis and interpretation; TJG, SHS, KAH, TBJ, MJM, RP, NS, AT, and MWW were responsible for the writing of the paper; and TJG, SHS, KAH, TBJ, MJM, RP, NS, AT, and MWW issued the final approval of the manuscript.

Conflicts of Interest

TJG has grants or contracts through his institution from Bristol-Myers Squibb, Merck, AstraZeneca/MedImmune, Lilly, Bayer, Incyte, Tesaro/GSK, Ipsen, Seattle Genetics, and Genentech, as well as consulting fees from Tempus. SHS is an employee of the American College of Radiology, a grant awardee of the National Cancer Institute (NCI), and a sub-awardee of the Radiation Therapy Oncology Group (RTOG) Foundation (under NRG Oncology grant). KAH has grants or contracts from RefleXion Medical and Jazz Pharmaceuticals; consulting fees from AstraZeneca, RefleXion Medical, and Janssen Pharmaceuticals; and leadership or fiduciary role in other board, society, committee, or advocacy group (paid or unpaid) such as AstraZeneca, RefleXion, and the NRG Oncology Board of Directors. TBJ has a leadership or fiduciary role in other board, society, committee, or advocacy group (paid or unpaid) such as Chair of NRG Communications Committee. RP has grants or contracts from entities such as NCI (Grant # U10CA180822; NRG Oncology Statistics and Data Management Center). AT has grants or contracts from entities such as Sanofi (research paid to institutions) and Syndax (research paid to institution). She also has support for attending meetings or travel from Genentech (meals to discuss federal grant); participates in a Data Safety Monitoring Board or Advisory Board form BeyondSpring Pharmaceuticals and Lilly (Advisory Board); and has stock or stock options from Pfizer, Johnson and Johnson, Gilead, and Bristol Myers Squibb. MWW has grants or contracts from NRG Oncology; has leadership or fiduciary role in other board, society, committee, or advocacy group; is Chair of Protocol Operations Management Committee of NRG Oncology (not paid); is member at RTOG Foundation Board of Directors; and has other financial or nonfinancial interests such as principal investigator for NRG Oncology at Thomas Jefferson University, Philadelphia, PA. MJM, SHS, and NS have no conflicts of interest to declare.

Multimedia Appendix 1
Principle Investigator tool kit instructions.
[PDF File (Adobe PDF File), 300 KB - cancer_v8i3e38514_app1.pdf]

Multimedia Appendix 2
Site accrual summary.
[PDF File (Adobe PDF File), 236 KB - cancer_v8i3e38514_app2.pdf]

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Abbreviations

CIRB: central institutional review board
CTSU: Clinical Trials Support Unit
NCI: National Cancer Institute
NCTN: National Clinical Trial Network
PI: principal investigator
POM: Protocol Operations Management

Edited by A Mavragani; submitted 05.04.22; peer-reviewed by E Godfrey, CMJ Wong; comments to author 27.06.22; revised version received 13.07.22; accepted 14.07.22; published 25.08.22.

Please cite as:
Higgins KA, Thomas A, Soto N, Paulus R, George TJ, Julian TB, Hartson Stine S, Markham MJ, Werner-Wasik M
Creating and Implementing a Principal Investigator Tool Kit for Enhancing Accrual to Late Phase Clinical Trials: Development and Usability Study
JMIR Cancer 2022;8(3):e38514
URL: https://cancer.jmir.org/2022/3/e38514
doi:10.2196/38514
PMID:36006678

Original Paper

A Multimethod Evaluation of Tobacco Treatment Trial Recruitment Messages for Current Smokers Recently Diagnosed With Cancer: Pilot Factorial Randomized Controlled Trial

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Abstract

Background: A cancer diagnosis can catalyze motivation to quit smoking. Tobacco treatment trials offer cessation resources but have low accrual rates. Digital outreach may improve accrual, but knowledge of how best to recruit smokers with recent diagnoses is limited.

Objective: This study aims to identify the message frames that were most effective in promoting intent to talk to a physician about participating in a tobacco treatment trial for smokers recently diagnosed with cancer.

Methods: From February to April 2019, current smokers diagnosed within the past 24 months were recruited from a national web-based panel for a multimethod pilot randomized trial (N=99). Participants were randomized to a 2×3 plus control factorial design that tested 3 unique message frames: proximal versus distal threats of smoking, costs of continued smoking versus benefits of quitting, and gains of participating versus losses of not participating in a tobacco treatment trial. The primary outcome was intent to talk to a physician about participating in a tobacco treatment trial. In phase 1, the main effect within each message factor level was examined using ANOVA and compared with the control condition. Other message evaluation and effectiveness measures were collected and explored in a multivariable model predicting intent to talk to a physician. In phase 2, open-text evaluations of the messages were analyzed using natural language processing software (Leximancer) to generate a thematic concept map and Linguistic Inquiry Word Count to identify and compare the prevalence of linguistic markers among message factors.

Results: Of the 99 participants, 76 (77%) completed the intervention. Participants who received the cost of continued smoking frame were significantly more likely to intend to talk to their physician about participating in a tobacco treatment trial than those who received the benefits of the quitting frame (mean costs 5.13, SD 1.70 vs mean benefits 4.23, SD 1.86; P=.04). Participants who received the proximal risks of continued smoking frame were significantly more likely to seek more information about participating (mean distal 4.83, SD 1.61 vs mean proximal 5.55, SD 1.15; P=.04), and those who received the losses of not participating frame reported significantly improved perceptions of smoking cessation research (mean gain 3.98, SD 0.83 vs mean loss 4.38, SD 0.78; P=.01). Male participants (P=.006) and those with greater message relevancy (P=.001) were significantly more likely to intend to talk to their physician. Participants' perceptions of their smoking habits, as well as their motivation to quit smoking, were prevalent themes in the open-text data. Differences in the percentages of affective words across message frames were identified.

Conclusions: Multimethod approaches are needed to develop evidence-based recruitment messages for patients recently diagnosed with cancer. Future tobacco treatment trials should evaluate the effectiveness of different message frames on smoker enrollment rates.

Trial Registration: Clinicaltrials.gov NCT05471284; https://clinicaltrials.gov/ct2/show/NCT05471284

(JMIR Cancer 2022;8(3):e37526) doi:10.2196/37526

KEYWORDS

teachable moment; cancer; tobacco treatment trial; smoking; message framing; recruitment

Introduction

Background

Continued cigarette smoking is prevalent in approximately 10% to 30% of patients with recently diagnosed cancer [1,2]. Persistent smoking after diagnosis is associated with numerous adverse outcomes, including decreased treatment effectiveness, increased risk of recurrence, development of second primary cancer, and poorer overall survival outcomes [3-7]. The prevalence of smoking among patients with cancer underlines the need for timely tobacco treatment. Smokers are more likely to attempt to quit immediately after a diagnosis, suggesting that a diagnosis can serve as a *teachable moment* for smoking cessation, in which the motivation to quit is temporarily increased [8,9].

A way of leveraging this teachable moment is to enroll patients with a recent diagnosis in a tobacco treatment clinical trial. Tobacco treatment trials provide evidence-based pharmacological and behavioral therapies that personalize behavioral treatment content to address the concerns and motivations unique to smokers with cancer. However, accrual for tobacco treatment trials is suboptimal [10]. To leverage this teachable moment, as well as to attempt to overcome accrual challenges, the proactive recruitment of smokers through digital outreach offers promise. One such digital recruitment strategy is the dissemination of brief, patient-centered videos featuring clinicians describing the purpose of the trial and its relevance to the patient. This form of outreach permits investigators to deliver targeted trial information to potentially eligible smokers soon after diagnosis, when the motivation to quit may be the highest. However, to date, there has been a limited empirical examination of what content is most effective for inclusion in these outreach videos.

Although a recent diagnosis may provide an opportunity to promote cessation, it is also a time wrought by stress, guilt, stigma, and fatalism among many patients with cancer who smoke [10-16]. As such, recruitment message content promoting smoking cessation and trial participation must balance the appropriate amount of risk and benefit information to encourage participation in tobacco treatment trials.

Health communication theories can inform the content that should be used in digital outreach videos. The construal-level theory proposes that temporal distance determines how we evaluate outcomes [17]. Thus, near or more proximal outcomes are perceived more concretely, whereas distal outcomes are more abstract. Within the context of risk assessment, message cues that prompt judgments of more immediate health risks (eg, daily), compared with more long-term risks (eg, yearly), have been demonstrated to increase risk perception more effectively [18]. For individuals with a recent cancer diagnosis, it is important to understand whether smoking outcomes associated with a current diagnosis (eg, worse treatment outcomes), compared with the prospect of a future diagnosis (eg, recurrence or new primary cancer), are stronger motivators for trial enrollment and cessation initiation.

The prospect theory has been extensively studied in the context of smoking cessation [19-25]. The theory offers a framework within which to understand how individuals evaluate equivalent health messages, depending on how those messages are framed. Gain-framed messages present the likelihood of attaining desirable outcomes, whereas loss-framed messages present the likelihood of avoiding undesirable outcomes [26]. Past studies have found that gain-framed messages are more effective at conveying the short-term benefits of cessation [19]; however, there has been limited investigation into whether this strategy is as effective among patients with a recent cancer diagnosis. This is an important area of inquiry as quitting can result in important short-term benefits by reducing cancer treatment side effects, as well as improving overall energy levels and reducing levels of stress [4,8]. Determining whether to frame the benefits of cessation or the costs of not quitting on these short-term outcomes can act as an important mechanism for motivating cessation and trial enrollment during cancer treatment.

A recent investigation has explored whether it is more effective to use gain- versus loss-framed recruitment messages to motivate patient participation in a tobacco treatment clinical trial for individuals undergoing lung cancer screening (authors blinded for review). Although framing did not significantly alter motivation among smokers, it may have been more effective after a recent cancer diagnosis. The prospect theory offers contextual understanding as to why the utility of each message frame often depends on the type of health decision for which they are presented. For example, gain-framed messages are more successful at encouraging risk-averse choices, whereas loss-framed messages are more successful at motivating choices in which the outcome is more uncertain or risky [26]. However, little is known about whether these choice motivations are influenced by greater residual risk perception (ie, an active cancer diagnosis). To the best of our knowledge, no previous study has investigated gain- versus loss-framed recruitment messages within a population of patients with cancer to motivate participation in tobacco treatment trials.

Objective

The objective of this study was to conduct a pilot factorial randomized trial to identify the message frames that are most effective in promoting participation in a tobacco treatment trial for current smokers recently diagnosed with cancer. To do so, we used a multimethod approach to evaluate 3 different message frames across evaluation, effectiveness, and outcome measures. We combine findings from a message design experiment with textual analytic software to provide a holistic understanding of how message frames may or may not differentially affect tobacco treatment trial participation within the context of a cancer diagnosis.

Methods

Ethics Approval

Participants received a small compensation for their participation, and institutional review board approval was obtained from Massachusetts General Brigham Hospital (#2018P002035) before data collection began.

Sample and Procedures

From February to April 2019, a total of 99 participants were recruited from Dynata Panels, a proprietary opt-in web-based panel company, to complete a 20-minute survey. Participants were required to be English speaking, have a recent cancer diagnosis (within the past 24 months), be aged >18 years, and report any cigarette use within the past 30 days.

Participants were randomly assigned to 1 of 9 conditions as part of a 2×3 plus control factorial design. The factorial design is presented in Table 1. The first factor tested framing of the threat of continued smoking (distal vs proximal); the second factor tested framing of the response efficacy to quitting smoking (costs of continued smoking vs benefits of quitting), and the third factor tested framing of the response efficacy of participating in a cessation study (gains of participating in a smoking cessation study vs losses of not participating in a smoking cessation study). The control condition was a kernel message that included study information present in all conditions but did not include any of the message factors (described in detail in the *Stimuli* section). All participants completed premessage survey measures. After viewing 1 of the 9 videos, participants immediately completed postmessage survey measures, including open-text evaluation responses.

Table 1. Intervention conditions (3-factor, fully crossed factorial design).

Condition	Threat of continued smoking (distal vs proximal)	Response efficacy to quit smoking (cost vs benefit)	Response efficacy of participating in the study (gain vs loss)
1	Proximal	Cost	Loss
2	Proximal	Cost	Gain
3	Proximal	Benefit	Gain
4	Proximal	Benefit	Loss
5	Distal	Cost	Gain
6	Distal	Cost	Loss
7	Distal	Benefit	Loss
8	Distal	Benefit	Gain
9 (control)	N/A[a]	N/A	N/A

[a] N/A: not applicable.

Stimuli

A total of 9 videos were created specifically for this study with the aim of selecting 1 video for use as part of the primary video recruitment strategy in the parent trial (SmokeFree Support Study 2.0). Each video comprised an oncologist speaking directly into the camera and was segmented into six sections, including four kernel sections that all videos possessed: (1) introducing the aims of the *Smoke Free Support Study*, (2) confirming the patient as eligible because of their recent cancer diagnosis and smoking status, (3) describing resources available in the study intervention (ie, access to remote counseling and nicotine replacement therapy), and (4) expectation setting that a study team member would contact the patient in the future to discuss willingness to participate.

Regarding the threat of continued smoking factor, the distal frame read as follows:

> *Every year, patients with cancer have worse outcomes because they keep smoking. By continuing to smoke, you reduce the effectiveness of your care, which means your cancer may come back and you may develop a new cancer at a later date.*

The proximal frame read as follows:

> *Every day, patients with cancer have worse outcomes because they keep smoking. By continuing to smoke, you reduce the effectiveness of your care, which means your cancer may keep growing and you may be less likely to respond to your treatment.*

For the quitting smoking factor, the costs of not quitting frame read as follows:

> *We want you to be aware that continuing to smoke after your cancer diagnosis can cause you to experience more side effects, increase your anxiety and stress, and have less energy.*

The benefits of quitting frame read as follows:

> *We want you to be aware that stopping smoking after your cancer diagnosis can cause you to experience fewer side effects, decrease your anxiety and stress, and have more energy.*

For the participation factor, the loss frame read:

> *The not-so-good news is, quitting, or even reducing the number of cigarettes you smoke each day could be more difficult without the support of our study. In fact, the Smoke Free Support Program has shown that the average patient is 3 times less likely to successfully quit smoking than patients who participate. By not participating, you can lose out on learning how to control your cravings and have a greater quality of life.*

The gain frame read as follows:

> *The good news is, quitting, or even reducing the number of cigarettes you smoke each day, could be much easier with the support of our study. In fact, the Smoke Free Support Study has shown that patients who participated were 3 times more likely to successfully quit smoking than the average patient. By participating, you can benefit from learning how to control your cravings and have a greater quality of life.*

Quantitative Measures

Sociodemographics

The following sociodemographic characteristics were measured: gender (male, female, transgender, gender nonconforming, or other), race (American Indian or Alaskan Native, Asian, Black or African American, Native Hawaiian or Pacific Islander, White, or other), ethnicity (Hispanic and Latino or not Hispanic and Latino), age (in years), household income (≥US $40,000), and highest level of education (after high school education or above).

Cancer Characteristics

The type of cancer diagnosis (prostate, lung, breast, pancreas, skin, stomach, gynecological, colorectal, and other) and months since diagnosis (>6 months, 7-12 months, or 13-24 months) were assessed.

Smoking Characteristics

The following smoking characteristics were assessed: the number of years smoked or how long the participant had smoked cigarettes in years, Heaviness of Smoking Index measured across 2 items or how many cigarettes the participant smoked per day, how soon after the waking up does the participant smoke (within 5 minutes, 6-30 minutes, 31-60 minutes, and after 60 minutes) [27], and smoking urge or how much of the time the participant felt the urge to smoke in the past 24 hours (all the time, almost all the time, much of the time, some of the time, a little of the time, or not at all). Participants' attitudes toward quitting were measured using the 4 dimensions previously used by the authors (blinded for review): importance or how important it was that the participant quit smoking, ranging from 0 (not important at all) to 10 (very important); confidence or how confident the participant was they could quit smoking, ranging from 0 (not confident at all) to 10 (very confident); how much quitting smoking would reduce the participant's chances of developing cancer, ranging from 0 (not at all) to 10 (very much); and Biener Contemplation ladder for stage of motivation to quit smoking ("I have decided to continue smoking"; "I do not think about quitting smoking"; "I rarely think about quitting and have no plans to quit"; "I sometimes think about quitting but I have no plans yet"; "I often think about quitting but I have no plans yet"; "I plan to quit smoking in the next 6 months"; "I plan to quit smoking in the next 30 days"; "I have begun to make changes in my smoking"; "I have made changes in my smoking but I need to keep working at it"; and "I have already quit smoking") [28].

Message Evaluation

Message Relevance

Perceived message relevance was measured using 2 items from the Perceived Message Relevance Scale [29,30]. Items measured how personalized or customized the stimuli were (eg, "The video seemed to be made personally for me"). Items were measured on a 5-point Likert scale, with response categories ranging from 1 (strongly disagree) to 5 (strongly agree; α=.79; mean 4.26, SD 0.91).

Message Credibility

Perceptions of informational credibility were measured using items from Appelman and Sundar [31] and assessed participants' perceptions that the video was accurate, credible, and believable. The 3 items (eg, "The information discussed in the video is accurate") were rated on a 5-point Likert scale, with response categories ranging from 1 (strongly disagree) to 5 (strongly agree; α=.81; mean 4.34, SD 0.68).

Message Clarity

Perceptions of message clarity were adapted from Cacioppo et al [32] and measured the extent to which participants perceived the content of the video to be clear, which was measured on a 1-item, 5-point Likert scale, with responses ranging from 1 (strongly disagree) to 5 (strongly agree). The item stated, "The content in the video is clearly explained" (mean 4.34, SD 0.68).

Message Effectiveness

Improved Perceptions

Improved perceptions of smoking cessation research were measured using a 1-item, investigator-developed measure on a 5-point Likert scale, with response categories ranging from 1 (strongly disagree) to 5 (strongly agree). The item stated, "The video improved my view of smoking cessation research" (mean 4.08, SD 0.85).

Information Seeking

Information seeking about participation in a smoking cessation study was measured using a 1-item investigator-developed measure on a 5-point Likert scale, with response categories ranging from 1 (strongly disagree) to 5 (strongly agree). The item stated, "I am interested in more information about enrolling in a smoking cessation study" (mean 4.74, SD 1.48).

Informed Decision-making

Informed decision-making about participation in a smoking cessation study was measured using a 1-item, investigator-developed measure on a 5-point Likert scale, with response categories ranging from 1 (strongly disagree) to 5 (strongly agree). The item stated, "With this video, I believe I can make an informed decision on participation in a smoking cessation study" (mean 4.15, SD 0.77).

Message Outcome: Intent to Talk to a Physician About Participating

The intent to participate in a smoking cessation study was measured using a 1-item, investigator-developed measure on a 5-point Likert scale, with response categories ranging from 1 (strongly disagree) to 5 (strongly agree). The item stated, "I intend to talk to my doctor about enrolling in a smoking cessation study" (mean 4.28, SD 1.86).

Qualitative Measure: Open-Text Responses

Participants provided open-text feedback on the video by responding to the following prompt: "In the space below, please tell us what you thought about the video you just saw."

Statistical Analyses

Phase 1: Message Design Experiment

Summary statistics were used to report means with SDs for continuous variables and frequencies with percentages for categorical variables. Message evaluation, message effectiveness, and message outcome variables were compared using ANOVA to examine the main effect of the 3 message factors compared with the control and within-message factor levels. This study was not powered for interactions among the 3 factors. To determine the predictors of intent to talk to a physician about participating in a smoking cessation study, univariate analyses were conducted to determine the relationships among participants' sociodemographic characteristics, cancer characteristics, smoking characteristics, and message evaluation and effectiveness measures of intent to participate. Variables with $P \leq .10$ were included in the multivariable model, as well as message factors that were shown to have a main effect on intent. A generalized linear model was used to identify significant predictors in the multivariable model with a 2-sided significance level of .05. All analyses were conducted using IBM SPSS Statistics for Mac software (version 26).

Phase 2: Open-Text Response Analysis

Open-text data were analyzed using 2 software packages: Leximancer and Linguistic Inquiry Word Count (LIWC). First, Leximancer was used as a text-mining software to generate a concept map. Leximancer uses machine learning to generate a codebook, identify related keywords to form concepts, and then map the relationships between concepts based on the level of association between words or phrases. Second, Leximancer was used to conduct automated thematic analysis. Themes are generated when clusters of concepts are linked and can encapsulate broader phenomena. Themes are then given *hits* to determine their frequency or salience in the text. Within the concept map, the size of the theme is directly proportional to its frequency in the data. To form the map, themes are linked together with pathways that help to provide insight into whether the themes are connected. Previous studies have used Leximancer as a tool to triangulate qualitative data [33], analyze a large corpus of open-text data to identify markers of risk communication [34], and evaluate the mechanisms by which tailoring risk messages to promote colorectal cancer messages may be effective [35].

For this study, participant responses were uploaded to Leximancer to generate a preliminary concept map to understand the primary grouping and frequencies of the concepts. The experimental conditions were not separated and used to generate independent concept maps because of sample size limitations. Upon reviewing the preliminary concept map, study team members (JN, CS, and LB) identified and then grouped similar words (eg, *quits*, *quitting*, and *quit*) to refine the autogenerated concepts and create the final concept map. Leximancer used the cleaned data to generate the best-fitting quotes for each theme, and this output was analyzed by the study team members to generate a definition for each theme and pick an exemplary quote. To ensure rigor within this iterative process, the study used the constant comparative method [14]; that is, 2 coders (CS and LB) independently reviewed the Leximancer output and then reviewed together afterward to discuss reflections. These 2 members then brought their impressions and any discrepancies to a 3-member consensus group (JN, CS, and LB), which met weekly. A senior investigator and expert in qualitative methods (EP) then provided a process evaluation and a final review of the concepts.

LIWC is a textual analysis software that compares text-based data with a group of built-in dictionaries. The LIWC dictionaries are summary language variables and specific language variables. LIWC has been used to identify linguistic markers or conduct sentiment analysis within diverse open-text data, interpersonal or web-based medical communication contexts [36], and extensively within contexts related to cancer [37-41]. This study used LIWC to analyze word count and selected 4 summary language variables (analytical thinking, clout, authenticity, and emotional tone), presence of relevant psychological variables (overall affect, positive emotion, and negative emotion), and drives and needs variables (reward and risk). The summary language variables were calculated and converted to percentiles based on standardized scores from large comparison samples, whereas the specific language variables were calculated as a percentage of the total words used in the given language sample. ANOVA was used to examine the main effect of the 3 message factors compared with the control and within-message factor levels across summary and specific language variables.

Results

Participant Characteristics

A total of 99 participants were recruited and consented to participate in the study (Figure 1). Of the 99 participants, 22 (22%) participants were excluded from the final sample as they indicated that the video did not display (7/99, 7%), had a benign tumor (1/99, 1%), or failed the study attention check (15/99, 15%). Thus, 76 participants were included in the final analysis. Table 2 reports the characteristics of the 76 participants, who had a mean age of 53.4 (SD 1.6) years, were male (42/76, 55%), were predominantly White (65/76, 86%), and completed formal education after high school (62/76, 82%). Almost all participants had health insurance (73/76, 96%), and most had a household income >US $40,000 (56/76, 73.7%). The most frequently reported cancers were of the skin (23/76, 30%) and breast (10/76, 13%), with over one-third of the participants diagnosed with cancer in the past 6 months (29/76, 38%). Participants reported a lifetime of nicotine use through the number of years in which they smoked cigarettes (mean 28.93, SD 16.41), as well as a current dependence on cigarettes smoked per day (mean 11.84, SD 7.91) and time to first cigarette (<30 minutes; 24/76, 31.6%).

Figure 1. CONSORT (Consolidated Standards of Reporting Trials) flow diagram.

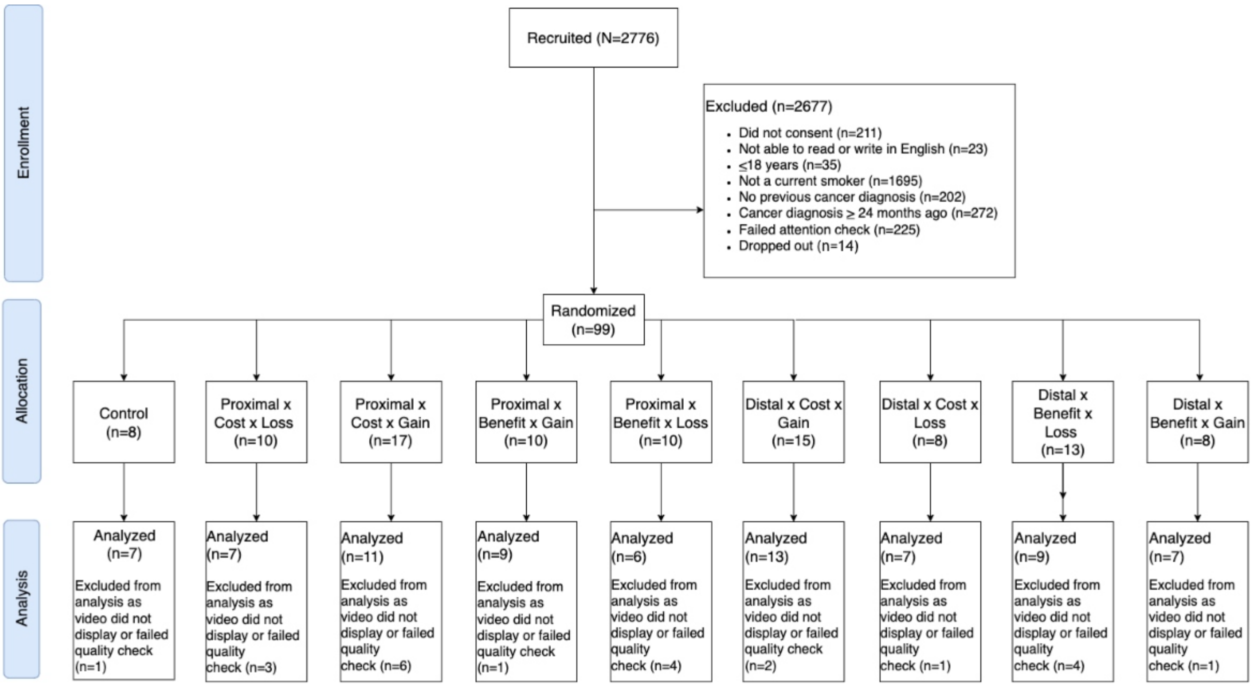


Table 2. Participant characteristics compared across 9 conditions (N=76).

Participant characteristics	Total	Control	Proximal, cost, loss	Proximal, cost, gain	Proximal, benefit, gain	Proximal, benefit, loss	Distal, cost, gain	Distal, cost, loss	Distal, benefit, loss	Distal, benefit, gain
Age (years), mean (SD)	53.4 (1.6)	57.6 (17.8)	59.7 (11.9)	48.5 (16.9)	54.8 (11.3)	63.8 (9.2)	52.9 (15.1)	49.1 (12.6)	52.9 (12.4)	45.4 (15.0)
Gender, n (%)										
Male	42 (55)	5 (71)	4 (57)	7 (64)	1 (11)	3 (50)	9 (69)	4 (57)	4 (44)	5 (71)
Female	34 (45)	2 (29)	3 (43)	4 (36)	8 (89)	3 (50)	4 (31)	3 (43)	5 (56)	2 (29)
Race, n (%)										
White	65 (86)	6 (86)	5 (71)	9 (82)	7 (77.8)	6 (100)	13 (100)	6 (86)	8 (89)	5 (71)
Non-White	11 (15)	1 (14)	2 (29)	2 (18)	2 (22)	0 (0)	0 (0)	1 (14)	1 (11)	2 (29)
Ethnicity, n (%)										
Hispanic	7 (9)	0 (0)	1 (14)	0 (0)	0 (0)	1 (17)	1 (8)	2 (29)	0 (0)	2 (29)
Education, n (%)										
After high school education	62 (82)	6 (96)	4 (57)	11 (100)	6 (67)	4 (67)	12 (92)	7 (100)	7 (78)	5 (71)
Health insurance, n (%)										
Insured	73 (96)	6 (86)	7 (100)	11 (100)	8 (89)	6 (100)	13 (100)	6 (86)	9 (100)	7 (100)
Income (US $), n (%)										
≥40,000	56 (74)	6 (86)	4 (57)	9 (82)	5 (56)	3 (50)	8 (62)	7 (100)	8 (89)	6 (86)
Time frame of cancer diagnosis (months), n (%)										
<6	29 (38)	2 (29)	5 (71)	4 (36)	3 (33)	2 (33)	5 (39)	2 (29)	4 (44)	2 (29)
7-12	28 (37)	3 (43)	1 (1)	3 (27)	3 (33)	2 (33)	5 (39)	4 (57)	3 (33)	4 (57)
13-24	19 (25)	2 (29)	1 (14)	4 (36)	3 (33)	2 (33)	3 (23)	1 (14)	2 (22)	1 (14)
Cancer screening history, n (%)										
Prostate	7 (9)	0 (0)	1 (14)	4 (36)	1 (11)	0 (0)	0 (0)	0 (0)	0 (0)	1 (14)
Lung	5 (7)	0 (0)	0 (0)	1 (9)	0 (0)	0 (0)	1 (8)	2 (29)	0 (0)	1 (14)
Breast	10 (13)	1 (14)	0 (0)	2 (18)	3 (33)	1 (17)	0 (0)	1 (14)	2 (22)	0 (0)
Pancreatic	3 ()	0 (0)	2 (29)	0 (0)	0 (0)	0 (0)	1 (8)	0 (0)	0 (0)	0 (0)
Skin	23 (30)	1 (14)	3 (43)	2 (18)	1 (11)	2 (33)	4 (31)	2 (29)	5 (56)	3 (43)
Stomach	3 (4)	1 (14)	0 (0)	1 (9)	0 (0)	0 (0)	0 (0)	0 (0)	0 ()	1 (14)
Gynecological	7 (9)	0 (0)	0 (0)	1 (9)	2 (22)	1 (17)	1 (8)	1 (14)	1 (11)	0 (0)
Colorectal	7 (9)	1 (14)	1 (14)	0 (0)	0 (0)	0 (0)	2 (15)	1 (14)	1 (11)	1 (14)
Other	10 (13)	2 (29)	0 (0)	0 (0)	2 (22)	2 (33)	4 (31)	0 (0)	0 (0)	0 (0)
Never screened for any test	1 (1)	1 (14)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Smoking characteristics, n (%)										
eHealth literacy										
Values, mean (SD)	3.90 (0.65)	3.73 (0.76)	3.93 (0.68)	3.73 (0.78)	3.75 (0.49)	4.31 (0.39)	3.78 (0.71)	3.88 (0.77)	4.14 (0.34)	4.09 (0.77)
Values, range	2.0-5.0	2.4-4.5	2.5-4.5	2.3-4.9	2.9-4.4	3.8-4.8	2.0-4.5	2.8-5.0	3.8-4.8	2.6-5.0
Years smoked										
Values, mean (SD)	28.93 (16.41)	33.29 (22.49)	27.86 (15.77)	24.00 (19.69)	33.67 (8.65)	38.00 (15.79)	32.46 (16.25)	23.71 (14.87)	25.67 (14.14)	22.43 (18.28)
Values, range	2-57	2-54	10-50	2-54	17-42	18-55	10-55	5-45	3-51	2-57

Participant characteristics	Total	Control	Proximal, cost, loss	Proximal, cost, gain	Proximal, benefit, gain	Proximal, benefit, loss	Distal, cost, gain	Distal, cost, loss	Distal, benefit, loss	Distal, benefit, gain
Cigarettes smoked per day										
Values, mean (SD)	11.84 (7.91)	13.57 (10.53)	6.86 (3.67)	12.09 (4.89)	9.67 (5.92)	15.67 (7.53)	12.92 (7.92)	9.00 (8.64)	13.25 (11.30)	13.43 (10.05)
Values, range	0-35	0-30	3-12	5-20	0-18	9-30	0-30	0-25	0-35	2-30
Minutes to first cigarette, n (%)										
>30	24 (32)	2 (29)	2 (29)	4 (363)	5 (56)	0 (0)	3 (23)	3 (43)	4 (44)	1 (14)
<30	51 (67)	5 (71)	5 (71)	7 (64)	4 (44)	6 (100)	10 (77)	4 (57)	4 (44)	6 (86)
Quit importance										
Values, mean (SD)	8.28 (1.86)	7.71 (2.36)	9.43 (0.79)	8.60 (1.58)	8.00 (2.18)	7.00 (2.97)	8.31 (1.49)	8.00 (2.38)	8.44 (1.51)	8.71 (1.38)
Values, range	3-10	5-10	8-10	6-10	4-10	3-10	6-10	3-10	5-10	7-10
Quit confidence										
Values, mean (SD)	7.07 (2.41)	7.00 (1.83)	8.43 (1.51)	6.73 (2.57)	7.33 (2.06)	6.83 (2.48)	5.38 (3.07)	8.00 (0.82)	7.33 (3.00)	8.00 (1.73)
Values, range	1-10	5-10	6-10	2-10	3-10	3-10	1-10	7-9	2-10	5-10
Benefits of quitting to reduce cancer risk										
Values, mean (SD)	4.96 (2.73)	4.86 (3.19)	5.57 (2.23)	3.45 (2.21)	6.22 (2.95)	5.17 (1.94)	5.08 (3.15)	4.29 (2.75)	5.67 (3.43)	4.57 (1.90)
Values, range	1-10	1-10	1-8	1-6	1-10	3-8	1-10	2-10	1-10	1-7
Intention to quit smoking										
Values, mean (SD)	2.94 (1.08)	3.17 (0.75)	2.67 (1.63)	2.64 (1.21)	2.75 (1.16)	2.83 (0.75)	2.85 (0.90)	3.17 (1.17)	3.14 (1.21)	3.57 (0.98)
Values, range	1-5	2-4	1-5	1-5	2-5	2-4	2-5	1-4	1-5	2-5

Message Design Experiment

Message Evaluation, Message Effectiveness, and Message Outcome

First, the message frames were compared with those of the control (Table 3). The control condition reported lower mean values for almost every measure; however, there were no statistically significant differences. Next, message frames were compared within the factors (eg, proximal vs distal). Across message evaluation measures, all messages performed equally well across the perceived message relevance, credibility, and clarity measures. In the message effectiveness measures, participants who received the proximal threat message frame reported a significantly greater interest in talking to their physician about participating in a smoking cessation research study when compared with the distal frame ($F_{1, 67}$=4.49; mean distal 4.83, SD 1.61, v. mean proximal 5.55, SD 1.15; *P*=.04). There were no statistically significant differences between the cost of smoking frame versus the benefits of quitting frame. However, participants who received the loss of not participating message frame reported significantly improved perceptions of smoking cessation research ($F_{1, 67}$=4.20; mean gain 3.98, SD 0.83, vs mean loss 4.38, SD 0.78; *P*=.04). In the message outcome measure, participants in the costs of not quitting message frame reported significantly greater intention to speak to their physician about enrolling ($F_{1, 67}$=4.47; mean cost 5.13, SD 1.70) vs mean benefit 4.23, SD 1.86; *P*=.04).

Table 3. Main effects for message evaluation, message effectiveness, and message intent for each message factor.

Message factor	Control, mean (SD)	Distal, mean (SD)	Proximal, mean (SD)	*P* value[a]	Cost, mean (SD)	Benefit, mean (SD)	*P* value[a]	Gain, mean (SD)	Loss, mean (SD)	*P* value[a]
Message evaluation										
Message relevance	3.50 (1.29)	3.99 (0.87)	4.18 (0.84)	.34	4.16 (0.81)	3.98 (0.90)	.40	4.06 (0.82)	4.10 (0.91)	.85
Message credibility	3.95 (0.78)	4.46 (0.68)	4.29 (0.63)	.29	4.38 (0.62)	4.39 (0.71)	.95	4.33 (0.68)	4.45 (0.64)	.48
Message clarity	4.43 (0.68)	4.64 (0.64)	4.64 (0.64)	.99	4.58 (0.68)	4.71 (0.53)	.39	4.58 (0.64)	4.72 (0.59)	.33
Message effectiveness										
Improved perceptions about smoking cessation research	3.43 (0.79)	4.14 (0.87)	4.15 (0.80)	.95	4.18 (0.80)	4.10 (0.87)	.67	3.98 (0.83)[b]	4.38 (0.78)[b]	.04[b]
Informed decision-making about participating in a smoking cessation research study	4.71 (0.49)	4.22 (0.83)	4.36 (0.74)	.46	4.29 (0.80)	4.29 (0.78)	1.0	4.30 (0.72)	4.28 (0.88)	.90
Interest in further information about participating in a smoking cessation research study	4.14 (1.57)	4.83 (1.61)[b]	5.55 (1.15)[b]	.04[b]	5.18 (1.37)	5.16 (1.56)	.95	5.15 (1.49)	5.21 (1.40)	.87
Message outcome										
Intent to talk to a physician about participating in a smoking cessation research study	4.43 (2.07)	4.78 (2.00)	4.67 (1.63)	.80	5.13 (1.70)[b]	4.23 (1.86)[b]	.04[b]	4.60 (1.89)	4.90 (1.72)	.51

[a] *P* values are for comparison of main effects between message factor levels.

[b] *P* values <.05

Predictors of Intention to Speak to a Physician About Enrolling in a Smoking Cessation Study

Participants' sociodemographic characteristics, smoking and cancer characteristics, and message evaluation and message effectiveness predictors were explored to determine their association with the message outcome—their intention to speak to their physician about enrolling in a smoking cessation study. Univariate predictors that were associated with intent to speak to a physician included younger age (*P*=.06), male gender (*P*=.003), greater urge to smoke (*P*=.02), greater importance of quitting (*P*=.002), greater confidence in quitting (*P*=.04), greater perceived message relevance (*P*<.001), and improved perceptions about smoking cessation research (*P*=.002). In the multivariable model (Table 4), univariate predictors and cost versus benefit message factors were included because of the significant main effects discussed previously. The overall model was significant ($F_{8,55}$=6.33; *P*<.001), explaining 47.9% of the variance in the intention to speak to a physician about participating. Within the model, male participants were significantly less likely (β=−.24, *P*=.02), whereas participants who reported greater baseline importance of quitting (β=.24, *P*=.046) and perceived the message as relevant to their situation (β=.37, *P*=.004) were significantly more likely to intend to speak to their physician about participating in the study. With the inclusion of the study covariates, the main effect of the cost versus benefit message factor was no longer statistically significant (β=−.17, *P*=.12).

Table 4. Multivariable predictors of intent to speak to a physician about enrolling in a smoking cessation research study.

Predictor	β	SE	*t* test (*df*=8)	*P* value	95% CI
Age (years)	−.01	0.01	−0.88	.38	−0.03 to 0.01
Gender (male)	−.90	0.32	−2.85	.006	−1.54 to −0.27
Urge to smoke	.30	0.15	1.94	.06	−0.01 to 0.61
Quit importance	.17	0.09	1.82	.07	−0.02 to 0.36
Quit confidence	.09	0.08	1.11	.27	−0.07 to 0.24
Improved perceptions about smoking cessation research	−.09	0.22	−0.40	.69	−0.52, 0.35
Message relevance	.77	0.22	3.58	.001	0.34 to 1.20
Cost versus benefit condition (cost as referent)	−.29	0.32	−0.91	.37	−0.93 to 0.35

Open-Text Analysis

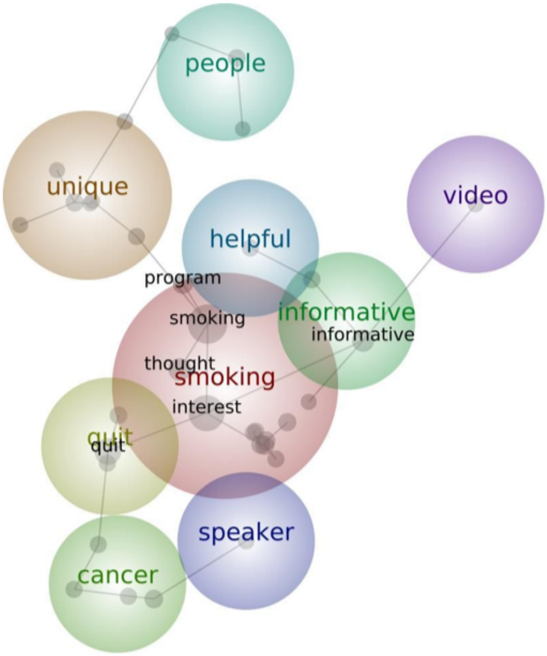
Leximancer

The Leximancer analysis resulted in 8 main themes that emerged from the open-text responses to the participants' video evaluations. The themes, operational definitions, exemplary quotes, and experimental conditions of the participants are detailed in Table 5. The concept map (Figure 2) visually displays the connectedness of the themes and where thematic bubbles overlap, indicating that sentiments expressed in each concept are not mutually exclusive. There were 3 distinct paths on the concept map, all of which branched from the smoking theme. The first pathway, which links *informative* to *helpful* to *video*, is a cognitive evaluation of the videos and an acknowledgment that their primary function was to inform about a trial that connects smokers to cessation resources. The second pathway, comprising *unique* and *people*, highlights the connection between the type of cessation resources and the person offering those resources (an oncologist) as either unique or not unique. The third pathway, from *quit* to *cancer* to *speaker*, highlights the teachable moment context in which the trial is offered. The participants connected quitting with their treatment and cancer outcomes.

Table 5. Selection of an exemplary quote for each theme, along with the frequency of hits for each theme and condition for each quote (N=111 hits).

Theme	Theme definition	Hits of a theme among responses, n (%)	Quote	Participant condition
Smoking behavior and perceptions	Participants' perceptions about their smoking habits	38 (34.2)	"[The speaker] got me to thinking about my smoking habits, even though I only smoke 4 cigarettes per day."	Proximal, cost, loss
Motivation or readiness to quit	Participants' interest, motivation, and readiness to quit smoking	18 (16.2)	"It gave me different options to quit smoking. I really do want to quit, but I don't think I can."	Control
How informative the video was	Participants' explanations of the video being informative	17 (15.3)	"It was very informative and interesting. Being honest about smoking will help in heath related issues"	Distal, benefit, gain
Cancer diagnosis	Participants' framing of the aspects of the video with regard to their cancer diagnosis	9 (8.1)	"The speaker brought up some good points, such as lower energy levels after being diagnosed with cancer. My energy level hasn't regained to where I want it to be since prostate surgery."	Proximal, cost, loss
How relevant the video was	Participants' descriptions of the video as beneficial or not for people like them	8 (7.2)	"I felt that by joining the study I could get the help I need to stop smoking"	Distal, benefit, gain
Evaluation of the tobacco treatment services offered in the study	Participants' overall perception of the uniqueness of the program, both positive and negative	7 (6.3)	"A generous offer to participate but nothing presented was unique in that all outlined methods of smoking cessation therapy are already readily available."	Distal, benefit, loss
Overall opinion of the video	Participants' overall opinion of the video	6 (5.4)	"It was a very informative and interesting video. I enjoyed watching it."	Proximal, benefit, loss
Evaluation of the speaker in the video	Participants' reactions and feedback regarding the video speaker	2 (1.8)	"The speaker was very professional, and not scolding or condescending."	Distal, cost, loss

Figure 2. Leximancer-generated concept map detailing participant responses when asked to evaluate the video.



Theme 1: Smoking Behavior and Perceptions

Smoking behavior was the most common theme, accounting for 34.2% (38/111) of the total hits. The participants reflected on their smoking habits and how they often functioned as a stress management tool. One of the participants indicated the following:

> *I've made three serious attempts and numerous casual attempts at quitting. I will try again this year, but my failure has always been [the] use of smoking as a coping mechanism for stress* [distal, cost, gain]

Another stated the following:

> *I've reduced the number of cigarettes, but have found no other mechanism for coping with stress despite attempts* [proximal, cost, loss]

Others revealed that the video prompted self-reflection on the need to address their smoking habits:

> *She got me to thinking about my smoking habits, even though I only smoke 4 cigarettes per day* [proximal, cost, loss]

Theme 2: Motivation or Readiness to Quit

According to the concept map, the quitting theme understandably overlapped with the smoking theme. However, unique instances of participants' motivation and hope to quit successfully after previous failed attempts were also identified. One of the participants highlighted the following:

> *I've tried many times and different ways to quit in the past with no success. Maybe one of these ways will help* [control]

Another reflected on a broader message of hope, potentially resulting from learning about the success rates of treatment discussed in the video:

> *I thought it gave me hope to quit smoking* [proximal, cost, gain]

However, others mentioned that learning about new treatment options does not necessarily translate to greater self-efficacy to quit by saying the following:

> *It gave me different options to quit smoking. I really do want to quit, but I don't think I can* [control]

Theme 3: How Informative the Video Was

Participant responses categorized under this theme primarily comprised explaining the usefulness of the information in the video. One of the participants commented the following:

> *It was very informative and interesting. Being honest about smoking will help in [health] related issues* [distal, benefit, gain]

Other participants reported similar views and added that the videos were honest as well as helpful:

> *I thought it was very well thought out and honest. Also seemed very helpful for people like me* [proximal, cost, gain]

Theme 4: Cancer Diagnosis

Responses within this theme were related to smoking cessation in the context of personal cancer diagnoses. Comments reflected a diagnosis acting as a teachable moment and motivating quit attempts, albeit not always successfully:

> *It sounds interesting. I have tried numerous times to quit even though I have been diagnosed with cancer* [distal, cost, gain]

Some responses demonstrated that the participant had internalized the risk message frame they received and identified with the negative consequences of continued smoking after a cancer diagnosis:

> *The speaker brought up some good points, such as lower energy levels after being diagnosed with cancer. My energy level hasn't regained to where I want it to be since prostate surgery* [proximal, cost, loss]

Theme 5: How Relevant the Video Was

This theme reflected on the personal support structures the trial would provide:

> *I felt that by joining the study I could get the help I need to stop smoking* [distal, benefit, gain]

Other responses were as follows:

> *informative, relatable, held interest and would be a welcome program (support study) in my area* [proximal, benefit, loss]

Theme 6: Evaluation of the Tobacco Treatment Services Offered in the Study

Perspectives on the trial diverged greatly depending upon the participant's impressions of how unique they felt the resources offered as part of the trial were. For example, one of the participants commented that the study was "extremely unique, valuable, appealing, and potentially lifesaving. Hard to believe program is free, and offers patches to assist in overall probable successful, life changing outcome" (proximal, benefit, loss), whereas another participant commented the following:

> *a generous offer to participate, but nothing presented was unique in that all outlined methods of smoking cessation therapy are already readily available* [distal, benefit, loss]

Theme 7: Overall Opinion of the Video

This theme was composed of a range of perspectives but broadly discussed the method of presenting trial information digitally. The participants commented that "it was a very informative and interesting video. I enjoyed watching it" (proximal, benefit, loss).

Theme 8: Evaluation of the Speaker in the Video

Participants' responses under this theme evaluated the speaker within the video, focusing on the oncologist's tone and demeanor when presenting the importance of quitting after a diagnosis. One of the participants commented the following:

> *the speaker was very professional, and not scolding or condescending* [distal, cost, loss]

Another participant similarly discussed the following:

> *I thought the speaker was very informative* [proximal, cost, loss]

LIWC Analysis

Within the LIWC analyses, there were no significant differences between control and message factors or within message factor levels (eg, distal vs proximal) for the 5 summary variables (word count, analytic thinking, clout, authentic, and emotional tone). Next, comparisons were made across psychological processes (affect, positive emotion, and negative emotion) and drivers and needs (reward and risk). Compared with the control group (mean control 28.32, SD 35.82), participants in both the distal and proximal message frames used linguistic markers that reflected statistically significant lower levels of affect ($F_{2,72}$=3.13; mean distal 17.20, SD 22.04; mean proximal 9.54, SD 10.17; *P*=.05), as did the gain and loss message frames ($F_{2,72}$=3.47; mean gain 17.16, SD 20.51, mean loss 8.55, SD 11.34; *P*=.04). Compared with the control (mean control 15.02, SD 37.52), the distal and proximal ($F_{2,72}$=5.70; mean distal 0.05, SD, 0.30, mean proximal 0.71, SD 2.49; *P*=.005), cost and benefit ($F_{2,72}$=5.68; mean cost 0.20, SD 0.95, mean benefit 0.57, SD 2.41; *P*=.005), and gain and loss ($F_{2,72}$=5.69; mean gain 0.60, SD 2.30, mean loss 0.06, SD 0.32; *P*=.005) message frames reported significantly lower levels of negative emotions.

Within message factor levels, participants who saw the distal message used linguistic markers that reflected significantly greater positive emotions than participants who saw the proximal message ($F_{1,66}$=3.87; mean distal 17.16, SD 22.07 vs mean proximal 8.84, SD 10.40; *P*=.05). However, participants who watched the proximal message used linguistic markers that reflected a significantly greater risk than those who saw the distal message ($F_{1,66}$=4.13; mean distal 0.00, SD 0.00 vs mean proximal 0.98, SD 2.85; *P*=.05). There were no differences in the cost versus benefit message frames. Within the gain versus loss message frame, participants who watched the gain message used linguistic markers that reflected significantly greater affect ($F_{1,66}$=4.16; mean gain 17.16, SD 20.51 vs mean loss 8.55, SD 11.34; *P*=.05).

Discussion

Principal Findings

Access to evidence-based tobacco treatment among smokers with recent diagnoses remains a priority. A method of increasing access is participation in tobacco treatment trials. Although accrual rates remain suboptimal, targeted digital outreach through short recruitment videos may offer promise but has not been assessed specifically among patients newly diagnosed with cancer. Multimethod approaches are required to optimize the content of these videos. Therefore, this pilot factorial randomized controlled trial explored which message frames were most effective for a video to recruit smokers with a recent cancer diagnosis for a tobacco treatment trial.

In phase 1, a message design experiment assessed 3 message frames: message evaluation, effectiveness, and outcome measures. For the primary outcome, the costs of not quitting the frame increased the intent to speak to a physician about participating in a cessation study significantly when compared with the benefits of the quitting frame. This is an important finding that does not align with most of the literature, in which gain-framed messages have been predominantly demonstrated to be more effective at promoting cessation [19,20]. However, when cancer treatment outcomes are central, highlighting the negative side effects of continued smoking, including psychological (ie, an increase in anxiety and stress) and physiological (ie, a decrease in energy) effects, motivation to avoid these side effects may be a stronger mechanism for the uptake of cessation resources. However, it should be noted that in the multivariable model, this effect did not remain significant.

As with our previous work, perceptions of the relevance of the message, irrespective of what message frames were used, were much more strongly predictive of intent to want to participate (authors blinded for review). Information processing theories (eg, the Elaboration Likelihood Model [42]) explicate those greater perceptions of message relevance are associated with deeper systematic processing, which elicits greater perceptions of argument strength and motivation to adhere to a message's call to action (ie, participating in a tobacco treatment trial). Interestingly, message relevance was even more strongly associated with intent to participate than baseline quit importance or confidence. This suggests that identification with the content and context in which a recruitment message is presented may be a more influential mechanism than pre-existing cessation attitudes.

Participants who received the proximal message frame (vs the distal frame) were more likely to report a greater interest in seeking information about participating in a cessation study.

Specifically, the proximal message frame used (1) social norms (eg, "Every day, patients with cancer...") and (2) reduced psychological distance between smoking and inferior treatment outcomes (eg, "may keep growing and you may be less likely to respond to your treatment"). Existing models (eg, the Planned Risk Information Seeking Model [43,44]) indicate that greater perception of individual risk for a disease or adverse outcome is predictive of greater information-seeking intentions. However, motivating intentions through increased risk perception among smokers may be difficult. Previous studies have demonstrated that risk communication interventions for individuals who have received threat-based messages about behavior over extended periods (eg, heavy smokers) may have a limited effect [45,46]. By focusing on cancer treatment efficacy rather than repeating the common negative physiological effects of smoking, the risk message frame seemed more successful in increasing seeking intention.

Participants who received losses from the nonparticipating frame (vs gains from participating) were more likely to report that the recruitment video positively changed their perspective on smoking cessation research. Patients with cancer may be more sensitive to losses as they have likely recently experienced other *losses*, such as control of their health, their day-to-day routine, or even a loss of their old identity, and now see themselves as patients or survivors of cancer. The prospect theory explicates that losses can loom larger than commensurate gains and losing out on an opportunity framed to have short-term self-efficacy (ie, more difficult without the resources provided through the trial) and long-term response efficacy outcomes (ie, 3 times less likely to stop smoking on own) may have been more compelling when describing the advantages of participating in tobacco treatment trials, especially for patients with cancer.

In phase 2, the multimethod evaluation provided a further understanding of how the recruitment videos were appraised. In the Leximancer analysis, participants commonly made statements that were thematically associated with smoking and quitting. Smoking was discussed as a coping mechanism for stress, although stress was not specifically discussed as a result of a diagnosis. Some participants reflected on the need to address their smoking habits, admitting that despite their recent diagnosis, they continued to smoke and that tobacco treatment was necessary. The Leximancer analysis did not compare data by message frame; however, some responses highlighted that the participants reflected on the information provided in at least one of the message frames to which they were randomized. For example, participants were able to identify with the risk messaging, make a connection to their own cancer journey, and mention how they felt because of continuing to smoke after the diagnosis (eg, how severe their side effects were during treatment).

The LIWC analysis compared the linguistic differences in the open-text data between the message factors to the control condition and within the message factor levels. The findings demonstrated that participants in the control condition used language to describe the video with significantly greater levels of negative emotion than those in the intervention conditions. This finding suggests that the information included in any of the message frames, irrespective of the frame, reduced negative emotions. Although the control condition functioned as a kernel message and encompassed all the necessary trial information, the message frames provided intrinsic and extrinsic motivations to want to participate and likely reduced psychological reactance when presented with the trial. Within the message factor levels, a noteworthy finding was that participants who viewed the proximal message frame had linguistic markers that reflected a significantly greater internalized risk than participants who viewed the distal message. This finding is consistent with the psychological distance of risk explicated within the construal-level theory, which suggests that individuals will construe future events more concretely if they are temporally more proximal [17]. As the short-term risk associated with a current diagnosis (eg, worse treatment outcomes) is temporally and psychologically more concrete, participants used language to describe the video that incorporated more linguistic markers of proximal risk. Measuring risk internalization in this way is novel but also underscores the challenge of using threat-based messaging to invoke perceptions of risk. This was exemplified in comparison with the distal message frame, in which participants used linguistic markers with more positive emotions, suggesting that risk internalization can create an emotional response if experienced immediately and, thus, more concretely.

Limitations

This study has a number of strengths, although there are also limitations. First, the recruitment videos promoted a specific cessation trial (ie, Smoke Free Support 2.0), which was not actively available for the enrollment of participants. The findings of this study could have been further tested if participants who had indicated they intended to quit smoking were then directed to n web-based resource that connected them to an active cessation trial in their community (eg, Research Match). Second, the sample was predominantly White and educated and had health insurance. This limits generalizability and does little to address the crucial need to test recruitment videos with underrepresented groups who report greater medical mistrust and lower representation in clinical trials [47]. To address this issue, we are actively conducting multiple studies to develop and disseminate bilingual, culturally tailored recruitment materials to increase the participation of underrepresented groups within a National Cancer Institute–funded tobacco treatment trial. Third, the inclusion criteria (eg, cancer diagnosis) were self-reported rather than verified through an electronic health record, as in the parent trial. Relatedly, we did not collect prognostic measures for the cancer stage. Risk internalization was a key mechanism for understanding the effect of message factors and was a potential confounder. However, we decided against collecting this measure as self-reported prognosis from patients would likely be inaccurate and skewed to a greater perceived likelihood of survival [48,49].

Implications and Future Research

The primary purpose of this study was to pretest recruitment messages before implementation in the SmokeFree Support 2.0 parent trial, an ongoing nationwide clinical trial across 49 subaffiliates in the National Cancer Institute Oncology Research Program. Findings from this pilot factorial randomized controlled trial identified that message frames that focused on consequences and more immediate outcome expectancies (ie, proximal risks, costs of continued smoking, and the losses of not participating) were the most effective. However, as this study was not powered for interaction effects and the main effects of the message factors were not significant in the multivariable model, a clinical research advisory board discussed whether recruitment messages that used all 3 negative frames would be dissuading for patients so soon after diagnosis. Concerns were also discussed regarding whether clinicians would be comfortable recording and using a script that included multiple negative outcome expectancy frames for patients at their site. As a result, an informed decision was made to implement a recruitment video at sites that included the proximal threat frame but focused on the benefits of quitting and the benefits of participation message frames.

Future studies should first replicate these pilot findings within a clinical sample so as to further explore whether recency and type of diagnosis, as well as stage, affect intention to participate in a tobacco treatment trial. The combination of these factors may result in a greater *teachable moment* (eg, invitation to join a trial the day of a diagnosis compared with 6 months after diagnosis), which may have a meaningful effect on risk internalization and can only be feasibly conducted at a clinic. Furthermore, as perceived message relevancy remained the strongest predictor in the multivariable model, future studies should manipulate other message components to increase perceptions of relevancy. These may include the source (eg, clinician vs patient), medium (eg, text vs video), and the degree to which the content is tailored to each potential participant (eg, tailored to the current motivation to quit and perceived barriers to trial participation).

Conclusions

Reducing smoking rates among patients with recently diagnosed cancer remains a public health priority. Clinical trials on tobacco treatment can provide timely, evidence-based interventions to facilitate cessation. This study used a novel multimethod approach that leveraged both experimental and open-text data to guide decision-making on how best to design recruitment messages for an ongoing national tobacco treatment trial. The findings indicated that focusing on the negative and more immediate outcomes of not quitting was the most effective. The development and testing of theory-driven and evidence-based recruitment messages should be a key process in all trials seeking to leverage digital outreach to increase accrual rates.

Conflicts of Interest

EF has received speaker's honorarium from Medscape.

Editorial Notice

This randomized study was only retrospectively registered. The authors explained that the current pilot study was conducted to identify the optimal recruitment message prior to use in the parent trial. Due to time constraints and the need for preliminary data prior to establishing recruitment practices across multiple study sites, the pilot study was registered retrospectively to ensure timely commencement of recruitment for the parent trial. The editor granted an exception from ICMJE rules mandating prospective registration of randomized trials because the risk of bias appears low and the study was considered formative. However, readers are advised to carefully assess the validity of any potential explicit or implicit claims related to primary outcomes or effectiveness, as retrospective registration does not prevent authors from changing their outcome measures retrospectively.

Multimedia Appendix 1
CONSORT-eHEALTH checklist (V 1.6.2).
[PDF File (Adobe PDF File), 101 KB - cancer_v8i3e37526_app1.pdf]

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Abbreviations

LIWC: Linguistic Inquiry Word Count

Edited by A Mavragani; submitted 23.02.22; peer-reviewed by C Bullen; comments to author 18.03.22; revised version received 17.04.22; accepted 18.04.22; published 24.08.22.

Please cite as:
Neil JM, Senecal C, Ballini L, Chang Y, Goshe B, Flores E, Ostroff JS, Park ER
A Multimethod Evaluation of Tobacco Treatment Trial Recruitment Messages for Current Smokers Recently Diagnosed With Cancer: Pilot Factorial Randomized Controlled Trial
JMIR Cancer 2022;8(3):e37526
URL: https://cancer.jmir.org/2022/3/e37526
doi:10.2196/37526
PMID:36001378

Original Paper

Assessing Information Available for Health Professionals and Potential Participants on Lung Cancer Screening Program Websites: Cross-sectional Study

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Abstract

Background: Lung cancer is the leading cause of cancer death worldwide. The US Preventive Services Task Force (USPSTF) updated recommendations for lung cancer screening in 2021, adjusting the age of screening to 50 years (from 55 years) and reducing the number of pack-years used to estimate total firsthand cigarette smoke exposure to 20 (from 30). With many individuals using the internet to find health care information, it is important to understand what information is available for individuals contemplating lung cancer screening.

Objective: This study aimed to assess the eligibility criteria and information available on lung cancer screening program websites for both health professionals and potential screening participants.

Methods: A descriptive cross-sectional analysis of 151 lung cancer screening program websites of academic (n=76) and community medical centers (n=75) in the United States with information for health professionals and potential screening participants was conducted in March 2021. Presentation of eligibility criteria for potential screening participants and presence of information available specific to health professionals about lung cancer screening were the primary outcomes. Secondary outcomes included presentation of information about cost and smoking cessation, inclusion of an online risk assessment tool, mention of any clinical guidelines, and use of multimedia to present information.

Results: Eligibility criteria for lung cancer screening was included in nearly all 151 websites (n=142, 94%), as well as age range (n=139, 92.1%) and smoking history (n=141, 93.4%). Age was only consistent with the latest recommendations in 14.5% (n=22) of websites, and no websites had updated smoking history. Half the websites (n=76, 50.3%) mentioned screening costs as related to the type of insurance held. A total of 23 (15.2%) websites featured an online assessment tool to determine eligibility. The same proportion (n=23, 15.2%) hosted information specifically for health professionals. In total, 44 (29.1%) websites referred to smoking cessation, and 46 (30.5%) websites used multimedia to present information, such as short videos or podcasts.

Conclusions: Most websites of US lung cancer screening programs provide information about eligibility criteria, but this is not consistent and has not been updated across all websites following the latest USPSTF recommendations. Online resources require updating to present standardized information that is accessible for all.

(JMIR Cancer 2022;8(3):e34264) doi:10.2196/34264

KEYWORDS

lung cancer screening; communication; recommendation; lung cancer; cancer; cross-sectional study; cancer screening; screening program; screening

Introduction

The National Lung Screening Trial (NLST) demonstrated that annual low-dose computed tomography (LDCT) screening over 3 years can reduce lung cancer mortality in specific high-risk groups by 20% [1]. These findings were reinforced by results from the NELSON (Nederlands–Leuvens Longkanker Screenings Onderzoek) trial published in 2020, which, after a 10-year follow-up, demonstrated a reduction in lung cancer mortality to a similar magnitude of 24% [2].

Lung cancer screening involves identifying populations at high risk for the disease, with the aim to detect cancer at an early stage where curative treatment is available. The results of the NLST prompted the US Preventive Services Task Force (USPSTF) in December 2013 to recommend the implementation of LDCT screening [3]. The Level B recommendation was updated in March 2021, where age and smoking history were lowered to 50 years and 20 pack-years, respectively [4,5]. There was no change in the recommendation for the numbers of years quit for former smokers, which remained at 15 years.

Despite the implementation of lung cancer screening in the United States, screening uptake, according to the National Health Interview Survey in 2015, was estimated to be less than 4% of the 6.8 million American adults who meet the USPSTF screening criteria [6]. Screening uptake varies across US states, as demonstrated by self-reported data from the Behavioral Risk Factor Surveillance System in 2017, which showed uptake as high as 19.2% in Florida but lower uptake in Nevada (6.9%) and Georgia (11%) [7]. The combined uptake across these states was 16.3%.

A lack of awareness of screening, in both potential screening participants and health professionals, has been shown to be a challenge associated with implementing lung cancer screening [8]. Accessible and comprehensive information to address the information needs of potential screening participants may be important to promote a greater understanding of LDCT screening [9]. Potential screening participants may feel confused or anxious about the screening process, fear a cancer diagnosis or social stigma, and have cost concerns [10]; hence, they may seek answers from their family physician. Many health professionals discuss eligibility for lung cancer screening with potential screening participants according to the guidelines but often cannot achieve this equitably due to short consultation times [11]. Therefore, many potential screening participants turn to the internet for more health information, with the Health Information National Trends Survey showing that the internet is the first place people go to for health and medical information [12].

Use of the internet as a unique tool to facilitate interaction between health care providers and patients appears to be growing, and internet-based resources have been shown to increase participation in lung cancer screening [13]. It is important to understand whether potential screening participants are able to access accurate and reliable information and whether this information is consistent with current guidelines. Many US medical centers have created websites that are both academic and community focused and contain health and wellness program information, such as information about lung cancer screening. These sites may be the first or primary source of information about lung cancer screening for both potential screening participants and health professionals, and may affect their judgment on screening eligibility, how to navigate steps prior to screening, and, ultimately, uptake of screening.

A previous review examined these websites for benefits, harms, and recommended next steps for eligible individuals [14]. Given these websites are from academic and community-based lung cancer screening–designated centers in the United States and may be the first source of eligibility criteria for potential screening participants, our team aimed to assess whether eligibility criteria for potential screening participants were up-to-date on these websites following the latest updates to the USPSTF recommendation. As these websites may also be sources of information for health professionals, we wanted to investigate whether these websites contain any information to directly inform health professionals about lung cancer screening.

Methods

Procedure

The research team contacted the authors of a previously published article (Clark et al [14]) and obtained the list of 162 lung cancer screening program websites of academic centers (n=81) and state-matched community medical centers (n=81). Further detail on how the websites were selected is provided elsewhere [14].

Three team members each familiarized themselves with the content of 10 randomly selected websites. The team developed a data extraction tool to record eligibility criteria and other eligibility criteria (eg, family history, comorbidities) and whether there was information specific to health professionals (eg, link to an external website, a separate tab available on the website). We also recorded whether the websites mentioned any clinical guidelines (eg, USPSTF), included an online risk assessment tool, and gave any specific information about the cost of screening, whether smoking cessation advice was included, and whether there were any multimedia included on the websites.

The 162 websites were equally divided between 3 members of the team for data extraction. Using the data extraction sheet, we recorded whether each website was accessible, presented the above information or not, and details about what was included. Uncertainties about information were discussed, and decisions were resolved by the whole team. Each website took between 8 to 10 minutes to analyze and record the content into the checklist, with the checklist items iteratively updated during the process to reflect smoking cessation, specific cost, and use of multimedia.

Another member of the research team verified and updated the data extracted from all websites in March 2021, resolving any conflicts. A total of 11 websites were inaccessible due to main site errors. Where website pages were found to no longer be accessible, the institution homepage was accessed and the term “lung cancer screening” was entered into the search bar. Updated pages were then used for analysis. Where the original URL redirected to another website, the new page was used for analysis. All new web links were recorded.

Analysis

Descriptive analysis was used to evaluate the frequencies of the information reported across the websites. Statistical analysis was carried out using Microsoft Excel (Microsoft Corp).

Ethics Approval

Ethics approval was not required as the websites are in the public domain, and no human participants were involved.

Results

Details of Websites

Of the 162 websites, 11 were no longer accessible. Of the remaining 151 websites, (academic websites: n=76; community websites: n=75; Multimedia Appendix 1), 13 academic websites and 26 community websites had URL changes, largely because lung cancer screening information had been mapped to a different section of the website or a new website was built or refreshed (see an example in Multimedia Appendix 2). Therefore, of the 151 included websites, 39 website URLs were different from the original URLs reported by Clark and colleagues [14].

Eligibility Criteria

Age

Overall, 62.9% (95/151) of websites mentioned at least one professional guideline for lung cancer screening eligibility (Table 1). The standard age ranges reported across the 151 websites varied greatly. The 3 most reported eligible age groups were 55 to 77 years (n=66, 43.7%), 55 to 80 years (n=40, 26.5%), and 55 to 74 years (n=18, 11.9%); 17.2% (n=26) of websites mentioned more than one age group. Age was consistent with the latest USPSTF recommendations (≥50 years) in 22 (14.5%) websites but was mentioned specifically (ie, age of 50-80 years) in only 7 (4.6%) websites.

Table 1. Information about eligibility criteria on the lung cancer screening websites of academic and community centers in the United States.

Eligibility criteria	Academic center (n=76), n	Community center (n=75), n	Total (N=151), n (%)
Age range (years)			
≥50	9	3	12 (7.9)
>50	0	3	3 (2.0)
≥55	2	5	7 (4.6)
>55	1	0	1 (0.7)
50-74	1	2	3 (2.0)
50-77	0	1	1 (0.7)
50-80	6	1	7 (4.6)
55-70	0	1	1 (0.7)
55-74	11	7	18 (11.9)
55-77	34	32	66 (43.7)
55-78	0	1	1 (0.7)
55-79	2	1	3 (2.0)
55-80	20	20	40 (26.5)
55-88	1	0	1 (0.7)
Not mentioned	4	8	12 (7.9)
Smoking history			
Is a current smoker or has quit smoking within the last 15 years	73	68	141 (93.4)
Has a smoking history of at least 30 pack-years[a]	61	57	118 (78.1)
Not mentioned	3	7	10 (6.6)
Guidelines mentioned			
USPSTF[b]/NCCN[c]/ACR[d]/ACS[e]/others[f]	31	19	50 (33.1)
National Lung Screening Trial (National Cancer Institute)	23	10	33 (21.9)
Medicare/Medicaid/private insurance plans	27	23	50 (33.1)
Not mentioned	23	33	56 (37.1)
Other criteria			
Family history	10	11	21 (13.9)
Occupational or environmental exposure	12	13	25 (16.6)
No signs or symptoms of lung cancer, asymptomatic	17	23	40 (26.5)
Not mentioned	25	37	62 (41.1)

[a] Pack-years: packs per day multiplied by the number of years a person has smoked (meaning 1 pack a day for 30 years, 2 packs a day for 15 years, etc).

[b] USPSTF: US Preventive Services Task Force.

[c] NCCN: National Comprehensive Cancer Network.

[d] ACR: American College of Radiology.

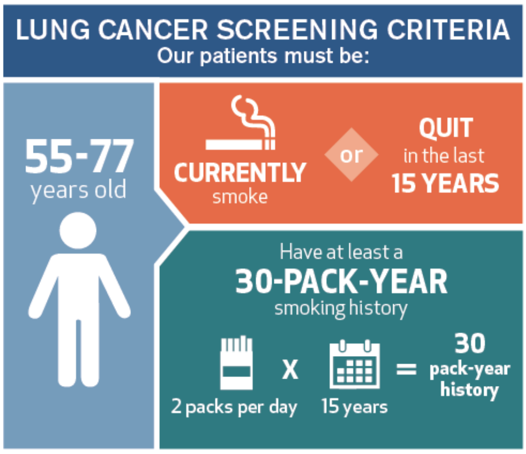
[e] ACS: American Cancer Society.

[f] Others mentioned only once include the American Thoracic Society, the American Society of Clinical Oncology, the American Lung Association, the Centers for Disease Control and Prevention, and the American Society of Clinical Oncology.

Smoking History

Most websites (n=141, 93.4%) listed the eligibility criteria of smoking history, while 78.1% (n=118) detailed information on those who have a 30 pack-year smoking history (see example in Figure 1 [15]). None of the websites had updated pack-year smoking history in line with the latest recommendations. In addition to the eligibility criteria listed in the guidelines, the most frequently mentioned other eligibility criteria were asymptomatic status (n=40, 26.5%), occupational or environmental exposure (n=25, 16.6%), and family history (n=21, 13.9%).

Figure 1. Example eligibility criteria from Houston Methodist [15].



Eligibility Criteria Using an Online Assessment Tool

A total of 23 (15.2%) websites promoted the use of an online assessment tool to determine eligibility for screening; 20 (13.2%) were related to risk and 3 (2%) were related to pack-year calculation only.

Information Targeted at Health Professionals

Among the 151 websites, 15.2% (n=23) listed information specifically for health professionals, with academic websites accounting for 26.3% (20/76) and community websites making up 4% (3/75). The most common resources were links to refer patients to treatment centers and PDF downloads, including order forms, patient booklets, shared decision aid guides, and posters.

Cost of Lung Cancer Screening

A total of 76 (50.3%) websites referred to the cost of lung cancer screening. Of these, 73.7% (n=56) mentioned that cost would be related to the type of insurance coverage held (ie, Medicare, Medicaid, or private insurers); 5.3% (n=4) mentioned self-pay cost only, ranging from US $99 to US $350; 17.1% (n=13) mentioned insurance coverage and self-pay cost, ranging from US $99 to US $361; 1.3% (n=1) mentioned insurance coverage and available scholarships (eg, Lung Cancer Screening Scholarships, funded by the McLeod Foundation's McLeod Men's group and McLeod Angels); and 2.6% (n=2) mentioned free screening where criteria were met (eg, a free annual LDCT lung cancer screening for those considered high risk and meeting Medicare's screening criteria).

Smoking Cessation Programs

A total of 44 (29.1%) websites referred to smoking cessation. Of these, 34.1% (n=15) mentioned that smoking cessation information or counseling was included in the screening program; 52.3% (n=23) provided information to access an in-house smoking cessation program; 20.5% (n=9) provided information for local, city, or state-based smoking cessation programs; 11.4% (n=5) provided information for national smoking cessation programs; and 2.3% (n=1) made a recommendation to enter a smoking cessation program but did not provide any further resources.

Multimedia Targeted at Participants

Multimedia formats were used in 30.5% (n=46) of websites to present information on topics such as promoting the benefits and harms of lung cancer screening and explaining the process of screening. Of these 46 websites, 67.4% (n=31) presented short video clips, 17.4% (n=8) presented patient testimony, 10.9% (n=5) presented podcasts, and 8.7% (n=4) presented infographics.

Promoted Associations and Registrations

A total of 49 (32.5%) websites referred to or displayed the logo of one or more relevant associations or membership registration. Over a quarter of the websites (40/151, 26.5%) listed were an American College of Radiology Lung Cancer Screening Center; 8.6 (n=13) were a Lung Cancer Alliance Screening Center of Excellence; 7.9% (n=12) were a GO2 Foundation for Lung Cancer Center of Excellence; 2% (n=3) were a National Cancer Institute–designated Comprehensive Cancer Center; and 1.3% (n=2) were a Commission on Cancer Accredited Program.

Discussion

Principal Findings

Our findings demonstrate that information was not standardized across websites about lung cancer screening, with the majority being out of date with the latest USPSTF recommendations regarding the revised eligibility criteria of a younger starting age and a reduced smoking history. About two-thirds of websites that referred to professional society guidelines were consistent in their recommendations about eligibility. The potential costs of screening and smoking cessation programs were less often reported on websites. Given the poor uptake of lung cancer screening across the United States, it is important to ensure potential screening participants can access accurate and sufficiently detailed information to determine and understand their eligibility.

General Population

The internet is a central source of health information that can empower patients, promote knowledge, and support decision-making [16]. When developing these community-facing websites, all the required information should aim to be in a format that is accessible to all language and literacy groups [17] and follow plain English guidelines as endorsed by the World Health Organization [18]. This is particularly important given the socioeconomic disparities known to exist among those who will be eligible for lung cancer screening [19]. For knowledge transfer and support in decision-making to occur, the information needs to be accurate and should be updated regularly by the institution, but the responsibility of evaluating health information found online lies with the consumer [20]. For website creators to maintain the accuracy of the information provided, this would require a standardized assessment tool such as the Health Sector Website Assessment Index, which assesses content, services, community interaction, and technological features [21]. Although this index is not suitable for this context, a multi-indicator tool that is easy to assess websites could be developed for regular auditing of websites containing health information to ensure the information stays up-to-date.

Previous research has found that health professionals have low awareness of eligibility criteria for lung cancer screening, showing that less than 50% are able to correctly answer the eligibility criteria for lung cancer screening [22,23]. These findings suggest that the conflicting information provided by these lung cancer screening program websites may confuse both potential screening participants and health professionals. For example, the USPSTF recommendations list the upper age limit for screening as 80 years old [24] whereas the upper age limit covered by the Centers for Medicare and Medicaid Services is 77 years old [25] and that listed on the websites of the NLST [1] and the American Cancer Society [26] is 74 years old. Variations in age given across the websites were explained to be due to differences in insurance coverage, risk factors, and recommended guidelines.

Having an interactive online tool that combines the age and smoking eligibility criteria was utilized in only a few of these websites, but provides a tangible tool for potential participants of lung cancer screening to determine their eligibility quickly. Online decision support tools have been shown to be efficiently implemented in breast cancer risk assessment, as well as in facilitating shared decision-making [27]. Providing these online tools can empower potential participants to determine their eligibility prior to approaching their family physician. Similarly, the use of multimedia tools on websites can aid in the understanding of potential participants, with incorporation of multimedia resources into the informed consent process shown to be preferred by culturally and linguistically diverse patients [28]. Providing interactive videos and tools on these websites may improve the understanding of potential participants and consequently improve participation in lung cancer screening.

In addition, this study found that smoking history and time to quit smoking are also prevalent on most websites as screening eligibility criteria. Despite this, only a third referred to smoking cessation resources. As lung cancer screening may provide an excellent opportunity to approach smoking cessation and act as a “teachable moment” [29,30], providing smoking cessation resources on these websites presents a unique opportunity to reach those at high risk of lung cancer who may be motivated to quit [31].

Health Professionals

Although most websites list recommended next steps for potential screening participants to take, few health professionals are given specific information to help guide these consultations and direct potential screening participants to a local health care team. For health professionals, the challenges generally include lack of awareness of eligibility standards and insurance coverage, difficulty in identifying eligible patients, insufficient time [32] or knowledge to make joint decisions, and the need for management guidance on lung cancer screening results and the balance between benefits and harms [10].

Of all the websites evaluated in this study, only 1 in 6 highlighted the important role that health professionals play in encouraging potential screening participants to consider participation. This study examined the content of lung cancer screening program websites, which may be the main source of information for many health professionals and potential screening participants. These sites provide an opportunity to fully cover eligibility criteria, screening costs, and recommended next steps. Providing this information may complement the shared decision-making process that occurs prior to screening, which aims to ensure patients make an informed choice about whether to undergo screening, and can improve outcomes [33].

Although these lung cancer screening program websites are not responsible for fully providing information recommended by the guidelines for shared decision-making, they can provide helpful advice for eligible individuals and advise them on the next steps when considering screening.

Limitations

This study has some limitations. It is possible that our content review of each website may have missed or misinterpreted some content, but by having a structured data extraction tool, as well as having 3 researchers randomly assigned to review the websites and a fourth who checked for accuracy and updates, we consider this limitation to be minimized. We limited the website review to focus on the key components of eligibility, but we may have missed other details that could influence the patient’s decision-making process such as distance to travel to a screening facility or convenience of when screening was available [8]. In addition, although online health information is now a main resource for patients and health professionals, we had no access to information about how often these websites are visited or what role they play in their decision-making process.

Conclusion

The study found that the information provided to health professionals and potential screening participants on the lung cancer screening program websites is not standardized or up to date with the latest USPSTF recommendations. Few websites mentioned the information needed for health professionals to facilitate shared decision-making. Considering the wide impact and potential low cost of using internet strategies to obtain health information, these findings can be used to inform the development of online resources for potential screening participants and health professionals, with the focus on presenting standardized information that is accessible to all literacy levels. Future qualitative research with potential screening participants and health professionals exploring their use of websites for lung cancer screening information would be beneficial.

Acknowledgments

We would like to thank Stephen D Clark, Daniel S Reuland, Chineme Enyioha, and Daniel E Jonas for welcoming further analysis of the websites and generously sharing the compiled list for further investigation.

Authors' Contributions

RHD and NMR conceived and designed the study, acquired the data set, and contributed to the drafting of the manuscript. CZ, ARS, JC, and RT analyzed and contributed to the manuscript. All authors reviewed the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Websites included in the study.
[DOCX File , 35 KB - cancer_v8i3e34264_app1.docx]

Multimedia Appendix 2
Examples of website changes.
[DOCX File , 13 KB - cancer_v8i3e34264_app2.docx]

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Abbreviations

LDCT: low-dose computed tomography
NELSON: Nederlands–Leuvens Longkanker Screenings Onderzoek
NLST: National Lung Screening Trial
USPSTF: US Preventive Services Task Force

Edited by A Mavragani; submitted 14.10.21; peer-reviewed by B Chaudhry, K Rathi, L Guo; comments to author 02.05.22; revised version received 21.05.22; accepted 07.06.22; published 30.08.22.

Please cite as:
Dodd RH, Zhang C, Sharman AR, Carlton J, Tang R, Rankin NM
Assessing Information Available for Health Professionals and Potential Participants on Lung Cancer Screening Program Websites: Cross-sectional Study
JMIR Cancer 2022;8(3):e34264
URL: https://cancer.jmir.org/2022/3/e34264
doi:10.2196/34264
PMID:36040773

Original Paper

Exploring Urological Malignancies on Pinterest: Content Analysis

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Abstract

Background: Pinterest is a visually oriented social media platform with over 250 million monthly users. Previous studies have found misinformative content on genitourinary malignancies to be broadly disseminated on YouTube; however, no study has assessed the quality of this content on Pinterest.

Objective: Our objective was to evaluate the quality, understandability, and actionability of genitourinary malignancy content on Pinterest.

Methods: We examined 540 Pinterest posts or pins, using the following search terms: “bladder cancer,” “kidney cancer,” “prostate cancer,” and “testicular cancer.” The pins were limited to English language and topic-specific content, resulting in the following exclusions: bladder (n=88), kidney (n=4), prostate (n=79), and testicular cancer (n=10), leaving 359 pins as the final analytic sample. Pinterest pins were classified based on publisher and perceived race or ethnicity. Content was assessed using 2 validated grading systems: DISCERN quality criteria and the Patient Education Materials Assessment Tool. The presence of misinformation was evaluated using a published Likert scale ranging from 1=none to 5=high.

Results: Overall, 359 pins with a total of 8507 repins were evaluated. The primary publisher of genitourinary malignancy pins were health and wellness groups (n=162, 45%). Across all genitourinary malignancy pins with people, only 3% (n=7) were perceived as Black. Additionally, Asian (n=2, 1%) and Latinx (n=1, 0.5%) individuals were underrepresented in all pins. Nearly 75% (n=298) of the pins had moderate- to poor-quality information. Misinformative content was apparent in 4%-26% of all genitourinary cancer pins. Understandability and actionability were poor in 55% (n=198) and 100% (n=359) of the pins, respectively.

Conclusions: On Pinterest, the majority of the urological oncology patient-centric content is of low quality and lacks diversity. This widely used, yet unregulated platform has the ability to influence consumers’ health knowledge and decision-making. Ultimately, this can lead to consumers making suboptimal medical decisions. Moreover, our findings demonstrate underrepresentation across many racial and ethnic groups. Efforts should be made to ensure the dissemination of diverse, high-quality, and accurate health care information to the millions of users on Pinterest and other social media platforms.

(JMIR Cancer 2022;8(3):e36244) doi:10.2196/36244

KEYWORDS

bladder cancer; Pinterest; prostate cancer; kidney cancer; testicular cancer; urological cancer; misinformation; genitourinary; malignancy; oncology; content; information; social media; accuracy; quality

Introduction

Social media has expanded rapidly over the past decade and has become a vital part of our day to day lives [1,2]. Increasingly, it is becoming the initial source for patients in search of supplemental information regarding their disease [3]. Users are drawn to the easy accessibility of health care information. Unknowingly, much of the material they encounter is non–evidence-based, leaving them susceptible to misinformation [4].

Social media platforms like Pinterest, Instagram, Twitter, and TikTok are commonly used among younger populations in search of information [2]. Pinterest is the fourth most popular social media site with over 250 million users per month [1]. It is a visually orientated platform with the ability to quickly disseminate medical information to consumers. Consumers from around the world are using social media platforms to search and exchange health-related information [3]. Previous studies have reported the wide dissemination of misinformative content about urological malignancies on YouTube [4,5]. This is primarily because prior studies on the quality of social media content about urological malignancies have focused on YouTube. Urological malignancies misinformation is a concerning phenomenon that requires further analysis on other commonly used platforms. Little is known about the quality of consumer-centric content about urological malignancies on Pinterest. Our objective was to perform the first comprehensive study assessing the quality of content related to bladder, kidney, prostate, and testicular cancer on Pinterest. We hypothesized that most of the consumer information on urological oncology will be of low quality, with poor understandability and actionability, and lacking racial or ethnic diversity.

Methods

We reviewed 540 Pinterest pins, using the following search terms: “bladder cancer,” “kidney cancer,” “prostate cancer,” and “testicular cancer” via an application programming interface. Pins were excluded if they did not contain relevant content (ie, if they did not mention gallbladder or thyroid cancer) or if they were not in English. This resulted in the following excluded data: bladder (n=88), kidney (n=4), prostate (n=79), and testicular cancer (n=10). Two reviewers independently scored each pin and linked content. Interrater discrepancies were addressed by group discussion.

Pins were assessed using 2 validated questionnaires: the DISCERN quality criteria and Patient Education Materials Assessment Tool (PEMAT) [6,7]. The DISCERN questionnaire assesses consumer health information using 16 items that are scored from 1 to 5 (ie, no to yes) [6]. PEMAT evaluates the understandability and actionability of patient education resources, using a questionnaire containing 17 items (13 on understandability and 4 on actionability) that are scored as “agree,” “disagree,” or “not applicable” [7]. Misinformation was characterized using a previously published Likert scale, ranging from 1=none to 5=high [5]. We also evaluated the presence of commercial bias (ie, link to paid subscription or endorsement of a service or product). Reviewers further examined the dissemination of information by calculating the number of repins and followers associated with the Pinterest posts. The action of repinning copies the image and adds the image to the user’s Pinterest board [1]. Finally, to examine the diversity of racial or ethnic representation, reviewers classified people in pins based on perceived race and ethnicity, as was done in previous studies [8]. Race was categorized as Black, White, Asian, or unknown (ie, unable to discern). Ethnicity was classified as Latinx, non-Latinx, or unknown (ie, unable to discern).

Results

Pin Characteristics

In total, 359 pins met the inclusion criteria (Table 1). The total pins excluded (Figure 1) per topic were the following: bladder (n=88), kidney (n=4), prostate (n=79), and testicular cancer (n=10). On average, bladder, kidney, prostate, and testicular cancer pins had 175,874 followers and 25 repins. The highest repins per topic were for bladder (n=521), kidney (n=1361), prostate (n=40), and testicular cancer (n=15; Figure 2). Testicular cancer had the lowest average number of followers. Bladder cancer and kidney cancer had higher mean repins. The majority of the urological cancer pins were published by health or wellness groups (n=162, 45%), followed by health care–based groups (n=57, 15%), that is, from hospitals or clinics, doctors, academic journals, and medical education.

Table 1. Analysis of urological oncology content on Pinterest (N=359).

Characteristics	Urological oncology content			
	Bladder (n=61)	Kidney (n=100)	Prostate (n=98)	Testicular (n=100)
Average number of followers, n	152,591	109,716	364,917	76,273
Average number of repins, n (range)	38 (1-521)	59 (1-1361)	2 (1-40)	1 (1-15)
Publisher type, n (%)				
Health care–based	9 (15)	14 (14)	18 (18)	16 (16)
Consumer or patient	5 (8)	10 (10)	2 (2)	3 (3)
Foundational or advocacy group	4 (7)	8 (8)	7 (7)	16 (16)
Governmental	2 (3)	0 (0)	1 (1)	3 (3)
News source or media outlet	1 (2)	6 (6)	11 (11)	5 (5)
Commercial media or industry	12 (20)	12 (12)	13 (13)	13 (13)
Health and wellness	28 (46)	50 (50)	41 (42)	43 (43)
Unknown/other	0 (0)	8 (7.6)	6 (6)	1 (1)
Race, n/N (%)[a]				
Black	0/43 (0)	2/63 (3)	2/39 (5)	3/63 (5)
White	41/43 (95)	54/63 (88)	30/39 (77)	53/63 (84)
Asian	0/43 (0)	2/63 (3)	0/39 (0)	0/63 (0)
Unknown	2/43 (5)	3/63 (5)	5/39 (13)	7/63 (11)
Ethnicity, n/N (%)[a]				
Latinx	0/43 (0)	0/63 (0)	0/39 (0)	1/63 (1)
Non-Latinx	41/43 (95)	58/63 (92)	32/39 (82)	53/63 (84)
Unknown	2/43 (5)	3/63 (5)	7/39 (18)	9/63 (14)
Characteristics discussed, n (%)				
Anatomy	15 (25)	37 (37)	33 (34)	43 (43)
Symptoms	16 (26)	29 (29)	14 (14)	30 (30)
Detection	4 (7)	8 (8)	10 (10)	30 (30)
Treatment	4 (7)	8 (8)	8 (8)	10 (10)
Side effects of treatment	0 (0)	0 (0)	2 (2)	4 (4)
Lifestyle or dietary modification	25 (41)	21 (21)	44 (45)	8 (8)
Commercial bias present, n (%)	4 (7)	1 (1)	14 (14)	0 (0)
Misinformation[b], n (%)	16 (26)	9 (9)	15 (15)	4 (4)
Shared decision-making, n (%)	1 (1)	2 (2)	3 (3)	5 (5)
Quality score ≤3, n (%)	50 (82)	87 (87)	94 (96)	67 (67)
PEMAT[c] understandability <75%, n (%)	37 (61)	62 (62)	69 (70)	30 (30)
PEMAT actionability <75%, n (%)	61 (100)	100 (100)	97 (99)	100 (100)

[a] "N" refers to the total number of people depicted in pins and "n" refers to the specific number of people based on perceived race and ethnicity.

[b] Likert score >1 out of 5.

[c] PEMAT: Patient Education Materials Assessment Tool.

Figure 1. PRISMA (Preferred Reporting Items for Systematic reviews and Meta-Analyses) diagram for urological malignancies on Pinterest (reproduced from Moher et al [9]).

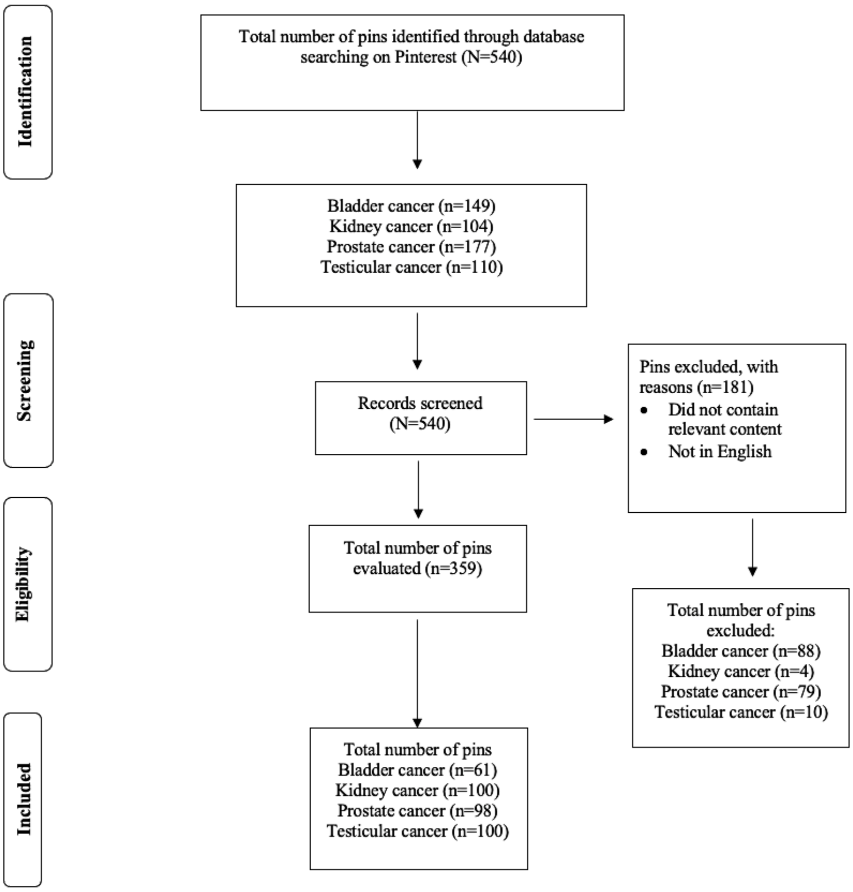
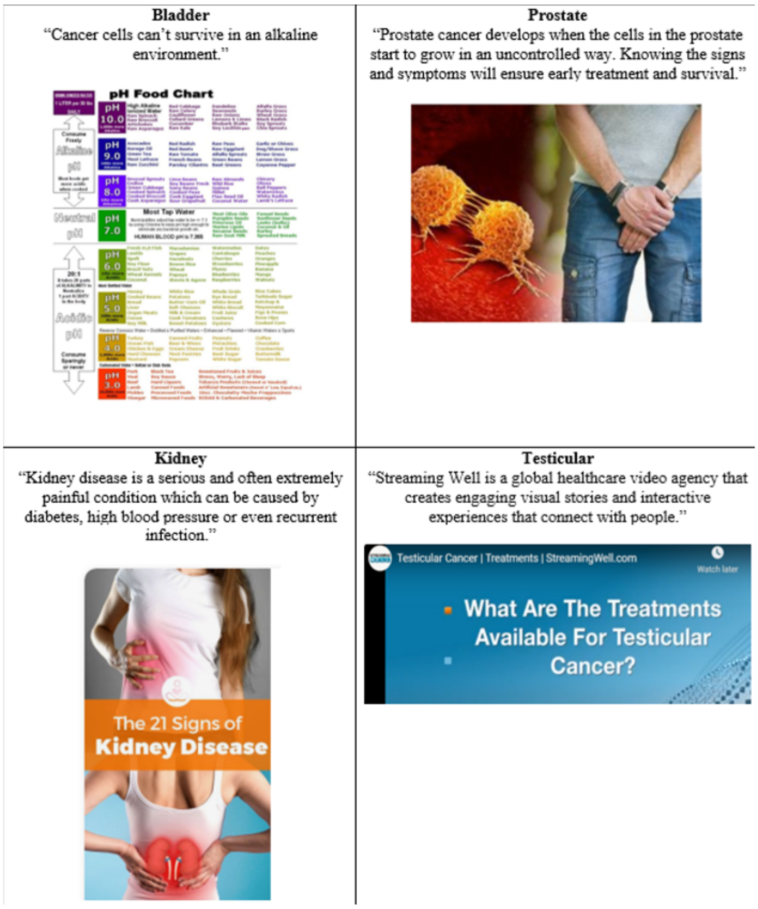


Figure 2. Highest repins for each urological malignancy.



Bladder
"Cancer cells can't survive in an alkaline environment."

Prostate
"Prostate cancer develops when the cells in the prostate start to grow in an uncontrolled way. Knowing the signs and symptoms will ensure early treatment and survival."

Kidney
"Kidney disease is a serious and often extremely painful condition which can be caused by diabetes, high blood pressure or even recurrent infection."

Testicular
"Streaming Well is a global healthcare video agency that creates engaging visual stories and interactive experiences that connect with people."

Quality of Pins

The overall quality of pins was low. Nearly three-fourths of the pins contained moderate- to poor-quality information, or a DISCERN ≤3. Poor-quality pins do not state its purpose, have relevant content, identify sources of information, address quality of life, risks of treatment, or other available treatment options. Nearly all pins failed to mention shared decision-making (n=348, 97%). Misinformation ranged from 4% (n=4) in testicular cancer to 26% (n=16) in bladder cancer pins (eg, cow urine for the treatment of bladder cancer). Over 60% (n=198) of bladder, kidney, and prostate cancer pins had low PEMAT scores for understandability, suggesting many of the pins were not easy to understand. Nearly all pins had low PEMAT scores for actionability, indicating they did not have readily actionable information for users.

Racial and Ethnic Demographics

Among the 206 total people depicted across all pins, the majority were perceived as White (n=178, 86%) and non-Latinx (n=184, 89%). Only 3% (n=7) of people were perceived as Black. Bladder cancer pins did not include a Black individual. Additionally, fewer than 1% (n=2) of individuals represented in pins were perceived as Asian.

Discussion

Principal Findings

This is the first study to comprehensively assess the quality of urological oncology content on Pinterest. We found that testicular cancer had fewer followers than other reported urological malignancies. This is not surprising as testicular diseases are less common, only affecting approximately 1% of men [10]. A concerning finding was the spread of misinformation on this platform, with one-fourth of bladder cancer pins containing misinformation, primarily shared through nonhospital and non–peer-reviewed websites. Urological oncology content on Pinterest also lacks actionable information, leaving users perplexed on what their next steps should be. Moreover, there is a paucity of racial and ethnic diversity within the urological oncology content present on Pinterest.

Comparison With Prior Work

As the intersection between social media and medicine expands, the dissemination of misinformative and inaccurate content on social media platforms is becoming a major societal concern. We found that 26% (n=16) of bladder cancer pins contained misinformation. This aligns with the findings of previous studies that showed 29% of the top YouTube bladder cancer videos had misinformative content [11]. Similarly, a prior study evaluating the quality of breast cancer information on Pinterest found that over half of the pins contained misinformation. Although we do not know the full impact of this content on users' decision-making capabilities, we are aware that they are frequently shared. Alsyouf et al [12] found that inaccurate or misleading articles on urological cancers were 28 times more likely to be shared on Facebook, Pinterest, Twitter, and Reddit in comparison to fact-based articles. This highlights how patients are susceptible to misinformation and the potential influence it can have on their medical decision-making [12]. Pinterest is primarily used as a search engine, and we hope that medical providers will link useful content to Pinterest to increase the quality of information available to users on urological malignancies [13]. Pinterest, like other social media platforms, is a powerful medium with the ability to enhance the knowledge of lay users; however, it has the propensity to disseminate misinformative content.

Approximately all urological oncology content on Pinterest lacks actionable information. Previous studies evaluating the actionability of prostate cancer information on YouTube found that over two-thirds of videos contained actionable content. We reported 99% (n=358) of the pins lacked actionable content or the ability to determine the next steps of action. This is likely due to the brevity of the pins content, which mostly focused on the symptoms associated with various urological conditions. Despite these findings, prior literature has found that well-informed patients have better health-related outcomes and are better able to identify and seek help for their symptoms [14]. Comprehensive patient educational materials that describe actionable steps may help patients determine urgency in seeking medical care [14]. Ultimately, generating patient-centric information that enhances the ability to comprehend their disease will improve shared decision-making among patients and providers [15].

This study corroborates the paucity of racial or ethnic representation of urological malignances on social media [8]. Borno et al [8] found that only 4% of people depicted in YouTube videos on prostate cancer were perceived as Black. African Americans are disproportionately affected by certain urological cancers (ie, prostate cancer) and should have a better representation in patient-centric educational content. Nearly half of Black individuals screened reported receiving health care information from web-based sources [16]. We must ensure that accurate and reliable information is disseminated to make more informed decisions. Across social media platforms, there is a critical need for diverse, actionable, and high-quality patient education materials to help improve health outcomes.

Limitations

Our study is limited to Pinterest, which is just one of many web-based networks. However, since Pinterest is the fourth most commonly used social media platform and no study to date has assessed its urological oncology content, our results fill an important gap. Also, the application of the validated questionaries to the Pinterest interface is a limitation. More work is needed to further develop methods in quality assessment across different social media platforms [17]. We are limited to the subjective nature of pin scoring among reviewers. Efforts were made to mitigate this through the use of validated instruments to assess consumer health information and perform coding comparisons to verify interrater reliability; however, some metrics such as perceived racial and ethnic representation remain subjective. Our search terms only included English-language pins about the 4 most common urological cancers. Pins in other languages and those about less common urological malignancies (eg, penile cancer) or benign conditions were not included; these are important areas for further study. Moreover, further research is warranted to understand why some pins received more engagement than others. Currently, we are unable to assess potential associations, that is, the specific country of origin that the pins are from and the type of urological cancers reported. Our results, nevertheless, provide an important and comprehensive snapshot into the type and quality of information on this widely used network.

Conclusions

In summary, there is a vast array of urological oncology information available on Pinterest, but most of it is of moderate to very poor quality. The importance of addressing and improving eHealth literacy is taking the forefront as the number of individuals using web-based networks increases. The creation of patient-centric information within organizations, which addresses the perspectives and needs of the patients and caregivers, is fundamental [15]. Medical providers can look for credible users on Pinterest to provide higher-quality content. Our study emphasizes the need for collaborative, expert-curated content addressing urological cancers on social media websites like Pinterest.

Conflicts of Interest

ASH, AM, and NH declare they have no conflicts of interest. RDM is an advisor for Urovant. SL declares equity in Gilead and is supported by Sanofi.

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Abbreviations

PEMAT: Patient Education Materials Assessment Tool

Edited by A Mavragani; submitted 07.01.22; peer-reviewed by M Roberts, E Chavarria; comments to author 04.05.22; revised version received 24.05.22; accepted 09.06.22; published 22.08.22.

Please cite as:
Herbert AS, Hassan N, Malik RD, Loeb S, Myrie A
Exploring Urological Malignancies on Pinterest: Content Analysis
JMIR Cancer 2022;8(3):e36244
URL: https://cancer.jmir.org/2022/3/e36244
doi:10.2196/36244
PMID:35994318

Original Paper

Public Deliberation Process on Patient Perspectives on Health Information Sharing: Evaluative Descriptive Study

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Abstract

Background: Precision oncology is one of the fastest-developing domains of personalized medicine and is one of many data-intensive fields. Policy for health information sharing that is informed by patient perspectives can help organizations align practice with patient preferences and expectations, but many patients are largely unaware of the complexities of how and why clinical health information is shared.

Objective: This paper evaluates the process of public deliberation as an approach to understanding the values and preferences of current and former patients with cancer regarding the use and sharing of health information collected in the context of precision oncology.

Methods: We conducted public deliberations with patients who had a current or former cancer diagnosis. A total of 61 participants attended 1 of 2 deliberative sessions (session 1, n=28; session 2, n=33). Study team experts led two educational plenary sessions, and trained study team members then facilitated discussions with small groups of participants. Participants completed pre- and postdeliberation surveys measuring knowledge, attitudes, and beliefs about precision oncology and data sharing. Following informational sessions, participants discussed, ranked, and deliberated two policy-related scenarios in small groups and in a plenary session. In the analysis, we evaluate our process of developing the deliberative sessions, the knowledge gained by participants during the process, and the extent to which participants reasoned with complex information to identify policy preferences.

Results: The deliberation process was rated highly by participants. Participants felt they were listened to by their group facilitator, that their opinions were respected by their group, and that the process that led to the group's decision was fair. Participants demonstrated improved knowledge of health data sharing policies between pre- and postdeliberation surveys, especially regarding the roles of physicians and health departments in health information sharing. Qualitative analysis of reasoning revealed that participants recognized complexity, made compromises, and engaged with trade-offs, considering both individual and societal perspectives related to health data sharing.

Conclusions: The deliberative approach can be valuable for soliciting the input of informed patients on complex issues such as health information sharing policy. Participants in our two public deliberations demonstrated that giving patients information about a complex topic like health data sharing and the opportunity to reason with others and discuss the information can help garner important insights into policy preferences and concerns. Data on public preferences, along with the rationale for information sharing, can help inform policy-making processes. Increasing transparency and patient engagement is critical to ensuring that data-driven health care respects patient autonomy and honors patient values and expectations.

(JMIR Cancer 2022;8(3):e37793) doi:10.2196/37793

KEYWORDS

public deliberation; data sharing; health information exchange; patient engagement; health information; sharing; cancer; oncology; precision oncology; information; policy; personalized medicine; public preference

Introduction

Current State of Precision Oncology

Precision oncology is one of the fastest-developing domains of personalized medicine [1-5]. Genomic testing and molecular profiling of tumors that indicate highly targeted therapies are increasingly available in routine medical practice. Delivery of this type of care is a highly data-intensive enterprise, requiring the processing of electronic health records (EHRs), genomic sequence data, and patient-reported outcomes, among other types of data, from entire patient populations without patients' knowledge. Current policies, such as the 21st Century Cures Act, incentivize interoperability of data and stand to accelerate personalized medicine and other data-driven enterprises, such as learning health systems and artificial intelligence (AI)-enabled clinical decision support. Greater interoperability is a policy goal in order to enable data exchange for use by health systems, commercial companies, laboratories capable of performing genome sequencing, and registries that facilitate disease surveillance and monitoring. However, the policies governing the data ecosystem for precision health and related enterprises are typically opaque to patients, particularly when data are collected in the context of clinical care [6-9]. This paper evaluates the process of public deliberation as an approach to understanding the values and preferences of current and former cancer patients for different notification strategies that may be used to increase transparency about how health information is used and shared.

A number of strategies have been proposed for notifying people about how their data are used in the context of research data and biospecimens (eg, biobanks), which could be extended to the context of sharing clinical data. For instance, there has long been an emphasis on educating the public about health information sharing in "plain language," that is, using vernacular that is accessible to readers. This type of notification about the uses of health information could be delivered as signs posted in hospitals, clinics, or doctor's offices [10]. In the context of biobanking and longitudinal cohort studies, previous research has indicated public preferences for more notification each time health information is used or shared [11]. Technology such as patient portals or messaging via email or text could be leveraged to notify patients when, by whom, and for what purpose their clinical data are shared [12]. Previous work has also suggested that notification will be insufficient and argues that the ability to exercise autonomy and the ability to opt out of certain data uses is ethically required [13]. Given the commercial aspects of data use, still others have suggested payment for the use of personal data, which could extend to health data [14]. These different options to notify and maintain transparency with patients about clinical data sharing highlight different potential roles and responsibilities for the public in the health information ecosystem. What is more, patient preferences about these different approaches to notification remain unclear.

Deliberation to Understand Public Preferences

Here, we describe our use of a public deliberation approach to understand data sharing preferences of current and former cancer patients, particularly related to the use and sharing of clinical data. Public deliberation is a process that facilitates public input on social issues to develop policies and identify issues for future research that reflect public preferences [15]. The deliberative approach affords several benefits compared to interviews, focus groups, and surveys. For example, deliberations often bring together people with diverse values, opinions, interests, and life experiences, as well as diverse socioeconomic (eg, income and education) and racial backgrounds, offering an ideal opportunity for identifying commonalities in policy preferences across diverse deliberators [16]. They also reveal key complexities in decision-making processes and outcomes, enabling the generation of new policy recommendations with a better understanding of public preferences and the values underlying those preferences [17-19]. Public deliberation provides an opportunity to share information with participants (ie, deliberators) and to solicit perspectives at multiple levels (ie, from individuals, small groups, and the collective of deliberators). Since deliberators provide insights about real-life scenarios and voice their preferences, the deliberation process can also be empowering, giving deliberators the opportunity to actively develop and shape policies rather than simply being impacted by them [20].

Methods of a Deliberative Approach

We used a framework for describing public deliberation methods articulated by De Vries and colleagues [17,21] to guide our analysis. The framework proposes that 3 dimensions—*process*, *information*, and *reasoning*—reflect key characteristics of the deliberative approach and capture the primary methods that comprise deliberations. The *process* dimension is concerned with the design and implementation of the project itself. The *information* dimension considers whether and to what extent participants apply information presented to them in their discussions and seek new information. The *reasoning* dimension considers how participants balance and navigate different perspectives and how they ultimately reach mutual understanding within their group about a policy. In the current study, we sought to understand the perspectives of current or former cancer patients on the use and sharing of health information and on potential organizational policy that might increase transparency. Here, we describe the methodology of a public deliberation along the dimensions of *process*, *information*, and *reasoning* to inform investigation of other issues in the development and implementation of health information policy that would benefit from public input.

Methods

We conducted two public deliberations in the fall of 2019 with current or former cancer patients in Southeastern Michigan to hear their perspectives on how health information should be used, shared, and regulated.

Ethical Considerations

This study was approved by the University of Michigan Institutional Review Board and was deemed exempt from federal regulations (HUM 00158768). Participants provided written consent prior to participation.

Participant Recruitment

We recruited former and current cancer patients through a research platform managed by a large Midwestern academic health center [22]. The platform, resourced by the university's Clinical and Translational Science Institute, has a pool of nearly 48,000 individuals who represent a partnership between researchers and volunteers to encourage participant recruitment in research. Eligibility criteria for this study included comfort with speaking English, age 21 years or older, and a former or current diagnosis of cancer of any type. The study team also recruited purposively to ensure diversity in race, age, education, and gender. A total of 79 participants were enrolled, of whom 61 attended either session 1 (n=28) or session 2 (n=33). Table 1 summarizes the demographic characteristics of the participants. To recognize the participants' full-day contribution, they received US $100 and meals (breakfast and lunch).

Table 1. Demographic characteristics of participants (N=61).

Characteristics	Values
Gender, n (%)	
Female	36 (59%)
Male	25 (41%)
Age (years), mean (SD)	62.1 (10.2)
Race/ethnicity[a], n (%)	
African American or Black	11 (18%)
American Indian or Alaska Native	2 (3%)
Asian American or Asian	2 (3%)
Hispanic or Latino	3 (5%)
Middle Eastern or Arab American	0 (0%)
Pacific Islander or Hawaiian Native	0 (0%)
White	44 (72%)
Other	1 (2%)
Highest level of school completed, n (%)	
Less than Bachelor of Arts	16 (26%)
Bachelor of Arts	20 (33%)
More than Bachelor of Arts	25 (41%)
Working in health care field, n (%)	16 (26%)
Household income, n (%)	
Less than $50,000	23 (38%)
$50,000 to $75,000	9 (15%)
$75,000 to $100,000	9 (15%)
$100,000 to $150,000	9 (15%)
More than $150,000	5 (8%)
Prefer not to answer	6 (10%)
Employment status, n (%)	
Working	21 (34%)
Not working (retired)	24 (39%)
Not working (disabled)	11 (18%)
Not working (other)	4 (7%)
Prefer not to answer	1 (2%)
Health status[b], n (%)	
Excellent	7 (12%)
Very good	21 (35%)
Good	21 (35%)
Fair	10 (17%)
Poor	1 (2%)

[a] Participants were allowed to select more than one response.

[b] The total is less than 61 due to missing information from 1 participant.

Deliberation Process

For small group discussions, participants were randomly assigned to 1 of 5 groups with 6 to 8 participants in a large meeting space. Each small group had a facilitator trained in deliberative engagement principles. Eligible participants received an educational booklet that included a description of the study and overview of key terms by mail prior to the session. The educational booklet is included in Multimedia Appendix 1. Figure 1 summarizes the primary components of the deliberation sessions; the processes were identical for both sessions.

Figure 1. Components of deliberation sessions.

At the beginning of the session, participants completed a 20-minute survey about their views on health data sharing. Study team experts led one plenary session in the morning with the full group to provide information about how and why health data are collected, stored, and shared, along with major ethical considerations associated with health data sharing. Fifteen minutes were dedicated at the end of the initial informational session for participants to ask questions. This was followed by small group discussions about a scenario reflecting the life cycle of health data and policy preferences described in the plenary session (scenario A). After lunch, the same process was used with a second plenary presentation about the role of commercial companies in precision oncology and commercialization of health information. This was followed by questions and answers and small group discussions on a scenario and set of options for governing data sharing with commercial companies (scenario B). Both scenarios are described below. The second small group was followed by a final large group session, in which the small group facilitators reported their groups' preferences to the large group as a whole. At the end of the session, participants completed another 20-minute survey on health data sharing. The session agenda is available in Multimedia Appendix 2. A description of the two scenarios follows.

Scenario A: General Policy Preferences Related to Health Data Sharing

Participants read a 1-page scenario describing a patient with early-stage breast cancer whose information is added to a hospital cancer registry. Through the state health information exchange, the patient's information is shared between her health care providers and between hospital, state, and national registries that collect information about cancer over time, and also prompts her provider when it is time for a checkup. Participants were given a summary of the current policy related to this kind of health information sharing and then asked to consider the 4 scenario A policy options in Textbox 1.

In small groups, participants independently ranked their individual preference for each policy option from most preferred to least preferred. Individual responses were then aggregated to form a group-level ranking. Participants shared their concerns and considerations by framing their preferences in a facilitated discussion to arrive at a group-level recommended prioritization of options. At the end of the discussion, the facilitator asked participants to consider the policies once again to assess whether their individual preferences changed during the discussion. The final rankings for each small group were then aggregated with all the other groups in the session to arrive at a final session-level set of policy preferences.

Textbox 1. Policy options for deliberative dialogue sessions.

Scenario A. Preferences for notification about data sharing

1. "Plain language"—signs posted in clinics and hospitals
2. Text or email notification
3. Data sharing policy and instances displayed in patient portals
4. No change from current policy

Scenario B. Preferences for notification and policies for use of information by commercial companies

1. Data sharing policy and instances displayed in patient portals
2. Text or email notification
3. Opt-out of sharing data with commercial companies
4. Compensation—receive payment when data are accessed or used
5. No change from current policy

Scenario B: Policy Preferences on Health Data Sharing With Commercial Companies

We used the same process for scenario B in the afternoon session. This scenario described the same patient with early-stage breast cancer whose doctor suggests she undergo genetic testing to identify a tailored treatment. The doctor sends samples of her tumorous and healthy cells to a commercial company for genetic testing without her knowledge. Although the company sends results back to her doctor, the company retains her samples due to an agreement with the hospital to continue testing and aggregating samples from thousands of patients to ultimately advance research and treatments. The company can also sell samples to other companies, generating revenue from sales of samples and patient data. Participants were then given a summary of the current policy related to health information sharing and asked to consider 5 policy options, which they ranked in order of preference. The 5 scenario B policy options are summarized in Textbox 1.

Analysis

Audio recordings of the small group discussions were transcribed verbatim and deidentified. The framework for public deliberation described by De Vries and colleagues [21], which guided our descriptive study, includes 3 dimensions—*process*, *information*, and *reasoning*—which reflect key components of the deliberative approach that capture its key characteristics.

We describe the process of deliberations by considering the design and implementation of the project, including facilitation style, participant engagement, and respectful group dynamics. In our results, we also describe the preparation process for deliberations and descriptively analyze responses to survey items that assessed the quality of some aspects of the deliberation process methods. The following survey questions were answered on a Likert scale ranging from 1 (“not at all”) to 10 (“very much”): “Do you feel you were listened to by your facilitator?” “Do you feel your opinions were respected by your group?” and “Do you feel the process that led to your group’s responses was fair?”

The *information* dimension of the framework captures the extent to which participants apply information presented in educational sessions in their discussions and seek new information to make sense of complex issues. This dimension reflects whether participants use on-site experts, integrate new information, and apply this new information to form policy opinions. We analyzed the *information* dimension of our approach through qualitative and quantitative analyses: we (1) developed a qualitative code reflecting instances when participants recalled or reflected on something they learned in the educational session in their discussion; (2) assessed when a group would seek additional information from on-site experts; and (3) quantitatively analyzed whether participants learned new information by using the McNemar test to compare each participant’s pre-and postdeliberation responses to a series of true or false prompts about health information sharing. These prompts were a part of a postdeliberation survey (Multimedia Appendix 3) that included the following statements: (1) “Current health privacy laws prevent private companies from buying or accessing your health information” (false); (2) “State and local health departments collect information from physicians and clinics to monitor health” (true); (3) “Only health care providers can access medical records” (false); and (4) “Your physician determines all uses of information in your medical record” (false).

The *reasoning* dimension of the framework reflects whether and how participants navigate different points of view and reach consensus or mutual understanding about their position on a policy. This dimension assesses participants’ ability to justify their opinion with reasoning, their openness to complexity, and their adoption of a societal perspective (ie, thinking beyond their individual self-interest). We qualitatively coded transcriptions for expressions of the pros and cons of the various policy options, including the rationales deliberators provided for their positions, instances in the discussions where they presented multiple perspectives on an issue, and discussions related to the benefits and risks of different policy options to society.

Results

Deliberator Characteristics

The mean age of the participants (N=61) was 62.1 (SD 10.2) years, 72% (44/61) were non-Hispanic white, and 59% (36/61) identified as female. Nearly three-quarters (45/61, 74%) of participants had at least a bachelor’s degree and 26% (16/61) worked in health care.

Process

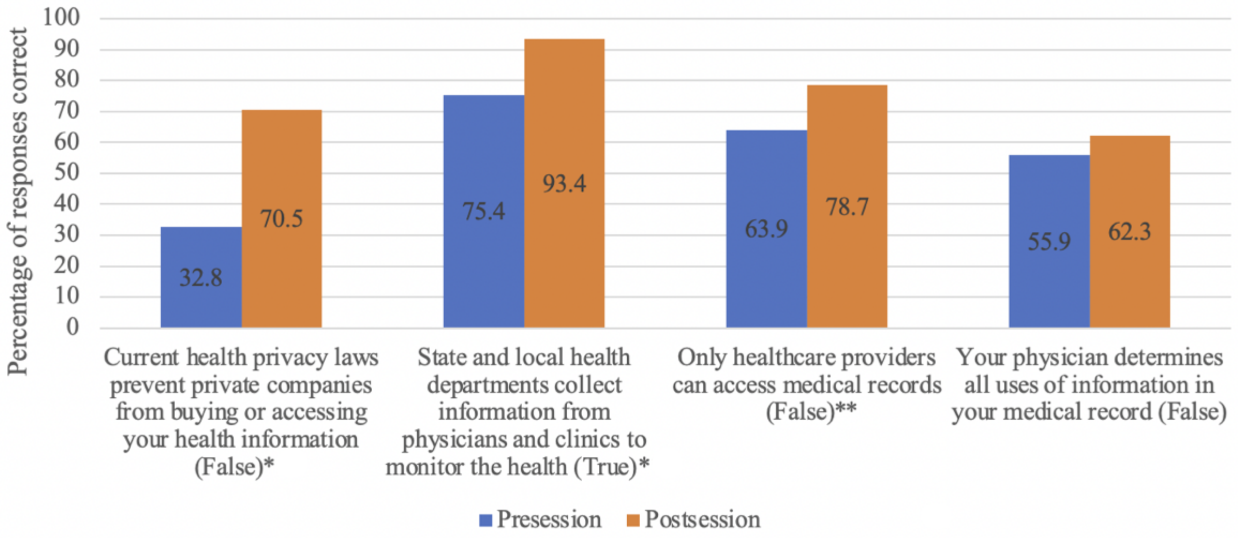
Examining the *process* dimension entailed focus on 3 areas: facilitation, participant engagement, and respectful group dynamics. Facilitators were given training materials summarizing the purpose and goals of the deliberative approach, prompts for small group discussions, and best practices for facilitation (eg, “fading into the background,” encouraging discussion between participants rather than through the facilitator, ensuring all participants had an opportunity to contribute, and utilizing conflict resolution strategies). Facilitators also underwent a 2-hour training session prior to the deliberations to orient them on all the materials. They also observed how a previously trained facilitator led a “mock” discussion and asked questions about the process (eg, policy ranking) and best practices (eg, active listening and ensuring inclusivity in small group discussions).

We captured participants’ perceptions of facilitation and respectful group dynamics through a survey with a Likert scale ranging from 1 (not at all) to 10 (very much). Participants on average felt they were listened to by their facilitator (mean score 9.9, SD 0.3), their opinions were respected by their group (mean score 9.7, SD 0.8), and that the process that led to their group’s responses was fair (mean score 9.8, SD 0.6).

Information

In our approach, we initially prepared the *information* dimension as educational materials and presentations, designated time for questions and answers, and then encouraged participants to use on-site experts as needed during small group discussions. We used postdeliberation survey responses to assess whether participants learned new information and formed opinions based on new information (Figure 2). The following informational components were reported to be very or extremely helpful (at least 8 on a 10-point scale) by at least 90% of respondents: (1) questions and answers with experts (56/61, 92%); (2) formal presentations given by the experts (57/61, 94%); and (3) discussing the issues with other participants (57/61, 94%). In addition, most participants reported that attending the session changed both their understanding of health information sharing (46/61, 77%) and their opinions about health information sharing (36/60, 60%). Finally, analysis of responses from the 4 knowledge questions indicated that participants gained knowledge throughout the course of the session, with the McNemar test indicating significant differences in prompts about current health privacy laws preventing private companies from buying or accessing health information ($P<.001$) and prompts about state and local health departments collecting information from physicians and clinics to monitor health ($P=.003$).

Figure 2. Changes in deliberators' knowledge pre- and postsession (N=61). **P*<.01, ***P*<.1.



Qualitative analysis also revealed that participants were integrating new information from the educational sessions into their small group discussions. For example, one participant drew on the educational presentations to talk about the role of trust and what it meant in relation to data sharing:

> *One of the things that was mentioned a couple times in the presentation is the word "trust." Two different medical entities having different types of information. You almost have to either trust them or not trust their honesty and integrity as to how they're going to use that.* [Deliberation #2, group 1]

Reasoning

Qualitative analysis of deliberations indicated that participants demonstrated reasoning when engaging in discussions about policy preferences during the process of reaching consensus. They engaged with trade-offs about both individual and societal perspectives, recognized complexity, and made compromises related to health data sharing. For example, participants supported the patient portal policy because they would have the flexibility of accessing the information at their convenience without the overwhelming nature of receiving notifications via text message. One participant explained their individual-level perspective:

> *I picked [access through patient portal] for my first choice because by the time I had my cancer treatments, I was quite ill, and I was not able to really speak for myself or understand things that were being thrown at me to sign. So I like the idea where you can wait until you're able to think more clearly.* [Deliberation #2, group 3]

At the same time, participants also looked beyond themselves, and recognized societal barriers to patient portal access:

> *So I don't think that the portal...or the smartphone...is really adequate to address the needs of certain communities.... There may be barriers in terms of getting to the locations that have the computers...just being able to get there transportation wise, but perhaps also work-life schedules not lining up with those public institutions and things. So those would be barriers.* [Deliberation #1, group 2]

They had similar individual concerns about notifications:

> *"My husband wouldn't know what to do if he got a text on his phone. You know, he's got a smartphone, but he [only] makes calls on it."* [Deliberation #2, group 2]

However, they also demonstrated consideration of a societal perspective:

> *The problem I have is that not everybody has a cell phone. Not everybody has access to electronics, and probably the people who are most underserved are those people. Probably the socioeconomic group odds are they don't have money to buy these fun things, or they don't have the education to be able to use them. So they're left in the dark, and they're probably the*

> *ones that are most easily taken advantage of.* [Deliberation #1, group 1]

Respondents recognized the complexity of different policy options and expressed concerns regarding the sufficiency of information through plain language communication, such as feeling overwhelmed by dense documentation with difficult jargon. When asked to explain the pros and cons of individual policy options to reach consensus, participants agreed nearly unanimously that the current policy was not working well:

> *Well, I did not know how freely they could share the information, that they are actually sharing them with payers. So, something needs to be done with that because we have a right to know where our information is going.... I sure wouldn't want it to start impacting hiring practices, even issues...reproductive rights, your insurance, your housing, all that.... I never thought about that when I signed up for All of Us, but now that it's out there...that concerns me because it can be used against us...and discrimination can occur.* [Deliberation #1, group 1]

Participants also suggested modifications to policies, such as being notified and then having the opportunity to access the portal for further information. These suggestions reflected that participants were making compromises to enable health data sharing while maintaining their comfort boundaries:

> *I chose to receive a text or email when my information is shared, but I would like that tweaked a little bit. I would like...just like they ask, "Is it okay to send the email, is it okay to access your Google account, is it okay to change this or change that," and you say, "Okay." I would like them to say, "is this okay?" And then you can answer it. You have a choice in whether they share it with whoever they're sharing it with.* [Deliberation #2, group 1]

Discussion

Principal Findings

Precision oncology is a data-intensive medical field involving multiple stakeholders. This study used a public deliberation approach to seek patient input on whether and how they would like greater transparency about the data sharing that is necessary to deliver precision care. Given the complexity of the field, a deliberative methodology best fit our goal of understanding preferences and the rationale behind those preferences. In our deliberations, the *process* dimension of conducting a deliberation involved training facilitators and establishing rapport among small groups of deliberators. We provided the *information* dimension to deliberators through educational sessions, and nearly all participants reported they found the information helpful and that it enhanced their understanding of health data sharing. Deliberators also integrated information into their small group discussions, using it to form opinions and navigate complexities of policies and the risks and benefits associated with each. Through this *reasoning* dimension, they ultimately reached mutual understanding about different policy options.

The deliberative process fostered an environment in which participants could collaboratively suggest modifications to policies and reach mutual understanding about the policies, as well as a broad range of considerations that guided their opinions. We found participants reasoned with complexities related to the practical, ethical, and social implications of health data sharing. For instance, participants noted the barriers to using the patient portal to share information, particularly in an environment with a persistent digital divide [23]. However, they also considered that current procedures for informing patients about potential uses of their data involve complicated and lengthy documents filled with jargon that can be incomprehensible during a typical visit and may be inappropriate in some circumstances, such as when a patient is receiving a cancer diagnosis. Participants also raised concerns about the uses of health data, expressing concerns about potential discriminatory practices, such as denial of life insurance.

Comparison With Prior Work

Our study suggests the deliberative approach can be valuable for engaging patients and can inform policy making in a way that reflects patient perspectives on complex topics [20,24]. Unlike surveys, interviews, or focus groups, which often limit opportunities for sharing information with participants, our deliberations increased awareness about health data sharing among participants and, with extended periods of facilitated discussion, also provided insight into how participants reason and negotiate their individual needs and preferences with the benefits and risks to society [24,25]. As patients with experience of different types of cancer, participants in this study recognized that the policies discussed had the potential to impact future patients with cancer.

Precision oncology and related data-intensive technologies and methods such as AI are rapidly evolving and increasingly incorporated within the medical system. Decisions about ethical uses of the data needed for these technologies should be informed by public input and should reflect public health values, including consideration of the benefits and risks to society, as well as health equity [26,27]. This will become increasingly important as large data sets reflect the populations and communities proximate to the hospitals and health care systems utilizing their data in precision health, AI and machine learning, and learning health systems.

Public deliberation—engaging patients in discussions to understand their concerns and policy preferences—is a promising approach for soliciting this input. There are a variety of models for conducting public deliberations, with variation in how participants are recruited, how the policy issue is presented and framed, and what lens frames the deliberation (ie, whether it is led by policymakers or researchers) [28,29]. Public deliberation models also vary in the number of deliberators and the length of the deliberation. For example, one recent deliberation was conducted over two 2-day periods, while others engage fewer people in a single session [30]. While it is possible that participants' perspectives may evolve over time and as they develop comfort with their fellow participants, our analysis found that there was positive engagement and candor in the groups in a short time period, comparable to other models [16,30]. Processes such as facilitator training were valuable, as they contributed to standardization in the conduct of small discussions across both sessions. The involvement and availability of experts was helpful for ensuring consistency in any additional information provided to participants (eg, in response to questions). While we conducted a debrief with facilitators following each session, conducting a formal evaluation may have generated further insights into the nature of discussions and any areas for improvement in future deliberations. Continuing to develop, evaluate, and systematically measure outcomes of these deliberative approaches is crucial for extending their utility in policy making.

Limitations

Our descriptive study has some limitations. Public deliberation assumes people are comfortable voicing opinions in a group setting, which can exclude certain participants, particularly those who do not feel empowered or comfortable sharing [31]. Despite the use of facilitator training that, among other things, emphasized the importance of inclusivity, it is possible that there were differences in facilitator approaches, such as their tone and responses to deliberator comments and questions. Finally, as the deliberators were from one specific geographic region and were current or previous patients at the same institution, it is possible that they all had similar experiences they were drawing upon when grappling with complex policy options that were potentially different from patients from other health systems. Further, as the deliberators had current or previous cancer, it is possible that their concerns and preferences were different from those of the general public; that is, people without cancer or other chronic conditions. Nevertheless, our approach enabled us to gain rich insights into the different types of needs and concerns of patients with current or former cancer diagnoses and to elaborate on the utility of public deliberation as a method for gathering data about patient preferences and the rationale behind those preferences.

Conclusion

The findings from our two deliberations—marked by the opportunity for education and informed dialogue—illustrate the value of deliberative approaches for soliciting patient concerns and preferences related to health data sharing and, by extension, other complex topics. The promise of health data sharing and learning health systems is contingent on patient trust and confidence that their health information is being used and shared in ways that meet their expectations. Using deliberative methods that provide information to patients and the opportunity to reason with complex information in accordance with public health values and the ideals of equity offers an important step for creating and nourishing patient trust and confidence.

Acknowledgments

We are grateful for support from the National Cancer Institute (5R01CA21482904) provided to SLRK and JP and from the National Institute of Biomedical Imaging and Bioengineering (1R01EB030492-01) to JP. We also thank Bradley Iott for his review of the manuscript, community partners for their support in recruiting participants, and the deliberation facilitators.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Educational booklet.
[PDF File (Adobe PDF File), 11372 KB - cancer_v8i3e37793_app1.pdf]

Multimedia Appendix 2
Session agenda.
[DOCX File , 16 KB - cancer_v8i3e37793_app2.docx]

Multimedia Appendix 3
Post deliberation survey.
[PDF File (Adobe PDF File), 31037 KB - cancer_v8i3e37793_app3.pdf]

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Abbreviations

AI: artificial intelligence
EHR: electronic health record

Edited by A Mavragani; submitted 07.03.22; peer-reviewed by L Nemati-Anaraki, ER Khalilian, R Zhao, M Clarkson; comments to author 16.06.22; revised version received 07.07.22; accepted 20.07.22; published 16.09.22.

Please cite as:
Raj M, Ryan K, Nong P, Calhoun K, Trinidad MG, De Vries R, Creary M, Spector-Bagdady K, Kardia SLR, Platt J
Public Deliberation Process on Patient Perspectives on Health Information Sharing: Evaluative Descriptive Study
JMIR Cancer 2022;8(3):e37793
URL: https://cancer.jmir.org/2022/3/e37793
doi:10.2196/37793
PMID:36112409

Original Paper

Providing Care Beyond Therapy Sessions With a Natural Language Processing–Based Recommender System That Identifies Cancer Patients Who Experience Psychosocial Challenges and Provides Self-care Support: Pilot Study

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Abstract

Background: The negative psychosocial impacts of cancer diagnoses and treatments are well documented. Virtual care has become an essential mode of care delivery during the COVID-19 pandemic, and online support groups (OSGs) have been shown to improve accessibility to psychosocial and supportive care. de Souza Institute offers CancerChatCanada, a therapist-led OSG service where sessions are monitored by an artificial intelligence–based co-facilitator (AICF). The AICF is equipped with a recommender system that uses natural language processing to tailor online resources to patients according to their psychosocial needs.

Objective: We aimed to outline the development protocol and evaluate the AICF on its precision and recall in recommending resources to cancer OSG members.

Methods: Human input informed the design and evaluation of the AICF on its ability to (1) appropriately identify keywords indicating a psychosocial concern and (2) recommend the most appropriate online resource to the OSG member expressing each concern. Three rounds of human evaluation and algorithm improvement were performed iteratively.

Results: We evaluated 7190 outputs and achieved a precision of 0.797, a recall of 0.981, and an F1 score of 0.880 by the third round of evaluation. Resources were recommended to 48 patients, and 25 (52%) accessed at least one resource. Of those who accessed the resources, 19 (75%) found them useful.

Conclusions: The preliminary findings suggest that the AICF can help provide tailored support for cancer OSG members with high precision, recall, and satisfaction. The AICF has undergone rigorous human evaluation, and the results provide much-needed evidence, while outlining potential strengths and weaknesses for future applications in supportive care.

(JMIR Cancer 2022;8(3):e35893) doi:10.2196/35893

KEYWORDS

artificial intelligence; natural language processing; online support groups; supportive care in cancer; recommender system

Introduction

Cancer and its treatment can significantly decrease the psychological well-being of patients and their families. Emotional distress, particularly related to symptoms of depression, is common among cancer patients and is associated with poor treatment adherence, reduced quality of life, and higher mortality rates [1-3]. The COVID-19 pandemic has amplified this psychological burden, resulting in a global rise in mental distress, especially among cancer patients, because of immunological concerns [4]. Virtual care, such as care from online support groups (OSGs), has become increasingly important in health care delivery, particularly with the more recent impact of COVID-19 that has resulted in the need for social distancing and minimal travel. OSGs offer a convenient and economical solution for those who cannot attend in-person support groups, and successfully reduce patient distress and anxiety [5-8].

Synchronized professionally led OSGs engage participants in therapeutic interactions. Group leaders facilitate the sharing of personal experiences among group members with similar challenges. The aim is to foster a mutually supportive environment to achieve an increased sense of empowerment via the vicarious learning that occurs through group membership and an increased sense of control through being better informed about the conditions [9].

A recent paradigm shift in health care, described as the learning health system, refers to a system of care involving the extraction of actionable information to inform clinical decisions whilst measuring patient experience responses for continued quality improvement [10]. Advances in artificial intelligence (AI), such as machine learning–based natural language processing (NLP), afford the development of learning systems that allow for real-time monitoring and responding to multiple participant care needs in virtual care settings. In a larger project, we leveraged machine learning–based NLP technology to monitor group session activities, track participant outcomes, detect psychosocial concerns in real time, and respond to these concerns automatically [11]. Our AI-based co-facilitator (AICF) system was developed to (1) identify participants at risk for increased emotional distress; (2) monitor in-session engagement and group cohesion levels, providing real-time alerts for the therapist; (3) generate postsession participant profiles that visualize individual emotional trajectories and psychosocial concerns; and (4) automatically suggest tailored online resources to participants based on their messages and participant profiles. Thus, the AICF personalizes support without adding burden to the patient or the therapist. Further, the application of medical resource recommender systems within the AICF can enhance individualized patient access to quality-verified resources that are tailored to the unique needs of patients. This study will report on the training process and performance of the AICF recommender system.

There are numerous applications of AI systems for health care delivery, including treatment recommendations, health education, and symptom management for patient populations [12-15]. A medical information search engine and recommender system called *personal health information recommender* (PHIR) provides personalized information based on individual patient profiles [13]. PHIR has a knowledge base of 855 online resources, which are registered by experts in the cancer domain. This knowledge base allows PHIR to tailor resources based on the user's medical conditions and user ratings on the resource selection history, and to perform similarity matching. PHIR incorporated qualitative feedback from physicians and patients to improve its performance and has shown promising results. Additionally, Vik [12] is a conversational agent equipped with intent classification and entity recognition to provide personalized text messages in response to common questions about medical conditions. The results of a blinded randomized controlled study of 142 breast cancer patients demonstrated noninferiority in user-rated quality between answers provided by Vik and those provided by a physician [12].

Although these AI applications were rated by users before deployment, the actual outputs of these recommender systems have seldom undergone rigorous testing or evaluation by human medical experts. More studies are needed to demonstrate the efficacy of health care recommender systems, particularly for supportive care in cancer [16].

Methods

Platform and Training Data Set

de Souza Institute offers CancerChatCanada (CCC) that has national, professionally led, synchronous, and text-based OSGs for cancer patients and caregivers in collaboration with 6 provincial agencies in Canada. OSGs vary in length, aims, and group intervention models. All groups are manually based and consist of 6 to 8 sessions. Patient participants were recruited through CCC as well as the webpage and social media accounts (Facebook and Twitter) of de Souza Institute. Patients had to be diagnosed with cancer and able to speak English to be included. The exclusion criterion was the presence of distress needing immediate psychological care. Group sessions built on each other, with each session focusing on a specific theme. In sessions, therapists facilitate discussions based on weekly readings, address concerns, attend to the emotional needs of the members as they emerge, and employ group therapeutic factors that promote a continuous sense of mutual support among 6 to 10 members [17]. The OSG typically employs self-management skills that can empower participants as suggested by the Chronic Care Model [18]. The model posits that through empowering patients with self-management knowledge and resources, patients will become informed and engaged as active participants of care, contributing a collaborative partnership with the health care team toward improved outcomes [18]. OSG therapists routinely recommend additional information postsession that provides education around diagnoses and various coping practices, such as mindfulness and positive psychology interventions, to enhance self-management support. To date, CCC therapists have curated about 37 online resources and webpages that cover a variety of topics on cancer self-management, including physical and psychological symptoms, diagnostics, and treatment options (surgery, hormonal therapy, biotherapy, and chemotherapy), as well as caregiving issues, such as loss and bereavement, for all cancer patients. Additionally, there is a body of information on advanced or metastatic diseases and their diagnosis; management of symptoms, such as pain, constipation, diarrhea, anxiety, and depression; end-of-life discussions, such as advanced care planning; concerns faced by young people; and lifestyle guides on food safety and exercise. To enhance the virtual care system, we designed the AICF to identify psychosocial concerns and automatically suggest the most relevant online resources based on in-session conversations.

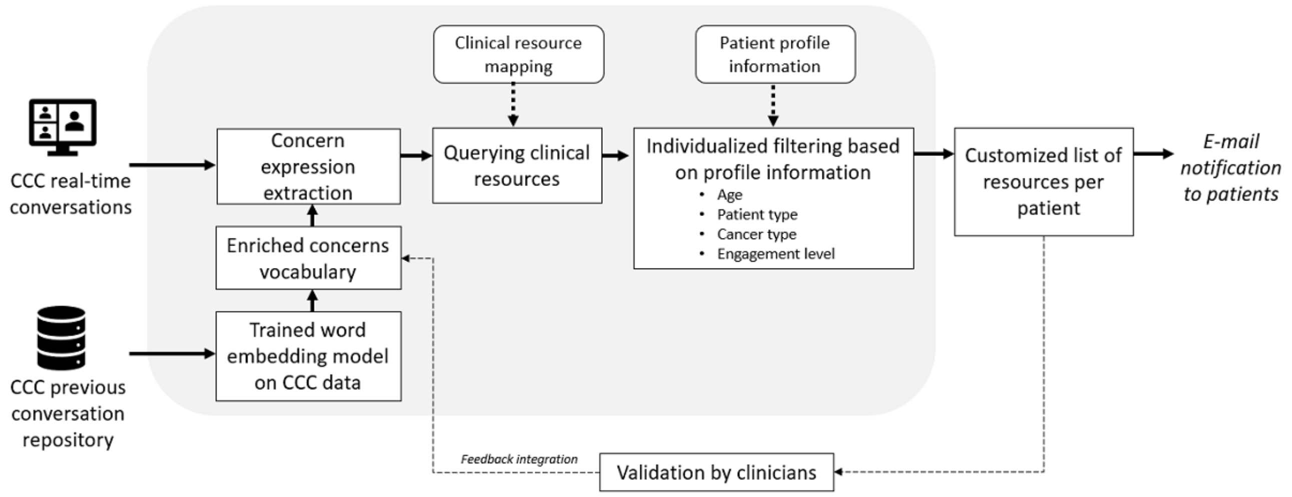
Ethics Approval

This study has been approved by the University Health Network Research Ethics Board (CAPCR Study ID 18-5354). Participants provided informed consent before signing up for the OSG.

NLP-Based AICF Algorithm

The AICF [11] was developed using an NLP-based approach with customization capabilities (Figure 1). First, a corpus of CCC chat sessions (approximately 80,000 messages) was used to train the AICF using word2vec, a word embedding model [19]. This model enabled creating a vector representation for each word in the corpus, thus positioning semantically similar expressions in closer proximity. Second, a team of therapists provided a list of common psychosocial concern keywords (Figure 2) that were fed into the trained word2vec model as inputs to generate semantically similar expressions by participants in session transcripts. Next, we queried for semantically similar expressions in the annotated sample. This enriched vocabulary list was used to extract concerns expressed in conversations. This allowed capturing of the terms and phrases related to each concern from patient posts. Third, once the concerns were identified, a concern-response matrix was used to match the best-suited resources for the patient. Finally, individual attributes were used to score the list of clinical resources to create the most appropriate recommendations. These attributes included age, cancer type, patient type (eg, caregiver status), symptoms of depression and anxiety, and engagement level in the group. This resulted in highly customized recommendations that best suited each patient (Figure 1).

Figure 1. Overview of the artificial intelligence–based co-facilitator recommender system framework. CCC: CancerChatCanada.



Psychosocial Concern Identification and Resource Database Evaluation

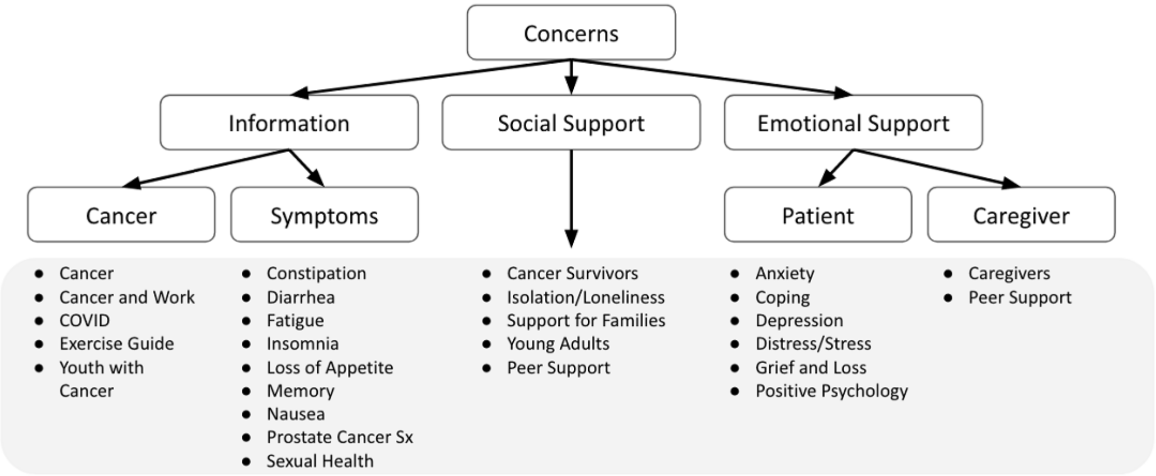
The team developed a literature-based list of psychological concerns relevant to cancer patients (Multimedia Appendix 1) and organized them into a taxonomy that formed the basis for AICF resource mapping (Figure 2) [20,21].

We reviewed 37 online resources curated by CCC therapists. Each resource was evaluated on a set of parameters adapted from the SQuaRE-Aligned Portal Data Quality Model (SPDQM), a model for website content quality evaluation [22,23]. This method aligns with the International Organization for Standardization (ISO) standard for software and data quality [24]. The quality parameters used are as follows: (1) accessibility, (2) understandability, (3) relevancy, (4) validity, and (5) attractiveness and readability (Multimedia Appendix 2).

Each online resource was rated on a Likert scale from 1 to 3 for the parameters listed above (1, *poor quality:* the resource should not be recommended; 2, *moderate quality:* the resource should be recommended to the patients with specific concerns or requests; 3, *high quality:* the resource would be recommended).

Only resources of moderate to high quality were included in the final list of resources available for AICF's recommendation, and included resources were paired with the most appropriate psychosocial concerns (Table 1). Each resource was rated twice by 2 evaluators (BP and RH) who were blinded to each other's rating. Consensus was reached through discussion with a third evaluator (YWL) to resolve discrepancies.

Figure 2. Taxonomy of the common psychosocial challenges of cancer patients. Patient concerns identified by the artificial intelligence–based co-facilitator were scored by a team of medical students and clinical experts based on a taxonomy created using their domain expertise. Sx: symptoms.



AICF Performance Evaluation

The AICF was applied to the chat history of new OSGs, and outputs were scored by 2 medical students (BP and RH) using a confusion matrix. Recall, precision, and F1 score were used as evaluation metrics [25]. F1 score is the harmonic mean of precision and recall, which takes both false positives and false negatives into account to produce a single measure of performance.

Using the established concern domains (Table 1), the team assessed whether the AICF system (1) correctly identified each output instance (true positive), (2) incorrectly identified an output instance (false positive), (3) correctly identified the lack of an output (true negative), or (4) missed the concern in a statement (false negative). All false-positive and false-negative recommendations were analyzed for their underlying reasons and addressed to improve the AICF in subsequent rounds.

Given that the AICF was designed to read deidentified data sentence by sentence, the human raters were lenient regarding true-negative outputs that may have potentially indicated a concern, but the subject and context of how the concern applies remained ambiguous. The raters would rate "true negative" on the following phrase example: "Yes, my social worker tells me that all I can do is listen and be there for him. But that's really hard to do." This phase may be interpreted as the struggles of a caregiver or a patient having difficulties coping; the role of the support group member and subject of concern remains ambiguous, and accurate resources cannot be recommended without additional context. Likewise, the rater rated "true negative" on the following phrase: "most don't want to feel bad, and they can say very heartless things." This phase may be interpreted as a support group member sharing personal feelings or as an observation that was used to connect and empathize with other members in the chat. Although flagging such ambiguous phrases may increase the sensitivity of the AICF, given that the objective of the AICF is to provide appropriate resources while avoiding information overload, we were lenient with negative outputs that had such ambiguity.

The evaluation results were used to retrain the model, while linguistic rules, part-of-speech tagging, and filtering based on the patient profile were applied to handle exceptions such as negations, past tense, and idioms of expression. Evaluators' feedback using their domain expertise was used to improve AICF's performance over the evaluation rounds until it achieved F1 >0.80 before deployment in real-time OSG sessions for beta testing [26].

Participants received an email containing the AICF-tailored recommendations postsession. Users evaluated AICF's recommendations. Automatically generated emails asked the current participants to further evaluate the system. The users judged each recommended resource on usefulness by answering the following question: "Our system has recommended some resources for you based on the last chat session. Please let us know if the links are helpful or not by clicking on the *Useful* or *Not Useful* button below." We also recorded the number of clicks on the recommended resources. Participant characteristics are presented in Table 2.

Table 1. The finalized concern-resource matrix.

Concerns	Type of resource							
	Website	Phone line	Learning modules	Online support group	PDF	Apps/games	Videos	Mindfulness
Newly diagnosed	Patient and Caregiver Cancer Connection Newly Diagnosed	Cancer support helpline	MyGrief.ca	Cancer Connection	—[a]	—	—	Nucare Manual
Anxiety & depression	Worried, Scared or Anxious Sadness and Depression	Cancer support helpline	MyGrief.ca	—	Sleeping Well Manual Anxiety Depression	—	—	Nucare Manual
Distress & intense emotions	Managing Stress	Cancer support helpline	MyGrief.ca	—	—	—	—	Nucare Manual
Grief & loss	Loss and Grief	Cancer support helpline	MyGrief.ca	—	—	—	Living My Culture	Nucare Manual
Isolation & loneliness	—	Cancer support helpline	—	Cancer Connection	—	—	—	Nucare Manual
COVID	COVID-19 and cancer	—	—	—	—	—	—	Nucare Manual
Finances & employment	Cancer and Work	—	—	—	Returning to Work	—	—	—
Caregiver support	—	Caregiver helpline	—	Cancer Support Community	—	—	—	—
Support for families	Family Support	—	—	—	—	Cancer in my family	—	—
Symptom management: Insomnia	Sleeping Well Manual	—	—	—	—	—	—	—
Symptom management: Pain	—	—	—	—	—	Pain and treatment side effects	—	—
Sexual health	—	—	—	—	Sexual Health	—	—	—
Symptom management: General	Symptom Management	—	—	—	—	—	—	—
Adolescents & young adults	Young Adult Cancer Cancer Fight Club	—	—	Young Adult Cancer	—	—	—	—

[a] Not available.

Table 2. Participant characteristics.

Characteristic	Value (N=48), n (%)
Gender	
Female	43 (90)
Male	4 (8)
Unknown	1 (2)
Age group (years)	
18-24	0 (0)
25-34	3 (6)
35-44	8 (17)
45-54	10 (21)
55-64	18 (37)
65+	9 (19)
Location	
British Columbia	18 (37)
Ontario	14 (29)
Alberta	7 (15)
Other provinces	9 (19)
Type of cancer	
Breast	24 (50)
Gynecological	3 (6)
Colorectal	5 (10)
Head and neck	3 (6)
Other cancers	12 (25)
Unknown	1 (2)
Treatment status	
Active treatment	8 (17)
Posttreatment	22 (46)
Other	18 (37)

Results

A total of 35,600 outputs from the AICF on the CCC chat history were extracted over 3 evaluation rounds. The months of the data collected were February 2020, April 2020, and June 2020. A random sample of 20% unique statements with AICF's decision outputs (n=7190) was evaluated by human raters using a confusion matrix. Example phrases from each category of the matrix are provided in Multimedia Appendix 1.

Among false negatives, the AICF failed to recognize culturally specific idioms of concern, which was reflected in the high number of errors. For example, the AICF failed to recognize the phrases "heart feels heavy" or "want to run away" as distress, "exhaustion" as fatigue, and "HER2" as breast cancer. Keywords in false-negative outputs were identified by human evaluators and used to retrain the AICF algorithm for improvement. As a result, the second and third rounds of evaluation added 75 and 17 new terms, respectively, to the AICF concern bank. This adjustment improved the false-negative rate from 54.8% (69/126) in the first round to 30.8% (16/52) in the second round and 6.9% (2/29) in the third round (Table 3).

Table 3. Classification accuracy.

Variable	Round 1 (N=4774), n	Round 2 (N=1195), n	Round 3 (N=1221), n
Accuracy	4648	1143	1192
True positive	84	85	106
True negative	4564	1058	1086
Total inaccurate	126	52	29
False negative	69	16	2
False positive	57	36	27
Phrase ambiguity	28	9	5
Reference to future/past	19	7	3
Reference to others	4	10	13
Offering opinion	6	10	6

False-positive outputs were classified into 1 of the following 4 subcategories: (1) *Phrase ambiguity:* there was insufficient information in the statement to fully assess whether a key concern was present; (2) *Reference to the future or past:* the statement maker was sharing a possible future or past event with other group members; (3) *Reference to others:* the statement maker refers to a concern pertaining to a person other than themselves; (4) *Offering an opinion:* the statement maker is offering their personal opinion or experience regarding a concern mentioned by another group member.

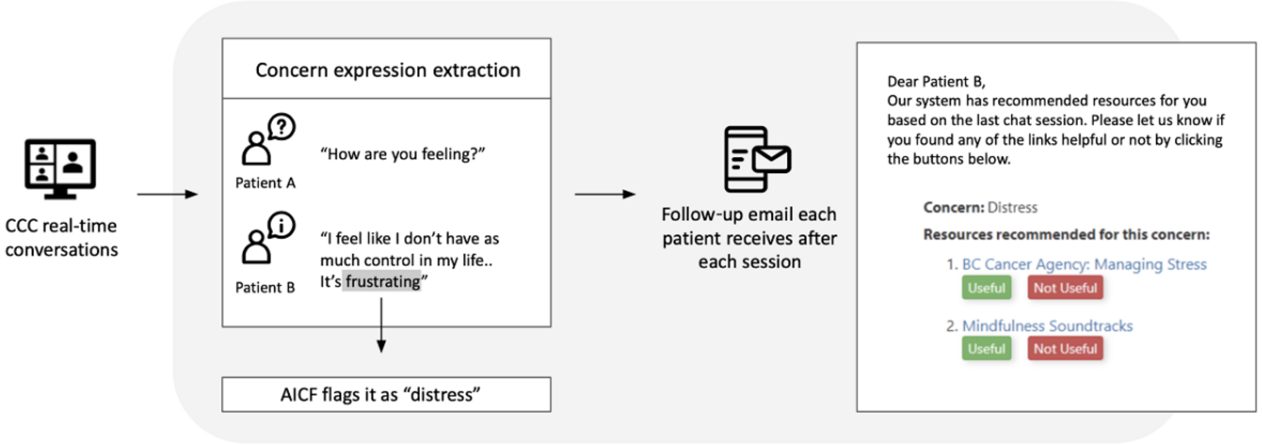
False positives were addressed by additional tagging techniques tailored for each underlying reason. The details are elaborated in the Discussion. Although the rate of false positives increased over 3 evaluation rounds (Table 3), this was most likely due to an increased sensitivity of the recommender system arising from the expanded vocabulary that was applied to address the false negatives, and the net result of these adjustments was an improvement in the F1 score from 0.571 in round 1 to 0.766 in round 2 and 0.880 in round 3 (Table 4).

Figure 3 illustrates the patient experiences with the AICF recommender system. The recommender system was tested in a convenient sample of 5 OSGs, reaching 48 participants. Each participant was recommended an average of 11.3 unique resources, ranging from 2 to 40. Twenty-five (52%) of these participants clicked at least one of the recommended resources. These 25 participants viewed an average of 4.4 (39.1%) tailored resources. Among the participants who viewed resources, 19 (76%) rated them as "useful" (Figure 3).

Table 4. Precision, recall, and F1 score following each round of artificial intelligence–based co-facilitator evaluation.

Round	Precision	Recall	F1 score
1	0.596	0.549	0.571
2	0.702	0.842	0.766
3	0.797	0.981	0.880

Figure 3. Patient experience with the artificial intelligence–based co-facilitator (AICF) recommender system. CCC: CancerChatCanada.



Dear Patient B,
Our system has recommended resources for you based on the last chat session. Please let us know if you found any of the links helpful or not by clicking the buttons below.

Concern: Distress

Resources recommended for this concern:

1. BC Cancer Agency: Managing Stress
Useful Not Useful
2. Mindfulness Soundtracks
Useful Not Useful

Discussion

Principal Findings

This study evaluated AICF's performance in identifying concerns and recommending resources for cancer patients based on transcripts from OSGs. The large amount of available information online can be overwhelming for resource seekers, especially for those who are affected by cancer. The aim of the AICF is to recommend high-quality resources that are tailored to concerns identified on the basis of each patient's OSG chat history. A recommendation system based on patients' needs expressed in the group discussion can potentially reduce the burden on patients to find the correct information and the burden on online therapists who need to respond to multiple participants simultaneously. The preliminary results show that the initial performance was low, indicated by an F1 score of 0.571, although accuracy was high (97.4%). For subsequent evaluation rounds, the AICF was retrained on the basis of feedback from human evaluators, which improved the performance to an F1 score of 0.880 by the third round of evaluation. These results demonstrate that the AICF displays sufficient accuracy in identifying concerns expressed by OSG participants and recommending relevant resources that can help to increase tangible support and service quality without incurring increased workload for therapists. Nineteen (76%) patients who viewed the AICF-recommended resources found them useful.

The AICF is a one-of-a-kind recommender system running behind the scenes of an OSG service without imposing on the therapist or participants. To date, there have been very few studies adopting a human expert in their system validation process. Compared to previous recommender systems, such as PHIR and Vik [27], the AICF adopted a human evaluator feedback loop and exhibited high performance and enhanced personalized support. The AICF performed a robust human evaluation on over 7000 outputs to produce values for accuracy, recall, and F1 scores. The AICF is unique in that it aims to provide automatic detection of psychosocial concerns and delivery of tailored resources for self-management. This technology augments therapist-led OSG sessions, while the other systems relied on patients actively seeking resources and using a search engine for resource delivery.

Among the recommender systems designed for health care delivery, the AICF is highly comparable to a conversational agent, Vik [27], based on common medical questions and physician answers. Vik uses intent classification and entity recognition to process user input texts. Intent classification identifies keywords from the user's textual inputs and classifies them into one of the predetermined question categories. Entity detection identifies names or titles in the user's inputs and classifies them into predefined categories. However, the AICF is embedded in an OSG and uses a statistical and rule-based approach with word embeddings, in which a subset of relevant keywords is extracted as intent, serving as inputs to the recommender. Furthermore, the AICF differs from Vik in that we incorporated user profile information, such as type of cancer, age, engagement level, anxiety and depression symptomatology, and caregiver status, to produce highly tailored recommendations. Another major difference is the fact that Vik was trained with a database consisting of questions asked by the users to their health professionals, while the AICF was trained on chat history data consisting of human-to-human text-based conversations in OSG format. The training data allowed the AICF to understand more diverse psychosocial concerns, but they are more complex to process.

The AICF showed high accuracy (97.4%) in the initial assessment, and it was stable over evaluation rounds. False negatives were reduced by expanding AICF's vocabulary bank to include key terms that had been missed, resulting in a greater than 8-fold reduction in the false-negative rate between round 1 and round 3. However, continuous monitoring and retraining by feedback from human raters will be required for the AICF to be sensitive to idiom use in different contexts and scenarios. Future work should explore the use of a language model [28] to detect the idiomatic and metaphorical parts in sentences.

For false positives, the AICF identified concerns that were deemed incorrect by the human evaluators. These were categorized into the following 4 subcategories: (1) phrase ambiguity, (2) reference to the future or past, (3) reference to others, and (4) offering an opinion.

Phrase Ambiguity

There was insufficient information in the statement to fully assess whether a key concern was present. The text was primarily characterized by short messages in which contextual information was missing. One or more keywords of psychosocial concern were present and were picked up by the AICF in the absence of contextual information. Phrase ambiguity was complicated by using a deidentified data set. All identifiable personal health information, including user handle names, hospital names, and doctor names, had been removed in accordance with the guidelines from the research ethics board. This often leads to disjointed data in which phrases are fragmented. Currently, the AICF is unable to link conversations between specific participants, resulting in lost information regarding who is replying to whom or which statements the speaker agreed or disagreed with. We also removed the therapist's statements to minimize the contamination of group outcomes arising from the therapist's validation of the group discussion. This resulted in the loss of contextual information for the AICF, contributing to the number of false positives identified. Future work should look into different deidentification methods that can better protect the linkage of conversations without compromising participant confidentiality.

Reference to the Future or Past

The statement maker was sharing his/her past experiences or future events that had not yet happened. For example, participants shared an experience, triggering the AICF to identify a concern and recommend resources. However, the phrases indicated to the raters that the participant was no longer actively dealing with the identified concern. To address these themes in false-positive outputs, a speech tagging technique was added to the algorithm after the second round of validation to detect the use of past and future tenses. Future work will explore other word embedding models, such as sense2vec, to improve performance further.

Reference to Others

The AICF identified concerns and recommended resources to participants when participants were in fact referencing the stories of a third party. The addition of a linguistic rule to detect story-telling, such as the use of third person pronouns, may help improve false-positive outputs. Once more chat transcripts become available, it will be a feasible adjustment to further improve the precision of the AICF.

Offering an Opinion

The statement maker was offering his/her personal opinion or experience regarding a concern mentioned by another group member. Future studies can explore modeling the relationship between messages to recognize the conversation thread.

Limitations

Apart from the limitations identified above, which are common as AI continues to improve itself, the 37 curated resources included in our recommender system can be seen as a relatively small set of information support resources in cancer care. These resources were selected for their relevance to assist OSG participants in dealing with the psychosocial challenges of living with different cancers. However, such resources could also be seen as too generic by participants and insufficient to meet their needs for a specific cancer. This may partially explain the fact that only 52% of the participants accessed a recommended resource. Additionally, the resources included were rated by medical professionals; however, there is obvious merit to additional evaluation by a more neutral party whose health literacy is more representative of the general public and patients who would utilize the AICF. The patient population included in this study was also likely more technologically savvy compared to the general public given that they had to be competent in maneuvering online webpages and social media to sign up for the OSG. While this may not be representative of all cancer patients, with the continued rise of internet usage and the strong need for additional remote support options with the COVID-19 pandemic, we predict that the population this system is geared toward will continue to become more representative of the general cancer patient population over the years. Next steps will involve conducting focus groups with OSG participants to explore their opinions on the AICF and expanding the resource rating team to include diverse backgrounds and perspectives in the rating process. Future work will expand the psychosocial resources to include those for particular cancers and develop NLP to recognize specific cancer types. Future work should also assess ethnicity/cultural parameters related to the AICF system.

Conclusion

Owing to increased mental health care demands and barriers for accessing in-person care, virtual care has become paramount in the provision of supportive care. We have embedded the AICF within OSGs to increase personalized support and expand patient self-management capacities by recommending credible online resources. All these goals can be achieved without additional work from therapists. Future projects include user focus groups, development of cancer-specific recommender systems, expansion to additional languages, and ultimately randomized controlled trials to inform effectiveness and ensure further development of policies, such as mandating AI-enhanced OSGs as the first line of patient education to build self-management capacities for cancer and chronic diseases. Eventually, this line of research will inform our health system on the use of AI for future personalized supportive care delivery.

Acknowledgments

This research was funded by the Ontario Institute for Cancer Research Cancer Care Ontario Health Services Research Network.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Themes, keywords, and examples of artificial intelligence–based co-facilitator outputs.
[PDF File (Adobe PDF File), 42 KB - cancer_v8i3e35893_app1.pdf]

Multimedia Appendix 2
Resource evaluation tool.
[PDF File (Adobe PDF File), 119 KB - cancer_v8i3e35893_app2.pdf]

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Abbreviations

AI: artificial intelligence
AICF: artificial intelligence–based co-facilitator
CCC: CancerChatCanada
NLP: natural language processing
OSG: online support group
PHIR: personal health information recommender

Edited by A Mavragani; submitted 22.12.21; peer-reviewed by A Buttazzoni, L Guo; comments to author 19.04.22; revised version received 14.05.22; accepted 29.05.22; published 29.07.22.

Please cite as:
Leung YW, Park B, Heo R, Adikari A, Chackochan S, Wong J, Alie E, Gancarz M, Kacala M, Hirst G, de Silva D, French L, Bender J, Mishna F, Gratzer D, Alahakoon D, Esplen MJ
Providing Care Beyond Therapy Sessions With a Natural Language Processing–Based Recommender System That Identifies Cancer Patients Who Experience Psychosocial Challenges and Provides Self-care Support: Pilot Study
JMIR Cancer 2022;8(3):e35893
URL: https://cancer.jmir.org/2022/3/e35893
doi:10.2196/35893
PMID:35904877

Original Paper

Integrating Top-down and Bottom-up Requirements in eHealth Development: The Case of a Mobile Self-compassion Intervention for People With Newly Diagnosed Cancer

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Abstract

Background: Psychosocial eHealth interventions for people with cancer are promising in reducing distress; however, their results in terms of effects and adherence rates are quite mixed. Developing interventions with a solid evidence base while still ensuring adaptation to user wishes and needs is recommended to overcome this. As most models of eHealth development are based primarily on examining user experiences (so-called *bottom-up* requirements), it is not clear how theory and evidence (so-called *top-down* requirements) may best be integrated into the development process.

Objective: This study aims to investigate the integration of top-down and bottom-up requirements in the co-design of eHealth applications by building on the development of a mobile self-compassion intervention for people with newly diagnosed cancer.

Methods: Four co-design tasks were formulated at the start of the project and adjusted and evaluated throughout: *explore* bottom-up experiences, *reassess* top-down content, *incorporate* bottom-up and top-down input into concrete features and design, and *synergize* bottom-up and top-down input into the intervention context. These tasks were executed iteratively during a series of co-design sessions over the course of 2 years, in which 15 people with cancer and 7 nurses (recruited from 2 hospitals) participated. On the basis of the sessions, a list of requirements, a final intervention design, and an evaluation of the co-design process and tasks were yielded.

Results: The final list of requirements included intervention content (eg, major topics of *compassionate mind training* such as psychoeducation about 3 emotion systems and main issues that people with cancer encounter after diagnosis such as regulating information consumption), navigation, visual design, implementation strategies, and persuasive elements. The final intervention, *Compas-Y*, is a mobile self-compassion training comprising 6 training modules and several supportive functionalities such as a mood tracker and persuasive elements such as push notifications. The 4 co-design tasks helped overcome challenges in the development process such as dealing with conflicting top-down and bottom-up requirements and enabled the integration of all main requirements into the design.

Conclusions: This study addressed the necessary integration of top-down and bottom-up requirements into eHealth development by examining a preliminary model of 4 co-design tasks. Broader considerations regarding the design of a mobile intervention based on traditional intervention formats and merging the scientific disciplines of psychology and design research are discussed.

(JMIR Cancer 2022;8(3):e37502) doi:10.2196/37502

KEYWORDS

eHealth; cancer; self-compassion; co-design; requirements; evidence-based; mobile phone

Introduction

Receiving a cancer diagnosis and undergoing treatments can disrupt many aspects of a person’s life, often affecting not only one’s physical but also one’s mental and social well-being [1-6]. Psychological interventions for people with cancer are effective in reducing symptoms of distress and improving well-being and are mostly delivered face to face in an individual or group format [7-10].

Although face-to-face interventions may offer important benefits such as live social support, they are often not adopted by people with cancer. People with cancer already face many demands, including medical appointments. Reasons for not participating in available interventions include the burden of travel, too many competing demands, and not feeling well enough to join sessions [11]. Interventions delivered through technologies such as eHealth may offer unique benefits such as increased accessibility and scalability [12], thereby reaching people who may not have otherwise participated. In addition, offering interventions in a mobile format may help with the integration of newly learned skills into daily life, as most people currently carry their mobile devices with them during daily activities [13].

Although eHealth interventions appear to be similarly effective in reducing mental distress compared with traditional intervention formats [14,15], results regarding the effects of psychological eHealth interventions in the context of cancer are still mixed [16,17], with varying rates of adherence [18]. Particularly when it comes to mobile interventions, many lack a solid foundation of theory and evidence [19]. More theory- and evidence-driven interventions are recommended for improving effectiveness and adherence [17,19-22]. Simultaneously, it is important to take into account the wishes, needs, and daily life of people with cancer to increase the chance that the intervention is successfully adopted by the target group [23,24]. Thus, what is needed to facilitate intervention success is an integration of both theory and evidence-based requirements (which we will call *top-down*; ie, from the *abstract* sphere of theory and evidence down to *concrete* experiences of daily life) and the experience-based requirements of people with cancer (which we will call *bottom-up*; ie, going from *concrete* experiences of daily life up to *abstract* theory and evidence).

This integration of top-down and bottom-up requirements may be facilitated by co-design. Co-design is a collaborative creative process through which members of the target group and stakeholders become active participants in intervention design rather than mere reactive subjects of user-centered design. In co-design, the user is not a passive object of study through only observations or interviews but an expert in their experience, with the researcher as a facilitator [25,26]. Top-down requirements could be introduced into the co-design process by researchers or other experts. Although in medical and behavioral research, top-down requirements for interventions are common [27,28], existing frameworks of eHealth development are predominantly based on bottom-up requirements and user-centered design (see the review by van Gemert-Pijnen et al [29] for an overview). Thus, it is unclear how top-down requirements can be optimally integrated into the co-design process. Without proper integration, a problematic outcome could be that an intervention has content and design that people like to use but no ground in scientific evidence. Another problematic outcome could be an application in which scientific evidence dominates the final solution, whereas experience-based requirements (gathered early on in a project) are neglected or overruled by the project team. Therefore, our overall objective is to use the co-design process to have top-down and bottom-up requirements and stakeholders explicitly meet and engage in a design conversation, leading to a coherent, integrated intervention that acknowledges the value of both types of requirements.

To meet this objective, we built on the case of the co-design of a mobile self-compassion intervention for people with newly diagnosed cancer. Although most of the discussed psychological interventions for people with cancer are based on cognitive behavioral techniques or mindfulness, compassion-based interventions for people with cancer are rapidly emerging [30]. These interventions focus on developing a compassionate acceptance of one’s distress and the motivation to alleviate the distress. Participants of various compassion-based interventions have reported increased acceptance of their illnesses and limitations, improved emotion regulation skills, and reduced feelings of isolation [30], making this type of intervention particularly relevant in the context of cancer. Indeed, our initial pilot study showed that people with cancer evaluated self-compassion as important and preferred to receive an intervention shortly after diagnosis in the form of a smartphone app [31].

Thus, the aim of our co-design study was to create an eHealth intervention that is grounded in both (1) theory and evidence-based requirements (eg, founded by established compassion-based interventions such as *compassionate mind training* [32]; ie, top-down requirements) and (2) experience-based needs, wishes, and requirements of people with cancer and oncology nurses (ie, bottom-up requirements). To achieve this integration, a set of co-design tasks were devised and evaluated throughout the development process. The co-design study yielded (1) a list of integrated top-down and bottom-up requirements, (2) a final design of a mobile self-compassion intervention for people with newly diagnosed cancer, and (3) an evaluation of the co-design process and tasks. On the basis of these outcomes, we will discuss the potential relevance of our co-design approach as a preliminary model for integrating top-down and bottom-up requirements in eHealth development.

Methods

Study Design

As recommended by the Centre for eHealth Research Roadmap approach to eHealth development, the design and development process constituted a participatory approach using continuous cycles of evaluation [29]. Throughout this process, co-design methods were used in which people with cancer and oncology nurses served as the experts in their experiences [25]. The study was led by a project team comprising researchers with a background in either psychology (including health psychology and compassion science) or design, as well as patient advisers, oncologists, clinical psychologists, and software developers.

A Priori Outline of Co-design Tasks and Top-down Requirements

Informed by existing eHealth development frameworks (see the review by van Gemert-Pijnen et al [29]), we adapted our approach to explicitly focus on the integration of top-down and bottom-up requirements. Accordingly, an outline of co-design tasks was formulated by the project team at the start of the project and adapted throughout the development process, resulting in the following four iterative co-design tasks: (1) *explore* bottom-up experiences, (2) *reassess* top-down content, (3) *incorporate* bottom-up and top-down input into concrete features and design, and (4) *synergize* bottom-up and top-down input into the intervention context (Textbox 1 provides an overview). These tasks were executed during a series of co-design sessions, as described in the following sections. In addition, to explore in-depth personal accounts of experiences with self-compassion after diagnosis, the development of intervention content was conjointly informed by semistructured individual interviews with people with cancer [33].

Textbox 1. The 4 iterative co-design tasks to enable the integration of top-down and bottom-up requirements.

Co-design task and description

1. *Explore* bottom-up experiences
   - Acquire input on experienced challenges and facilitators (in general and in relation to top-down scope) and the most important targets and topics for the intervention according to participants.
2. *Reassess* top-down content
   - Assess top-down content in the context of user recognition, appreciation, and suggestions for alterations.
   - Make adaptations to top-down content according to the needs and vocabulary of users and reframe user wishes based on top-down content.
3. *Incorporate* bottom-up and top-down input into concrete features and design
   - Specify and integrate bottom-up and top-down requirements by translating them into concrete features and design and then tangibly explore similarities and differences.
   - Assess which bottom-up features are put forward by participants and how participants experience features derived from top-down requirements.
   - Discuss and prioritize requirements (using co-design exercises and trade-off decision-making strategies).
4. *Synergize* bottom-up and top-down input into the intervention context
   - Focus on synergizing requirements into all levels of the intervention context.
   - Match the overall structure of the intervention (eg, ordering, logic, and main interface), communication channels (eg, level of external support), and interaction flow to both the top-down requirements (eg, regarding intervention rationale and implementation factors) and bottom-up requirements (eg, regarding routines and life patterns of the user and stakeholders).

Before the start of the co-design sessions, top-down requirements were formulated for the self-compassion intervention based on existing compassion theory and evidence on compassion-based interventions (for an overview of intervention elements and evidence of effectiveness, see the review by Austin et al [30]), as well as on the characteristics of effective eHealth interventions. Compassionate mind training served as the main framework for the intervention, which uses an evolutionary-based model of 3 emotion systems, and focuses on understanding our minds and emotions, developing feelings of compassion (including for experienced self-criticism) and compassionate acceptance, and developing skills such as mindful awareness and compassionate imagery [32,34,35]. There is increasing evidence that compassionate mind training, offered as part of compassion-focused therapy or in a nonclinical form, is effective in improving well-being and reducing distress in general populations and populations with chronic illness [30,36-38]. In addition, exercises from positive psychology and *Mindful Self-Compassion Training* [39] were included in the development process. Furthermore, characteristics that are known to promote the effectiveness of and adherence to eHealth interventions were considered top-down requirements, particularly persuasive design principles such as self-monitoring, receiving rewards, and social support [40]. In addition to compassion-based intervention content, compassion as a design value was considered a top-down design requirement. In face-to-face compassion training or therapy, the trainer models compassion throughout the training process (ie, with compassionate responses to difficulties and deshaming of experiences) [41]. An aim of the development process was to model compassion throughout different features and contents of the intervention (eg, providing compassionate feedback when a user indicates high levels of distress). Taken together, this input formed the theoretical starting point for the co-design sessions (ie, it provided the general frame and scope of the challenge to be explored with participants) and was introduced during various co-design exercises, particularly in the task *reassess top-down content* (Table 1 provides an overview of these co-design exercises).

Table 1. Overview of sessions, co-design exercises, and co-design tasks.

Sessions and co-design exercises	Co-design task
Session 1	
Mapping of individual obstacles and facilitators in dealing with the cancer diagnosis, visualized as rocks and ladders	Explore
Mapping of support that was or was not present from oneself, own network, or professionals after the diagnosis using a card sorting method	Explore
Identifying individual moments of self-compassion and self-criticism on sticky notes in relation to the diagnosis and then categorizing them together	Explore
Session 2	
Trying out self-compassion exercises in the 2 weeks before the session; building a desired app and an undesired app represented on paper smartphone models by categorizing and altering the self-compassion exercises	Reassess
Identifying additional topics and exercises to be addressed in the app by adding to and altering topics identified in the first session	Explore
Session 3	
Trying out other psychosocial apps in the week before the session; presenting the apps in small groups, highlighting positive and negative user experiences; creating a map of the similarities and differences in the experiences of functionalities in these apps, focused on filling out and sharing information, motivational elements, feedback, personalization, and mode of information	Integrate
Exploring language use in the app by playing a card game in which the story of the app was presented in 5 different ways (based on metaphors) on 5 cards, where participants “played out” their preferences	Integrate
Creating a diagram of the way the app could be offered and supported by nurses (when, to whom, how, and how often)	Synergize
Session 4	
Shaping the flow of and processes within the app using cardboard boxes representing different app modules to write on and move around	Synergize
Creating paper prototypes of parts of the app using both defined (eg, printed buttons) and undefined (eg, random or blank stickers) materials	Integrate
Session 5	
Interacting with a low-fidelity prototype of a home page and engaging with different home page designs represented on posters	Integrate
Role-plays around app implementation and app recommendation by nurses and people with cancer	Synergize
Interacting with a low-fidelity prototype of the content of an app module in the form of a smartphone app, as well as on paper	Reassess
Session 6	
Refining wireframes and high-fidelity prototypes provided by the app developer (also in participants’ home settings)	Integrate
Mapping implementation processes and challenges based on diagrams from session 3 (nurses only)	Synergize
Generating ideas for peer tips and experiences to be included in the app in a card-based group game	Explore
Session 7	
Evaluating the “final” version of the intervention in terms of bottom-up requirements (with minor changes still implemented) using whiteboards	(Evaluate)
Evaluating the co-design process using interview methods among participants	(Evaluate)

Participants and Procedures

Participants for the co-design sessions were recruited from 2 participating hospitals (1 community and 1 university hospital). Eligible participants were adults with any form of cancer diagnosed 6 to 24 months ago who were willing to participate in ≥1 session and had sufficient command of the Dutch language. In addition, oncology nurses who work with people with cancer were selectively recruited by the project's consulting oncologists. People with cancer received a study information leaflet from oncology nurses during regular consultations, which contained an overview of the study procedures and referred them to the study website for information about the study, privacy regulations, contact opportunities, and sign-up. A total of 15 people with cancer (n=8, 53% female, and n=7, 47% male; aged 29-64 years), who were diagnosed 6 to 24 months ago with a form of cancer (breast cancer n=6, 40%; all other forms n=1, 7% each), and 7 oncology nurses (n=4, 57% female, and n=3, 43% male; aged 31-54 years) with 9 to 28 years of experience working with people with cancer were included.

Ethics Approval

Written informed consent was obtained from all participants at their start of the first co-design session. Consent for visual recording (photo or video) was reconfirmed on each occasion (verbal or written). This study was approved by the Ethical Committee BMS of the University of Twente (approval number BCE18853).

Co-design Sessions

A total of 7 rounds of co-design sessions were conducted over a period of 2 years (November 2018 to November 2020). In each session, 2 to 3 oncology nurses, 3 to 6 people with cancer, and 2 to 3 facilitating researchers were present. The 7 sessions were conducted twice, with participants from 2 distinct geographical areas (ie, the 2 hospitals), once at a university medical center and once at a university. Each session lasted between 2 and 3.5 hours (session duration was adapted based on the energy levels of participants). The last round of sessions was delayed and partially conducted on the web because of the COVID-19 pandemic. Sessions generally comprised an introduction, with a recap of the previous session, followed by an icebreaker creative exercise, 2 to 3 co-design exercises, a general discussion, and a concluding evaluation questionnaire. A mix of group and individual co-design exercises was used to foster creative idea generation [42,43]. A variety of co-design exercises was used, which could be categorized as *making tangible things* (eg, creating 2D maps and prototyping); *talking, telling, and explaining* (eg, card sorting and group discussions); and *acting, enacting, and playing* (eg, group games and role-play) [43]. In contrast to user-centered design approaches in which user input is analyzed by researchers behind the scenes, input from the exercises was discussed, prioritized, and summarized during the co-design sessions as much as possible, ensuring participants' active role in the interpretation of the results. Small group exercises were conducted with people with cancer and nurses separately, after which the outcomes were integrated into collective discussions and exercises. This approach was chosen to benefit from multidisciplinary perspectives while also creating a safe environment to share experiences among peers. In addition, participants occasionally engaged in exercises between sessions in their home environment (eg, usability testing of high-fidelity prototypes). Data were collected using physical materials from the co-design tasks (eg, paper maps and sticky notes), as well as audio recordings, written notes, and occasional video recordings.

The 4 co-design tasks were used iteratively across sessions rather than only sequentially, thus encompassing the components of different sessions. Study-specific session evaluation questionnaires addressed satisfaction, burden, inspiration, collaboration, learning new things, alignment with personal expertise, sense of involvement with the project, and sense of influence over the design on a 5-point Likert scale, with room for open-text input (eg, "To what extent do you feel involved with developing a self-compassion app for people with cancer?"; Multimedia Appendix 1). During the last session, the full co-design process and final design were evaluated with participants. Table 1 provides an overview of sessions, co-design exercises, and tasks, and Figure 1 presents visual examples of paper materials used in the co-design exercises.

Figure 1. Examples of paper materials used in the co-design exercises. The co-design exercises are described in Table 1 . (A) Obstacle card (session 1, first exercise). (B) Desired and undesired apps (session 2, first exercise). (C) Map of motivational elements (session 3, first exercise). (D) Cardboard boxes representing the app modules (session 4, first exercise). (E) Poster of a home page design (session 5, first exercise). (F) Card game about the tips (session 6, third exercise).

Integrating Top-down and Bottom-up Requirements

The final requirements were yielded from the 4 co-design tasks, during which initial ideas for requirements were processed and prioritized (based on the MoSCoW categorization of *must haves* and *nice to haves* [44]). Trade-off decision-making was used to balance various (conflicting) requirements. For example, a top-down requirement was to include caregiver support within the app to increase intervention effectiveness [37,45], whereas bottom-up requirements were to minimize the workload of nurses and have a private intervention experience for people with cancer (see the study by Austin et al [46] for more details and examples of the strategies we used to merge conflicting requirements). Following the completion of a provisional list of requirements (session 4), collaboration with a commercial app developer agency was initiated. Financial and technical opportunities and constraints were then taken into account in the further prioritizing and refinement of requirements. Although some of the processing of requirements was done by the project team in between sessions (eg, gaining an overview of the financial impact of different requirements), most of the prioritization was done during co-design sessions in collaboration with participants (ie, with the aforementioned co-design exercises). The final requirements included functional (ie, what the intervention should do) and nonfunctional (ie, properties of the intervention such as usability) requirements [47]. Detailed software requirements (eg, “when user clicks X, Y should appear”) were derived from the final requirements and are beyond the scope of this paper, as are specific formatting and visual design issues.

Results

In this section, we describe the outcomes of the seven co-design sessions: (1) the final list of requirements for the intervention and how they were implemented; (2) the content and functionalities of the intervention; and (3) an evaluation of the co-design process, particularly the 4 co-design tasks. Evaluation and implementation of the intervention were not part of this study.

Final Requirements

Table 2 summarizes the main list of requirements. These requirements included aspects such as the content of the app (eg, psychoeducation about the 3 emotion systems tailored to the context of cancer), navigation (eg, having the option to skip or save exercises), visual design (eg, minimal and soothing), implementation (eg, a stand-alone app embedded in regular care), and persuasive elements (eg, receiving push notifications). The final requirements were the direct outcomes of the co-design sessions. For example, a co-design exercise addressing obstacles and facilitators after diagnosis (session 1, first exercise; Table 1) yielded experienced obstacles of a lack of energy and mental clarity. Furthermore, it became clear across sessions that participants would value help in remembering to engage with the app and staying motivated, without feeling pressured. Specifically, evaluating other apps (session 3, first exercise; Table 1) showed that subtle motivational elements in the form of viewing progress within the app or receiving inspirational messages (eg, a progress bar that changes color and a tip of the day) would be fitting, in contrast to earning badges or points: “You already feel miserable, you shouldn’t have to earn anything. But there has to be something that pulls you to the app.” Motivational elements were then further examined by prototyping (eg, session 4, second exercise; session 6, first exercise; Table 1). On the basis of these outcomes of various co-design exercises, requirement 8 regarding subtle persuasive elements was formed. Although these requirements are specific to this intervention, generalizable intervention characteristics may be inferred from each. For instance, the abovementioned example illustrates that noninvasive and inspirational persuasive design elements are implemented to make the intervention engaging without being perceived as inappropriate or coercive (eg, notifications containing a quote or brief exercise rather than an explicit reminder to complete an exercise). Similarly, in balancing tunneled versus freely available content, requirement 15 illustrates that we implemented both types of content, which were then cross-referenced (eg, pointing out relevant module content in the automated feedback of the mood tracker; a freely accessible exercise *light of the day* is expanded upon in 2 modules).

Following prioritizing and trade-off decision-making, all the main requirements were met in the intervention design. However, some functionalities were implemented in a simplified form, and some requirements were only partially met. For example, we included a mix of audio, video, text, and images to convey information; however, we were unable to include audio recordings for all written text to listen to instead of reading. The participants indicated that this would substantially help with concentration difficulties; however, financial constraints prevented us from implementing this. Textbox 2 presents an overview of the ways in which the final requirements (as listed in Table 2) were implemented in the intervention.

Table 2. Final list of matched top-down and bottom-up requirements.

Top-down requirements	Bottom-up requirements
1. Linking existing content of compassionate mind training to bottomup challenges to create a tailored intervention	1. Topics to include in the intervention: accepting the illness and limitations, taking care of one’s body, asking for and accepting help, guarding social and physical boundaries, motivating oneself in a positive way, coping with anxiety, and regulating information consumption
2. Main focus on self-compassion training that can be applied to various practical contexts	2. Receiving ample, practical, and localized information about the treatment of and living with cancer
3. Psychoeducation about 3 emotion systems, self-compassion, and self-criticism	3. To-the-point and practical psychoeducation tailored to the context of cancer
4. Reflective exercises about 3emotion systems, self-compassion, and self-criticism	4. Exercises that generate insight into and awareness of emotions and self-talk in the context of cancer
5. Mindfulness exercises, soothing rhythm breathing, and visualization exercises	5. Brief meditative exercises with down-to-earth, nonspiritual language that facilitate rest
6. Having compassion for one’s distress (offering compassionate feedback) and training own capacity to notice and reduce distress	6. Tips and tricks to “get rid of” distress (eg, in automated feedback)
7. Address all key elements of compassionate mind training, adapted from traditional intervention formats	7. Mix between “bite-sized” text, video, images, and audio to convey information (to help with concentration difficulties)
8. Persuasive design elements such as rewards and praise	8. Subtle motivational elements without too much gamification
9. Mood tracking to enhance awareness of emotions and facilitate compassionate responding	9. Mood tracking on multiple scales, having an overview of mood changes over time, and optional feedback
10. Use social support persuasive design elements such as social facilitation	10. Having a private app without direct peer contact while including experiences of peers
11. Pseudonymous rather than anonymous app use to collect research data (ie, creating a user account)	11. Onboarding and log-in process as simple and fast as possible while safeguarding privacy
12. Visual design that aligns with self-compassion training	12. Minimal and soothing visual design
13. Appealing to and reaching a broad range of people in a low-threshold way	13. Appealing to and reaching a broad range of people in a low-threshold way
14. Support of health professionals with(in) the app	14. Stand-alone private app for users, which does not create extra workload for nurses
15. Sequential, modular learning structure	15. Freedom to navigate to any relevant content (including skipping or saving content)

Textbox 2. Overview of implementation of the final list of requirements into the intervention.

Implementation of requirements into the intervention

1. Each main module addresses a main element from compassionate mind training; all such elements are explained in the context of bottom-up topics; submodules address different bottom-up topics
2. The intervention has a main focus on self-compassion training adapted to the context of cancer; an information page contains selected weblinks with practical cancer-related information
3. Psychoeducation about 3 emotion systems, self-compassion, and self-criticism tailored to the context of cancer and contains practical examples
4. Reflective exercises about 3 emotion systems, self-compassion, and self-criticism tailored to the context of cancer.
5. Brief mindfulness, soothing rhythm breathing, and visualization exercises with down-to-earth, practical guidance
6. Automated feedback using compassionate language (eg, recognizing distress, acknowledging that it is part of life) that stimulates self-regulation while also offering suggestions for exercises
7. Mix between images, videos, and audio to convey psychoeducation and exercises; the use of audio is limited to meditative exercises.
8. Subtle use of rewards and praise such as receiving a visual reward upon completing a module (eg, a new part of an incomplete image appears)
9. Mood tracker on 3 scales based on the 3 emotion systems, with an option to receive automated feedback and a graph showing mood progression over time
10. A private app without direct peer contact, with quotes from peers about their experiences related to the module theme
11. Simple onboarding that requires creating an account on registration while staying logged in for subsequent sessions
12. Minimal app design using a monochromatic color scheme
13. Nurses explain the app to people with cancer in their own words, emphasizing parts of the intervention that they expect to align with their needs
14. Stand-alone private app for users without in-app communication or information sharing with nurses, integrated into regular care
15. The app contains 6 modules that can be accessed after 1 week without having completed previous content; functionalities that are freely accessible at any time from the menu bar; option to mark pages as favorite

The Intervention: Compas-Y

The final mobile self-compassion intervention, *Compas-Y*, which resulted from the co-design sessions, comprises 6 sequential training modules and features that are accessible at any time from the home page. The intervention content is based on compassionate mind training, with a few additional elements of positive psychology (eg, functionality *light of the day*) and mindful self-compassion (eg, exercise “How would you treat a friend?”). Diversity, equity, and inclusion design aspects (see the study by Ramos et al [48]) were addressed to some extent, for example, by offering content that is understandable to people with various degrees of exposure to formal education, alternatives to breath-focused exercises, closed captions for videos, and diversity in visual representation. Textbox 3 provides a brief overview of the intervention content, and Multimedia Appendix 2 and Multimedia Appendix 3 [40] provide an extensive overview, including aims and user outcomes, and persuasive design elements, respectively. Each module has a theme (eg, recognizing and regulating emotions or taking care of your body) and includes psychoeducation and exercises aimed at cultivating self-compassion after a cancer diagnosis. Each module contains an optional component in which users can read the experiences (brief quotes) of peers and nurses related to the module theme. Each week, a new module becomes available regardless of the user’s progress. Features that are directly accessible from the app’s home page include a mood tracker, an exercise in which the user recalls a pleasant experience of the day (*light of the day*), a page with favorite exercises, and a practical information page. In both the module exercises and the mood tracker, automated feedback is provided based on user input (eg, “Your drive system is active. Perhaps you are feeling restless and rushed. Sometimes that is just the way it is. To not blow up this feeling, you could activate the soothing system. For example by taking a moment of rest, or by taking three deep breaths.”). Users can track their progress on the home page, where a compass symbol indicates which (components of) modules are completed, as well as which component was last opened. Push notifications are used to stimulate the integration of content into daily life. All content remains available after the intervention period of 6 weeks, and users can continue to use their favorite exercises, receive notifications, and restart the modules. Figure 2 presents screenshots of the *Compas-Y* intervention, and Multimedia Appendix 4 and Multimedia Appendix 5 present a video demonstration and additional screenshots per requirement, respectively.

Textbox 3. Overview of app modules and supportive functionalities with their key components.

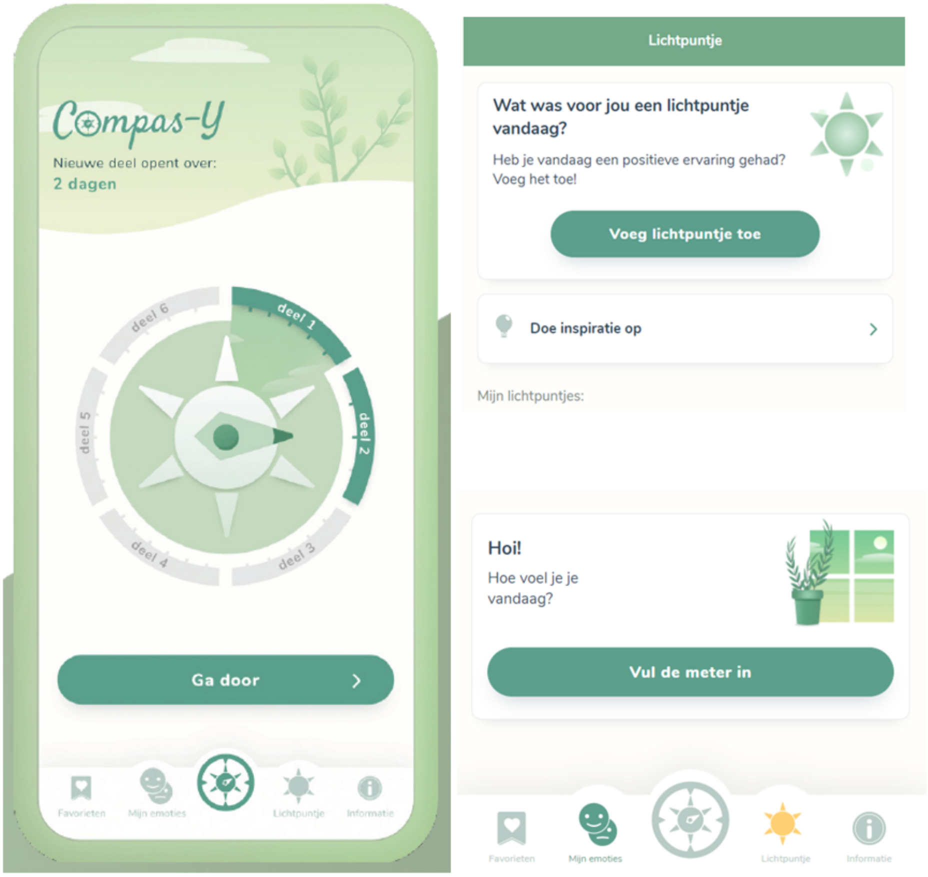
Module topics and key components

1. Introduction to the app and self-compassion
    - Psychoeducation about self-compassion
    - Exercises in mindful awareness and soothing breathing rhythm
    - Exercise in finding (brief) positive experiences throughout the day
2. Emotions in the context of cancer
    - Psychoeducation on 3 emotion systems (soothing, drive, and threat)
    - Soothing breathing rhythm exercise with imagery (soothing)
    - Compassionate information seeking; finding resources based on own needs (drive)
    - Psychoeducation about anxiety; practicing to recognize and allow anxiety (threat)
3. Self-compassion and self-criticism
    - Psychoeducation about self-compassion and self-criticism
    - Imagery exercises about compassionate self and inner critic
    - Soothing breathing rhythm exercise with a compassionate friend
    - Self-compassion; expressive writing exercise
4. Taking care of your body
    - Soothing breathing rhythm–based compassionate body scan
    - Psychoeducation and exercises about the difference between compassionate motivation and self-correction and self-critical motivation or attacking in the context of health and lifestyle behaviors
    - Psychoeducation about compassion for own needs in the context of sexuality and intimacy
5. The people around you
    - Psychoeducation about the 3 flows of compassion
    - Soothing breathing rhythm–based loving-kindness meditation
    - Setting boundaries and asking for help based on compassion for own needs
6. Continuing with resilience
    - Psychoeducation and exercises about positive psychology: gratitude, savoring, and strengths
    - Reflection on self-compassion practice and how to continue
    - Soothing breathing rhythm meditation with a focus on tone of voice and posture

Supportive functionalities

- Overview of modules: visual element central to the home page (compass symbol) that depicts the (availability of) 6 modules and user progress
- Mood tracker: mood tracking (1 question for each emotion system) with automated feedback based on 3 emotion systems
- Favorite exercises: marking exercises as favorite within the modules, which then appear in the user’s personal list of favorites
- Light of the day: exercise where the user inputs a (brief) positive experience of their day, supported by examples
- Practical information: list with weblinks about (living with) cancer, each with descriptions
- Push notifications: daily messages containing quotes and brief exercises, with an option to reduce the frequency or turn notifications off

Figure 2. Screenshots of the Compas-Y intervention. On the left, the home page of the Compas-Y intervention containing a central compass navigation element with 6 modules and a menu bar with supportive functionalities. On the top right, the start of the exercise light of the day; on the bottom right, the start of the mood tracker.



Nieuwe deel opent over:
2 dagen

Wat was voor jou een lichtpuntje vandaag?

Heb je vandaag een positieve ervaring gehad? Voeg het toe!

Mijn lichtpuntjes:

Hoi!

Hoe voel je je vandaag?

Evaluation of the 4 Co-design Tasks and Co-design Process

Evaluation of the 4 Co-design Tasks

Given that we were able to meet most requirements, our co-design experiences indicated that the 4 co-design tasks were successful in enabling the integration of top-down and bottom-up requirements. Throughout the development process, the co-design tasks helped address 2 main challenges. The first was the need to continuously balance integrating top-down content into the co-design exercises without being too leading. The *explore* bottom-up experiences task was helpful in examining any challenge or beneficial experience after diagnosis, as experienced by people with cancer and not only in the context of self-compassion. In contrast, the co-design exercises of the *reassess* top-down content task had the explicit goal of introducing top-down content. Thus, having 4 tasks each with its own function enabled us to give space to both types of requirements without overly prioritizing one or the other.

The second challenge that the co-design tasks helped address was prioritizing and dealing with conflicting top-down and bottom-up requirements (see the study by Austin et al [46] for our decision-making strategies). The tasks to *incorporate* bottom-up and top-down input into concrete features and design and *synergize* bottom-up and top-down input into the intervention context enabled the prioritization of requirements together with participants. This was done with explicit discussions but also by materializing the various requirements (eg, with paper prototypes), which allowed us to make conflicts and priorities tangible. These co-design exercises often quickly clarified which requirements were nonoptional (eg, bottom-up: not adding to the workload of nurses by offering a guided app; top-down: having some extent of a sequential learning structure). Thus, the 4 co-design tasks served as a guiding framework while investigating and merging different top-down and bottom-up requirements.

Evaluation of the Co-design Process

The 7 sessions were consistently positively received by participants, with a median score of 4 (scale of 1-5) for all workshops and evaluation questions. Thus, the sessions were well aligned with the energy levels and personal expertise of the participants and offered them inspiration and learning. Many participants particularly appreciated sharing experiences with each other and collaborating with both nurses and people with cancer to learn from and incorporate different perspectives. One of the participants described the following:

> *[The sessions] showed me how important such an app is, since so many people experience the same things. Yes each in their own way, but in the end quite similar.*

Some participants particularly valued working together in a guided creative process to help future people with cancer, whereas others emphasized personal benefits such as increased acceptance of their illness. One of the participants described the following:

> *Every session was surprising [...] in the beginning I always thought, I have no idea what to put on paper, but at the end of the day we looked back and it was special to see what we came up with.*

In retrospect, participants reported a sense of pride in the final design, and in it, they recognized the implementation of most of their expressed wishes and needs.

Discussion

Outline

This study aimed to explore ways in which top-down and bottom-up requirements can best be integrated into eHealth development by building on the case of the development of a mobile self-compassion intervention for people with newly diagnosed cancer. We discuss (1) the final requirements and the design outcome—*Compas-Y*—both as a testament to the apparent successful integration of bottom-up and top-down requirements and as an example of adapting a traditional intervention to the context of mobile technology and (2) the process of integrating top-down and bottom-up requirements using our 4 co-design tasks. Furthermore, the interdisciplinary aspects of this study, its strengths, and its limitations are addressed.

Final Requirements and Design Outcome: Mobile Self-compassion Intervention

Top-down requirements for the intervention included key components of compassionate mind training (eg, psychoeducation about 3 emotion systems and soothing breathing rhythm exercises) [32] and making use of persuasive design principles such as self-tracking [40]. Bottom-up requirements included addressing common challenges after diagnosis, such as coping with anxiety and regulating information consumption, and tailoring top-down content to the context of cancer by providing applied examples (of peers). Bottom-up requirements related to design and functionality, such as content offered in brief sessions, subtle motivational elements such as progress tracking, and simple navigation and visual design, are in line with other co-design projects of various mobile apps for people with cancer [49-51] and may indicate a common need for a reduced cognitive load when interacting with such apps. Moreover, the final requirements illustrate how we resolved design dilemmas that other eHealth designers may also face, including tunneled versus freely available content [52], offering push notifications without being too intrusive [53], and incorporating automated versus caregiver support [54]. The final design—*Compas-Y*—can be seen as a version of compassionate mind training (top-down input) that is fully adopted for people with cancer (bottom-up input) and also as bottom-up needs that are met with (elements of) compassionate mind training. For example, a bottom-up topic such as *information consumption* (ie, coping with the diagnosis by [excessively] seeking cancer-related information) is integrated with top-down content (eg, acquiring resources [information] as part of our innate drive system), and intervention-specific compassion exercises are offered (eg, observing what emotions are activated when seeking information). Similarly, top-down and bottom-up requirements are implemented at all intervention levels (eg, content, navigation, visual design, and implementation structures).

As there was no existing technology-enabled version of compassionate mind training available, our co-design process also involved adapting a traditional intervention format to a mobile intervention. Similar to most evidence-based psychological interventions, compassionate mind training was originally developed for face-to-face use, using a session-based, didactic training style [55]. However, holding on to this format may not necessarily be fitting or necessary for technology-based interventions and may limit researchers to adopting different means of achieving intervention goals that are unique to mobile- or technology-based interventions [56]. In our adaptation of compassionate mind training, we aimed to make use of the particular characteristics and opportunities of mobile apps (eg, self-tracking and push notifications to facilitate in-the-moment integration of skills; information presented in short texts, videos, audio files, and images; and use of persuasive design strategies and design approaches). Mobile technology not only offers the potential to offer content directed at enhancing users' own compassion but also to assist with the recognition of distress to model a compassionate response. In *Compas-Y*, this was implemented with a mood tracker that offers feedback adapted to the users' score (eg, a supportive message when anxiety is high). Other examples include the use of artificial intelligence to recognize the emotional load of text-based diary inputs [57] and the use of sensor-based technologies to track biomarkers related to emotional arousal [58]. With the further development of novel technologies, such opportunities will become more available and affordable and will likely shape further developments in compassion training.

The Process of Integrating Top-down and Bottom-up Requirements

To achieve the integration of the aforementioned top-down and bottom-up requirements, this study devised and evaluated four co-design tasks: (1) *explore* bottom-up experiences, (2) *reassess* top-down content, (3) *incorporate* bottom-up and top-down input into concrete features and design, and (4) *synergize* bottom-up and top-down input into the intervention context. Overall, the participants evaluated the co-design sessions as valuable and engaging, and the co-design tasks enabled the implementation of all the main requirements into the design. In our co-design study, the 4 tasks enabled us to deal with challenges such as integrating top-down content into the co-design exercises in a balanced way and dealing with conflicting top-down and bottom-up requirements. Dealing with conflicting requirements (and goals, expectations, and power dynamics) is a known challenge in co-design even without introducing top-down requirements [59,60], and working with co-design tasks may offer a helpful way of making divergences explicit. The 4 co-design tasks may be used in the context of established approaches to eHealth development, in which the consideration of theory-based requirements is generally lacking. Indeed, in a recent scoping review of methods used in eHealth development, Kip et al [61] found that very few studies reported on theory-based methods, and the main identified area for improvement for eHealth development models was to add explicit goals and activities aimed at the integration of evidence-based approaches. This study could guide this development, for example, by incorporating a *theoretical framework* as a development phase in existing models and using the 4 co-design tasks to synchronize this with development phases related to bottom-up requirements (eg, the *contextual inquiry* phase in the Centre for eHealth Research Roadmap [29]). Of note, the co-design tasks are likely to need adjustment and re-evaluation in light of the particular characteristics of other co-design projects, for example, when the modality of a design is undefined (eg, offline book or smartphone app) or when external experts rather than researchers represent top-down input during co-design sessions.

Interestingly, the focus on either top-down or bottom-up development of eHealth interventions largely represents differences in the scientific disciplines from which these approaches originate. In behavioral science, developing interventions based on theory and evidence is important not only for developing effective interventions but also for further developing and testing their underlying theories and mechanisms [28]. For example, in intervention mapping, theory-based intervention methods and strategies are selected to meet predefined intervention objectives [27]. By contrast, in design research, developing interventions based on creativity methods without too many predefined objectives is important to allow for innovation and charting of unknown territories. As both approaches have their merit, Schmidt [62] proposed a hybrid interdisciplinary model in which behavioral science can supply evidence-based approaches and design research can offer speculative hypotheses and innovative solutions. Indeed, in our interdisciplinary co-design study, we attempted to bridge both fields by integrating theory-driven (top-down) and contextual (bottom-up) knowledge, as well as by using methodologies from both fields. This resulted in iterative cycles of design and evaluation using (low-fidelity) prototypes while also creating a “final” version of the intervention that could be evaluated in a pre-post hypothesis testing design. Thus, although the underlying principles and quality requirements of these fields may clash at times, we concur that using both generative and analytical approaches offers complementary value in the development of eHealth interventions.

Strengths and Limitations

This study was strengthened by an extensive co-design development process of 2 years. This allowed for an in-depth exploration of both bottom-up and top-down requirements, as well as thorough field testing and evaluation of co-design tasks. The final intervention is not only a testament to the apparent successful integration of both bottom-up and top-down requirements but also to the adaptation of a traditional intervention to the context of mobile technology. However, this study was limited in several ways. First, the 4 co-design tasks are based only on a single co-design study, and their utility in other contexts remains unclear. A series of co-design studies might have resulted in a different set of tasks based on the challenges that arise across co-design settings. In addition, this study was shaped by predefined objectives based on acquired funding, such as having a working smartphone app after 2 years. Although this limits shifting the agenda to other potential solutions that may arise [63], such objectives can also be seen as a type of top-down requirement (similar to financial constraints) that simply becomes part of the development process. Finally, although this paper focuses on potentially divergent top-down and bottom-up requirements, it does not suggest that there are no divergent requirements *within* top-down (eg, conflicting evidence) or bottom-up (eg, different needs among participants) input (for further discussion of this issue, see the study by Austin et al [46]).

Conclusions

In the design of eHealth interventions to support people with cancer, an emphasis on evidence-based research needs to be met by taking lived experiences into consideration, and co-design may be used to do so. However, here, the question is, where in the co-design process do the theory and evidence come in? We devised and evaluated 4 co-design tasks to enable the integration of theory and evidence (top-down) requirements with the needs, wishes, and experiences of users and stakeholders (bottom-up). Executed within a series of group-based co-design sessions, the participants evaluated the co-design process as valuable and rewarding. We conclude that the 4 tasks form a helpful preliminary model for integrated top-down–bottom-up eHealth development by making both types of requirements explicit and brought into a shared design conversation. However, the utility of this approach in other co-design contexts (eg, with different financial constraints, design modalities, or project teams) remains unclear. The 4 co-design tasks yielded a final list of requirements, encompassing, for example, the need for tailored, bite-sized, and engaging psychoeducational content on coping with emotions after a cancer diagnosis. The resulting design—*Compas-Y*—is a compassionate mind training app comprising 6 training modules and several supportive functionalities and persuasive elements. This intervention serves as an applied example of how top-down and bottom-up requirements may be integrated into a design, as well as of the adaptation of a traditional intervention format to mobile delivery. Overall, these design and process outcomes serve to further inform technology-enabled compassion training in general and top-down and bottom-up eHealth development in particular, in the context of people with cancer and beyond.

Acknowledgments

We would like to sincerely thank all people with cancer and oncology nurses for openly sharing their experiences and co-designing with us and for future patients. We offer our thanks to DTT Amsterdam for collaborating with us on programming the application. We would also like to extend our gratitude to all of the experts on our project team, and to students Ruben Schouten and Sofie van den Berg for assisting us with some of the co-design sessions. Finally, we would like to thank The Dutch Cancer Society for funding this work.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Evaluation questionnaire for the co-design sessions.
[PDF File (Adobe PDF File), 106 KB - cancer_v8i3e37502_app1.pdf]

Multimedia Appendix 2
Comprehensive overview of app modules, aims, user outcomes, key components, and exercises.
[PDF File (Adobe PDF File), 68 KB - cancer_v8i3e37502_app2.pdf]

Multimedia Appendix 3
Overview of persuasive design principles incorporated in the intervention Compas-Y.
[PDF File (Adobe PDF File), 81 KB - cancer_v8i3e37502_app3.pdf]

Multimedia Appendix 4
Video demonstration of the intervention Compas-Y.
[MP4 File (MP4 Video), 2130 KB - cancer_v8i3e37502_app4.mp4]

Multimedia Appendix 5
Screenshots of the intervention Compas-Y for each final requirement.
[PDF File (Adobe PDF File), 629 KB - cancer_v8i3e37502_app5.pdf]

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Edited by A Mavragani; submitted 25.02.22; peer-reviewed by R Adler, J Drott; comments to author 10.04.22; revised version received 09.05.22; accepted 24.05.22; published 01.08.22.

Please cite as:
Austin J, Drossaert CHC, van Dijk J, Sanderman R, Børøsund E, Mirkovic J, Schotanus-Dijkstra M, Peeters NJ, Van 't Klooster JWJR, Schroevers MJ, Bohlmeijer ET
Integrating Top-down and Bottom-up Requirements in eHealth Development: The Case of a Mobile Self-compassion Intervention for People With Newly Diagnosed Cancer
JMIR Cancer 2022;8(3):e37502
URL: https://cancer.jmir.org/2022/3/e37502
doi:10.2196/37502
PMID:35916691

Original Paper

Knowledge Acquisition and Social Support in Online Health Communities: Analysis of an Online Ovarian Cancer Community

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Abstract

Background: Patients and caregivers widely use online health communities (OHCs) to acquire knowledge from peers. Questions posed in OHCs reflect participants' learning objectives and differ in their level of cognitive complexity. However, little is known about the topics and levels of participants' learning objectives and the corresponding support they receive from members of OHCs.

Objective: This study aimed to investigate the knowledge acquisition of patients and caregivers in an OHC. Specifically, we investigated the distribution and topics of posts with learning objectives at different cognitive complexity levels, the type and amount of social support provided to meet users' learning objectives at different cognitive complexity levels, and the influence of social support on the change in learning objectives.

Methods: We collected 10 years of discussion threads from one of the most active ovarian cancer (OvCa) OHCs. A mixed methods approach was used, including qualitative content analysis and quantitative statistical analysis. Initial posts with questions were manually classified into 1 of the 3 learning objectives with increasing cognitive complexity levels, from low to high, based on the Anderson and Krathwohl taxonomy: *understand*, *analyze*, and *evaluate*. Manual content analysis and automatic classification models were used to identify the types of social support in the comments, including emotional support and 5 types of informational support: *advice*, *referral*, *act*, *personal experience*, and *opinion*.

Results: The original data set contained 909 initial posts and 14,816 comments, and the final data set for the analysis contained 560 posts with questions and 3998 comments. Our results showed that patients with OvCa and their caregivers mainly used OHCs to acquire knowledge for low- to medium-level learning objectives. Of the questions, 82.3% (461/560) were either *understand*- or *analyze*-level questions, in which users were seeking to learn basic facts and medical concepts or draw connections among different situations and conditions. Only 17.7% (99/560) of the questions were at the *evaluate* level, in which users asked other OHC members to help them make decisions or judgments. Notably, OvCa treatment was the most popular topic of interest among all the questions, regardless of the level of learning objectives. Regarding the social support received for different levels of learning objectives, significant differences were found in the *advice* ($F_{2437.84}$=9.69; P<.001), *opinion* ($F_{2418.18}$=11.56; P<.001), and *emotional support* ($F_{2395.88}$=3.24; P=.01), as determined by one-way ANOVA, whereby questions at the *evaluate* level were more likely to receive *advice*, *opinion*, and *emotional support* than questions at the lower levels. Additionally, receiving social support tends to drive users to increase the cognitive complexity of the learning objective in the next post.

Conclusions: Our study establishes that OHCs are promising resources for acquiring knowledge of OvCa. Our findings have implications for designing better OHCs that serve the growing OvCa community.

(JMIR Cancer 2022;8(3):e39643) doi:10.2196/39643

KEYWORDS

online health community; ovarian cancer; health information needs; social support; knowledge acquisition

Introduction

Background

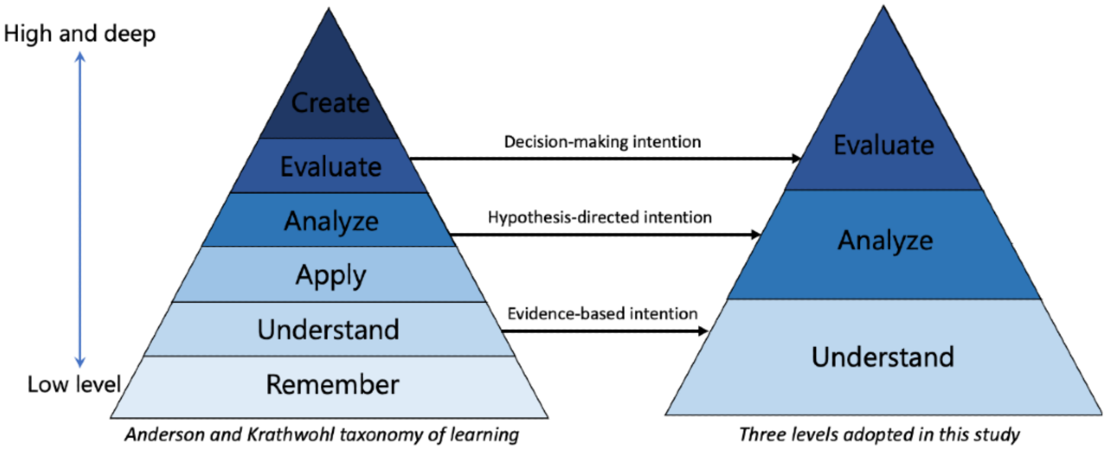
Online health communities (OHCs), also known as online support groups, are 1 of the 3 primary channels for health consumers seeking health information on the web in addition to search engines and health professionals [1]. Numerous studies have provided substantial evidence that patients benefit from OHC participation [2-5]. OHCs facilitate information exchange and knowledge acquisition among users. For people with cancer and their caregivers, who have a constant and evolving need for information, OHCs are particularly important for around-the-clock availability, immediate and asynchronous communication, and anonymity [6,7].

Users ask questions on OHCs for knowledge acquisition. Questions posed by patients to acquire knowledge to meet their learning objectives vary in cognitive complexity. The cognitive complexity of learning objectives describes the cognitive skills and abilities the learner desires to achieve. For example, a question seeking advice on treatment decisions from peers (eg, surgery vs biological therapies) is cognitively more complex than one looking for facts in medical directions (eg, how many times a day is a pill to be taken). To identify the cognitive complexity level of learning objectives in OHC users' questions, this study borrowed the Anderson and Krathwohl taxonomy of learning (A&K taxonomy) [8] from educational psychology. This taxonomy was first proposed by Bloom in 1956 [9] and later revised by Anderson and Krathwohl [8]. As shown in Figure 1, the A&K taxonomy defines 6 levels of learning objectives with increasing cognitive complexity. From low to high (ie, cognitively simple to complex), the 6 levels are *remember*, *understand*, *apply*, *analyze*, *evaluate*, and *create*. The theory assumes that to achieve a higher level of learning objectives, one must master the lower levels.

This study chose 3 levels, *understand*, *analyze*, and *evaluate*, rather than adopting all 6 levels because they are close to real web-based health information–seeking scenarios. As found in the analysis by Cartright et al [10], of queries from web search engines, there are 2 representative web-based health information–seeking intentions: evidence based and hypothesis directed. With the evidence-based intention, one mainly focuses on locating information regarding signs and symptoms, which can be mapped to the *understand* level of learning. The hypothesis-directed intention, which drives individuals to draw connections and discriminate among different uncertain situations and conditions, aligns with the *analyze* level. Finally, the *evaluate* level corresponds to the decision-making intention, which involves seeking information to make a treatment decision.

Reciprocity is another substantial benefit of OHCs [11,12]. Knowledge building and collaborative knowledge production take place through discourse among members of OHCs [13]. Peer users of the community, who usually face the same health condition and endure a similar experience, can provide social support by replying to the initial questions and follow-up discourse [3,14]. We focus on the 2 most frequently exchanged types of social support in OHCs: informational support (ie, offers information, such as the course of the condition, treatment, finance, and insurance) and emotional support (ie, expresses emotions such as caring and concern) [5,6,15].

Figure 1. Adapted from the Anderson and Krathwohl taxonomy of learning [8].



Objectives

Because OHCs are a promising learning resource for patients and caregivers, an in-depth study of users' learning objectives and the corresponding support they receive is needed. First, it must be examined whether patients and caregivers use OHCs to achieve cognitively complex or simple learning objectives. Topics and health conditions discussed in OHCs may affect the patients' learning objectives. Savolainen [16] found that >70% of the questions in OHCs for depression sought an opinion or evaluation of an issue, resembling a high-level learning objective, whereas contrasting results were found in an OHC for alcoholism, where approximately 50% of the posts looked for factual information that serves low-level learning objectives [17]. However, there is scarce literature regarding the learning objectives of users of OHCs for cancers. To deal with the numerous physical and psychosocial consequences of survival, patients with cancer and their caregivers have been using OHCs to address various cancer-related information needs and gain knowledge about cancer [18-20]. An examination of the learning objectives of people with cancer will add to the empirical knowledge on how OHCs facilitate knowledge acquisition for patients with different health conditions.

Second, it is unclear whether all levels of learning objectives are well supported in OHCs. Higher levels of learning objectives (eg, *evaluate*) are more difficult to achieve than lower levels of learning objectives (eg, *understand*) and require support from skilled and knowledgeable peers [17,21]. In this study, we examined the type and amount of support for different levels of learning objectives by measuring the corresponding social support qualitatively and quantitatively.

Third, we are interested in investigating how users' learning objectives change during their participation in an OHC. Moreover, if one's learning objective is well supported by peers in the OHC, will this drive them to modify their learning objective to ask a more cognitively complex question in the OHC? The answers to these questions will shed light on the effectiveness of OHCs and the designing of OHCs as web-based learning resources.

Therefore, this paper seeks to answer the following research questions (RQs):

- RQ1: What are the distributions and topics of posts at different levels of learning objectives?
- RQ2: What type and amount of social support are provided to posts at different levels of learning objectives?
- RQ3: How do users' learning objectives change during their participation in an OHC? Is the change in the learning objectives of users associated with the type and amount of social support received?

To answer these RQs, we collected 10 years of discussion threads from an OHC for patients with ovarian cancer (OvCa) and caregivers. Because OvCa is a rare cancer [22], health information seeking on the internet can be particularly challenging because of information scarcity and limited public awareness. In addition, OvCa is the deadliest cancer among women [22]. The 5-year relative survival rate of patients with OvCa from 2011 to 2017 in the United States was 49.1% [23]. For individuals with OvCa and their families, managing this cancer can be stressful because of intensive treatments and high rates of disease progression [24]. Owing to limitations in early detection, OvCa is often diagnosed at late stages when the likelihood of cure is low. In the United States, it is the most common cause of death due to gynecological malignancies [25]. People with OvCa use OHCs to address their OvCa-specific, treatment-related, and coping-related information needs [19]. However, owing to a lack of disease awareness, 69% of the patients with OvCa had not heard of or knew nothing about OvCa before their diagnosis, thus making the knowledge acquisition and learning process extremely difficult [26]. Furthermore, studies of people living with OvCa are relatively limited, although people with OvCa need a lot of support. There is a dearth of research investigating what information individuals with OvCa who use OHCs wish to acquire and what support they receive. The findings of this study also contribute to the knowledge on how to better support the OvCa community.

Methods

Research Setting: National Ovarian Cancer Coalition CancerConnect Community

We collected data from CancerConnect, an OHC for patients with OvCa, managed by the National Ovarian Cancer Coalition (NOCC). NOCC is a nonprofit OvCa advocacy organization that has devoted itself to educating and supporting patients with OvCa, survivors, and caregivers since its inception in 1991. The NOCC CancerConnect Community is one of the most active OvCa OHCs [27]. It is a peer-supported OHC with the goal of providing an open-access platform that encourages and enhances interpersonal learning via informational and emotional peer interactions. To this end, NOCC allows registered users to participate and contribute to the community in several ways, such as initiating and replying to posts, searching and reading posts and comments, creating profiles, joining groups, and sending and receiving private messages.

Ethical Considerations

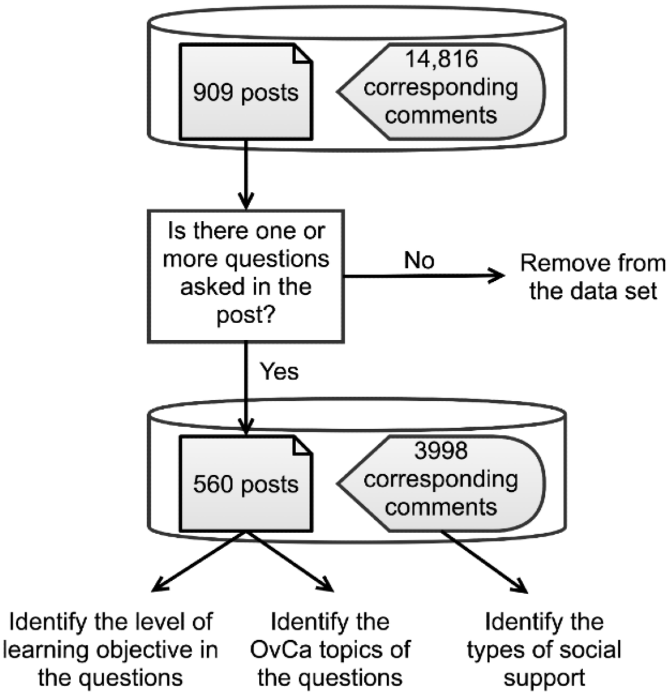
This study was reviewed and approved by the Institutional Research Board of University of Pittsburgh (STUDY20040102). In addition, permission was obtained from NOCC to conduct this study.

Data Analysis

Our NOCC data set contained 909 OvCa discussion threads posted between June 2010 and December 2020. Each thread was made of 1 initial post and corresponding comments if any. In total, there were 909 initial posts and 14,816 comments.

Figure 2 illustrates the overall data analysis process. We first performed manual annotations on the 909 initial posts to determine whether there was a question articulated in the post. As a result, 560 posts and their 3998 comments were retained for further analysis. The posts without any questions mainly consisted of sharing personal updates, sharing resources, provoking discussions, and providing inspiration. The posts were then coded in terms of the level of the learning objective and OvCa-related topics. For the 3998 comments on the initial posts, we first performed manual annotation on 500 randomly chosen comments to identify the types of social support. Automatic classification models were then trained and applied to predict different types of social support in the remaining comments.

Figure 2. Data analysis process. OvCa: ovarian cancer.



Identifying the Level of Learning Objective

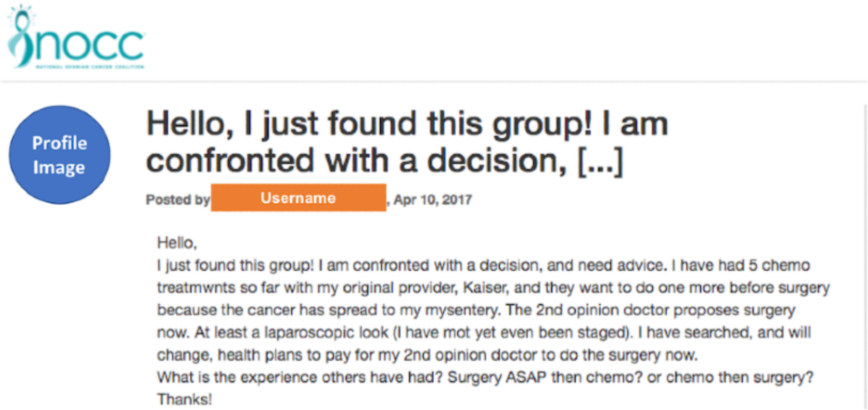
As mentioned earlier, we borrowed 3 levels from the A&K taxonomy of learning [8] to identify the level of learning objectives in the users' questions. The descriptions of each level of the learning objective and the deidentified example questions are displayed in Table 1. To achieve higher levels in the A&K taxonomy, one must master the lower levels in the hierarchy. Therefore, the 3 levels of learning objectives were coded mutually exclusively. For example, Figure 3 shows a post with the *evaluate* level of learning objective, as the poster described her situation and sought decision-related information from peers. The real username and user profile image are removed for privacy.

Two coders (YC and KT) applied the coding framework to 100 sample posts to determine the level of the learning objective that best describes the cognitive complexity of the questions. Substantial agreement was achieved between the 2 coders on the 100 sample posts (percentage agreement=0.79; Cohen κ=0.72), indicating an acceptable level of agreement [28,29]. The 2 coders then met to discuss any disagreements. Throughout the discussion, all disagreements were addressed, and no changes were made to the codebook. A coder annotated the remaining posts by using the codebook.

Table 1. Coding framework of learning objective in the initial post.

Learning objective	Description	Example question
Understand	Pursuit of facts, concepts, and ideas by describing, explaining, identifying, detailing, interpreting, summarizing, and so on	"Hi does anyone have information on AMG 386? Thank You"
Analyze	Pursuit of connections and relationships among multiple concepts by differentiating, comparing, distinguishing, contrasting, sorting, and so on	"I recently developed small red dots all over my legs, look like little blood marks. I'm on Avastin and wonder if anyone has experienced these marks on their body?"
Evaluate	Pursuit of decision or judgment given specific conditions by appraising, arguing, judging, selecting, critiquing, weighing, recommending, assessing, predicting, and so on	"Hi Sisters, I finished front line 12/8, and ca has be tested 3 times since. The last one showed 2 point increase and Dr wasn't concerned as said basically save number 28 to 30. This was 1/22. Today it has went up .8. Any reason to be concerned since trend is upward? I'm concerned of this continuing and I'm already full of worry."

Figure 3. An example of an evaluate-level question.



Hello, I just found this group! I am confronted with a decision, [...]

Posted by Username, Apr 10, 2017

Hello,
I just found this group! I am confronted with a decision, and need advice. I have had 5 chemo treatmwnts so far with my original provider, Kaiser, and they want to do one more before surgery because the cancer has spread to my mysentery. The 2nd opinion doctor proposes surgery now. At least a laparoscopic look (I have mot yet even been staged). I have searched, and will change, health plans to pay for my 2nd opinion doctor to do the surgery now.
What is the experience others have had? Surgery ASAP then chemo? or chemo then surgery?
Thanks!

Identifying the OvCa Topics of Questions

To better understand OvCa users' information needs at different levels of learning objectives, the topics of the questions in the initial posts were annotated through content analysis. The coding framework was inductively developed by a nurse practitioner by immersing herself in the posts. A coding framework with 13 topics was established initially.

Using this framework, the 2 coders individually annotated all the posts. Questions in each post included 1 or multiple topics. Later, topics that appeared in <10 posts were further grouped into *Others*. Consequently, 9 codes were used to classify the topics of information needs in the initial posts (Table 2). An acceptable interrater agreement was obtained between the 2 coders, with an average percentage agreement of 0.94 and Cohen κ coefficient of 0.72, ranging from 0.62 to 0.81 across 9 categories [28,29]. The 2 coders discussed and resolved all disagreements and reached an agreement in all cases.

Table 2. Coding framework of topics of questions.

Topic	Description	Code
Disease management	Information needs related to ovarian cancer disease management, such as diagnosis, prognosis, finding gynecologic oncologist, preparing for visit, advance care planning or advance directives, borderline malignant tumors, prophylactic surgery, secondary prevention, monitoring for recurrence, management of recurrence, and supportive care or palliative care	DM[a]
Symptom management	Information needs related to ovarian cancer symptom management, such as fatigue, sleep, bowel, pain, neuropathy, cognitive memory, nausea, vomiting, bloating, ascites, appetite, appearance, shortness of breath, lymphedema, urinary, early menopause, ostomy management, rash, anemia, mouth sore, and myelosuppression	SM[b]
Treatment	Information needs related to ovarian cancer treatment, such as medications, surgery, radiation, chemotherapy, biological therapies, and clinical trials	TM[c]
Treatment decision	Information needs related to ovarian cancer decision-making, such as how to make treatment decisions	TD[d]
Emotional management	Information needs related to emotional management, such as anxiety, depression, fear of recurrence, mood swings, coping, grief, and loss	EM[e]
Self-management	Information needs related to self-management, such as nutrition, spiritual support, physical activity, and relationship with loved ones	SF[f]
Practical needs	Information needs related to practical needs, such as finance, insurance, employment, legal, and community resources	PN[g]
Caregiving	Information needs related to caregivers' needs, such as stress, caregiver coping, grief, and loss	CG[h]
Others	Other ovarian cancer–related information needs, such as communication, sexuality, rehabilitation, complementary therapy and integrative medicine, ovarian cancer organization, and facilities	OT[i]

[a] DM: disease management.

[b] SM: symptom management.

[c] TM: treatment.

[d] TD: treatment decision.

[e] EM: emotional management.

[f] SF: self-management.

[g] PN: practical needs.

[h] CG: caregiving.

[i] OT: others.

Identifying the Types of Social Support

The 2 most common types of social support exchanged in OHC are informational and emotional support [5,6]. In this study, as the aim was to investigate what information users receive as answers to their questions, the informational support provided in the comment was further classified by using the framework proposed by Chuang and Yang [17]. Chuang and Yang [17] identified five types of informational support:

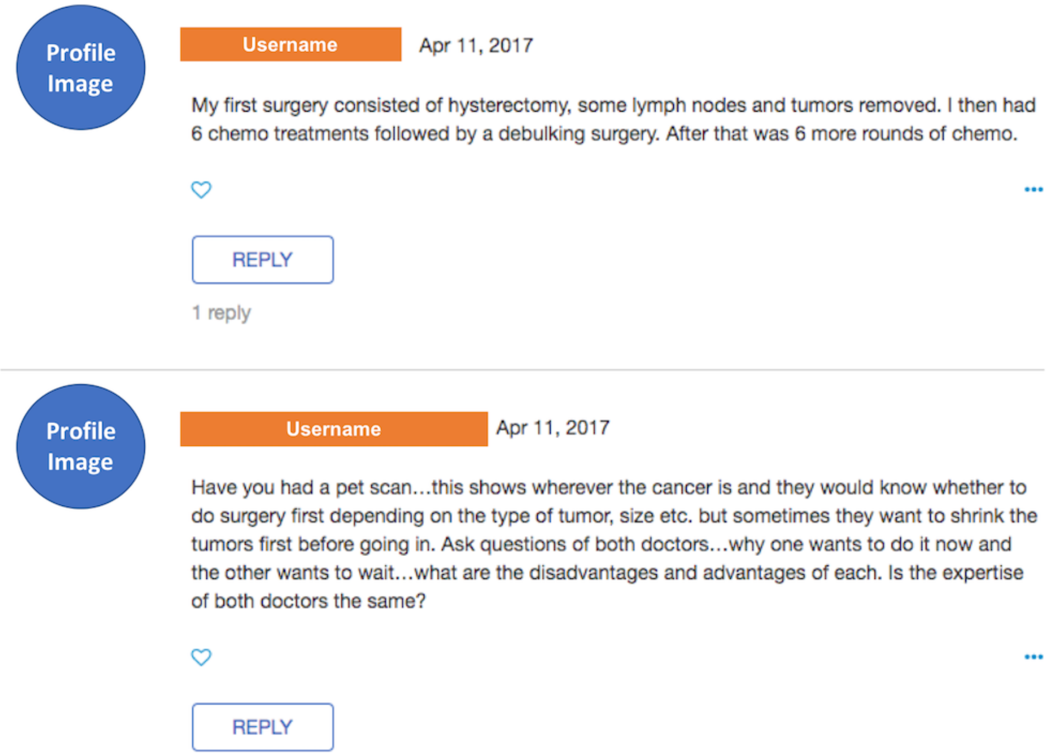
1. Advice: the comment offers ideas, suggestions, and actions to cope with challenges.
2. Referral: the comment refers to information sources such as books, websites, and contacts.
3. Fact: the comment offers facts or reassesses the situation.
4. Personal experience: the comment shares personal stories or incidents.
5. Opinion: the comment offers a view or judgment about something. However, this is not necessarily based on facts or knowledge.

In addition, emotional support was marked if a comment provided empathy, encouragement, or appreciation [12].

All 6 types of social support, including emotional support and 5 types of informational support, were coded in a binary fashion, and a comment could provide 0, 1, or multiple types of support. If no informational or emotional support could be identified, the comment was coded as "Others." For example, Figure 4 displays 2 comment examples that replied to posts shown in Figure 3. The first comment was coded as "1" for providing a *fact* and "0" for all other types of informational and emotional support. The second comment was coded as "1" for providing a *fact* and an *advice* and "0" for all others.

The social support types provided in the 3998 comments were identified in 3 steps. First, 2 coders coded 150 sample comments to ensure the reliability of the coding framework. On average, an agreement rate with percentage agreement of 0.94 and Cohen κ of 0.84 were achieved, indicating an almost perfect agreement [28,29]. Second, after addressing all disagreements, a coder coded 350 more comments. As a result, a data set of 500 comments was obtained, in which each comment contained a comment text and corresponding support labels. Third, as it would be impractical to annotate all 3998 comments, the decision was made to build machine learning–based classifiers by using the already annotated comments. In total, 6 machine classifiers were built for each support type. A pretrained Bidirectional Encoder Representations from Transformers (BERT) language model [30] was fine-tuned for each classification task. BERT was used because it obtained good classification accuracy with less data on different downstream text classification tasks, such as sentiment and emotion classification [30]. The data set was split into 3 folds with a 70:10:20 ratio for training, validation, and testing, respectively. The accuracy reported in Table 3 is based on the testing fold. The interrater agreement between the 2 coders and performance of the classification models are presented in Table 3. The code for the model and access to our model are listed on GitHub [31]. Finally, the models were applied to predict the social support types for the remaining comments.

Figure 4. Examples of comments.



My first surgery consisted of hysterectomy, some lymph nodes and tumors removed. I then had 6 chemo treatments followed by a debulking surgery. After that was 6 more rounds of chemo.

Have you had a pet scan…this shows wherever the cancer is and they would know whether to do surgery first depending on the type of tumor, size etc. but sometimes they want to shrink the tumors first before going in. Ask questions of both doctors…why one wants to do it now and the other wants to wait…what are the disadvantages and advantages of each. Is the expertise of both doctors the same?

Table 3. Interrater agreement between human annotators and classification score for social support types in the comments.

Support type	Interrater agreement		Support type prediction		
	Percentage agreement	Cohen κ	Precision	Recall	*F*-score
Advice	0.96	0.88	0.77	0.85	0.81
Referral	0.98	0.94	0.82	1.00	0.90
Fact	0.93	0.86	0.82	0.77	0.79
Personal experience	0.90	0.80	0.95	0.87	0.91
Opinion	0.93	0.79	0.81	0.81	0.81
Emotional support	0.91	0.82	0.91	0.74	0.82
Others	0.95	0.76	N/A[a]	N/A	N/A
Average	0.94	0.84	0.85	0.84	0.84

[a] N/A: not applicable.

Results

Overview

Of 909 initial posts, 560 (61.6%) were associated with learning objectives, as indicated by the questions asked in the posts. The following results were based on the analysis of the 560 initial posts with identified learning objectives and 3642 comments that provided at least one type of support.

Learning Objectives in the Initial Posts (RQ1)

Distribution of Users' Learning Objectives in the Initial Posts

Among the 560 posts with questions, the *analyze* objective was the most common, accounting for almost half of the total (257/560, 45.9%). Following this, 36.4% (204/560) of the posts with questions sought *understand*-level knowledge, whereas *evaluate*, the most complex learning objective, only accounted for 17.7% (99/560) of the question-asking posts. This result suggests that people with OvCa mainly use the NOCC community to look for simple knowledge, such as facts, concepts, or relationships between facts and concepts, rather than complex knowledge relating to treatment decisions and judgments.

Number of Topics

In most of the initial posts, users tended to seek information and knowledge about 1 (363/560, 64.8%) or 2 (176/560, 31.4%) topics per post. There were only 21 posts in which users consulted their peers on >2 OvCa topics (21/560, 3.8%).

The initial posts were grouped according to the 3 levels of learning objectives; the average number of topics in each group is presented in Table 4. A one-way between-subject ANOVA was performed on the number of topics in 1 post as a function of the level of learning objective. With violation of the assumption of homogeneity of variance, an *F*-test with Brown-Forsythe adjustment was conducted. The results suggested a statistically significant difference in the number of topics among the different levels of learning objectives ($F_{2193.364}$=72.54; *P*<.001). A Games-Howell post hoc test revealed that there were significantly more topics in the posts asking for an *evaluate*-level learning question (N=1.83; *P*<.001) than in posts with the *analyze*-level learning objective (N=1.50; *P*<.001). The posts seeking *understand*-level knowledge consisted of the least number of topics compared with the 2 higher levels (N=1.05; *P*<.001). The difference in the number of topics may indicate that people with OvCa tend to acquire information across multiple topics to obtain *evaluate*-level knowledge. By contrast, for lower-level learning objectives, their information needs were more likely to focus on 1 specific topic.

Table 4. Number of topics per post at each level of learning objective.

Learning objective	Topics per post, mean (SD)	Posts, n (%)
Understand	1.05 (0.24)	204 (36.4)
Analyze	1.50 (0.54)	257 (45.9)
Evaluate	1.83 (0.73)	99 (17.7)
Total	1.40 (0.57)	560 (100)

Category of Topics

Using the coding framework in Table 2, the questions in the initial posts were classified into 9 categories based on OvCa-related topics. In this section, 2 results for the topic categories are presented. First, topics were grouped by different levels of learning objectives to show what OvCa-related knowledge patients and caregivers wanted to acquire. Then, for posts with >1 topic, the frequencies of all topic pairs were examined to further demonstrate what topics tended to be inquired about together.

Figure 5 shows the distribution of the 9 OvCa-related topics at each level of learning objective. Each bar represents the posts of 1 of the 3 levels of learning objectives, whereas segments in the bar denote the portion of a topic among all posts with the same level of learning objective. Segments of the same color were comparable.

It is evident that *treatment* is the most popular topic of interest in all knowledge acquisition posts, with a higher proportion in the *analyze* level (175/385, 45.4%) than in the other 2 levels of learning objectives. This result indicated that comparing or differentiating treatment information was a common need among people with OvCa in OHCs. In addition, pursuing treatment information to understand or evaluate was frequent, which might be because the treatment information of OvCa was complex and scattered, making the topic of treatment the dominant information needed across all the learning objectives. *Analyzing symptom management* is the second most prevalent information needed, whereas understanding and evaluating symptom management information is not that popular. The results suggest that for symptom management, patients and caregivers struggle more with the differentiation or connection among different symptoms than with learning about basic symptoms or making judgments.

On the contrary, *disease management* was more associated with the *understand* and *evaluate* levels of learning objectives than the *analyze* level, implying that people with OvCa needed support for interpreting disease information such as diagnosis, prognosis, and recurrence on both a basic fact or concept level and a higher judgment or decision level. It is notable that *treatment decisions* accounted for a significant portion (30/181, 16.6%) of the *evaluate* level. However, it is questionable whether users should use OHC as a resource for making treatment-related decisions. *Emotional management* and *practical needs* presented similar patterns: the proportions of *understand* and *evaluate* questions were higher than *that of analyze* questions. Caregiving information accounted for a much greater share of *understand* questions than the other two. Finally, the ratios of the other topics were similar for all 3 levels of learning objectives.

Chi-square results revealed a significant association between the levels of learning objectives and the topics of *disease management* (χ^2_2=17.2; *P*<.001), *symptom management* (χ^2_2=40.2; *P*<.001), *treatment* (χ^2_2=38.6; *P*<.001), *treatment decision* (χ^2_2=85.8; *P*<.001), and *emotional management* (χ^2_2=7.7; *P*=.02). However, no significant association was found between the learning objective levels and topics of *self-management* (χ^2_2=0.0; *P*=.99), *practical needs* (χ^2_2=0.3; *P*=.19), *caregiving* (χ^2_2=0.4; *P*=.09), and others (χ^2_2=0.6; *P*=.71).

Figure 6 shows the proportions of different topic pairs among the 245 topic pairs extracted from questions with >1 topic. Notably, treatment and symptom management were most likely to appear together in a single post (72/245, 29.4%). In addition, patients with OvCa and their caregivers tended to learn about treatment along with disease management or treatment decisions.

Figure 5. Distribution of ovarian cancer topics at each learning objective level. A: analyze; CG: caregiving; DM: disease management; E: evaluate; EM: emotional management; OT: others; PN: practical needs; SF: self-management; SM: symptom management; TD: treatment decision; TM: treatment; U: understand.

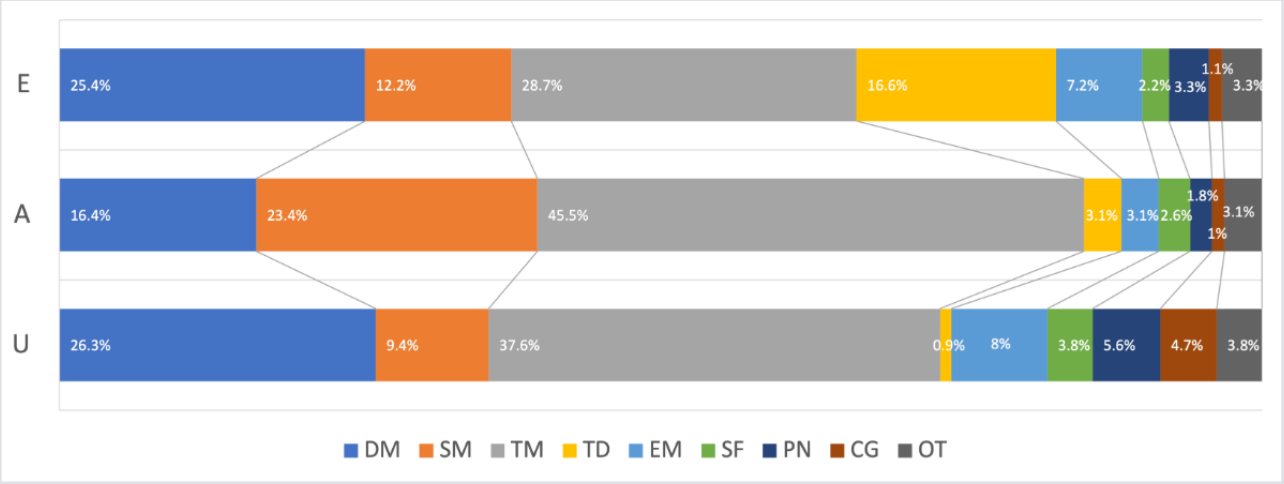
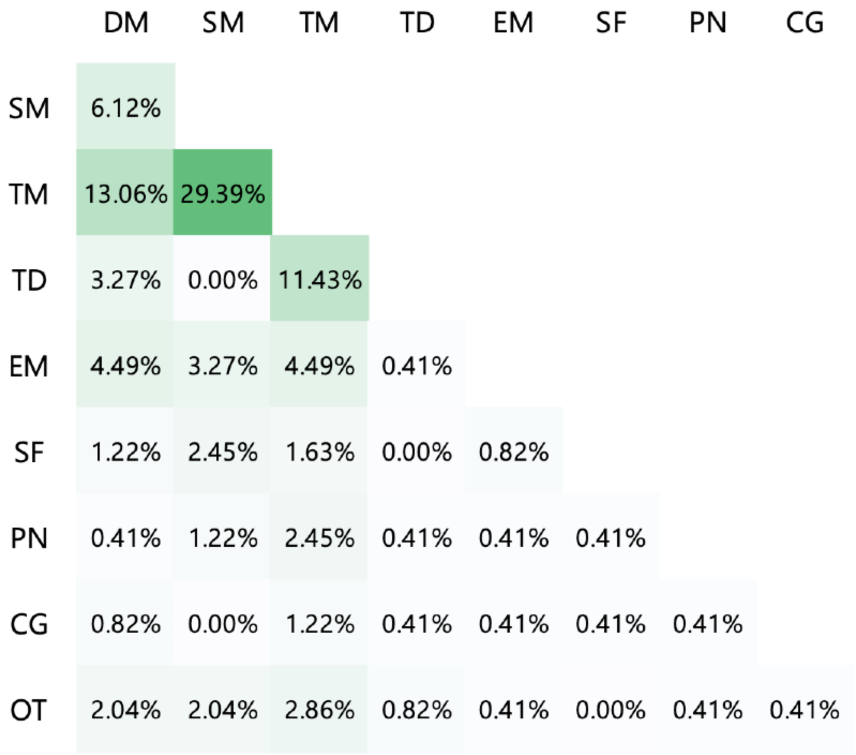


Figure 6. Co-occurrence of topic pairs in 1 post (darker color indicates larger proportions). CG: caregiving; DM: disease management; EM: emotional management; OT: others; PN: practical needs; SF: self-management; SM: symptom management; TD: treatment decision; TM: treatment.



	DM	SM	TM	TD	EM	SF	PN	CG
SM	6.12%							
TM	13.06%	29.39%						
TD	3.27%	0.00%	11.43%					
EM	4.49%	3.27%	4.49%	0.41%				
SF	1.22%	2.45%	1.63%	0.00%	0.82%			
PN	0.41%	1.22%	2.45%	0.41%	0.41%	0.41%		
CG	0.82%	0.00%	1.22%	0.41%	0.41%	0.41%	0.41%	
OT	2.04%	2.04%	2.86%	0.82%	0.41%	0.00%	0.41%	0.41%

Social Support in the Comments (RQ2)

Number of Replies to Posts at Different Levels of Learning Objectives

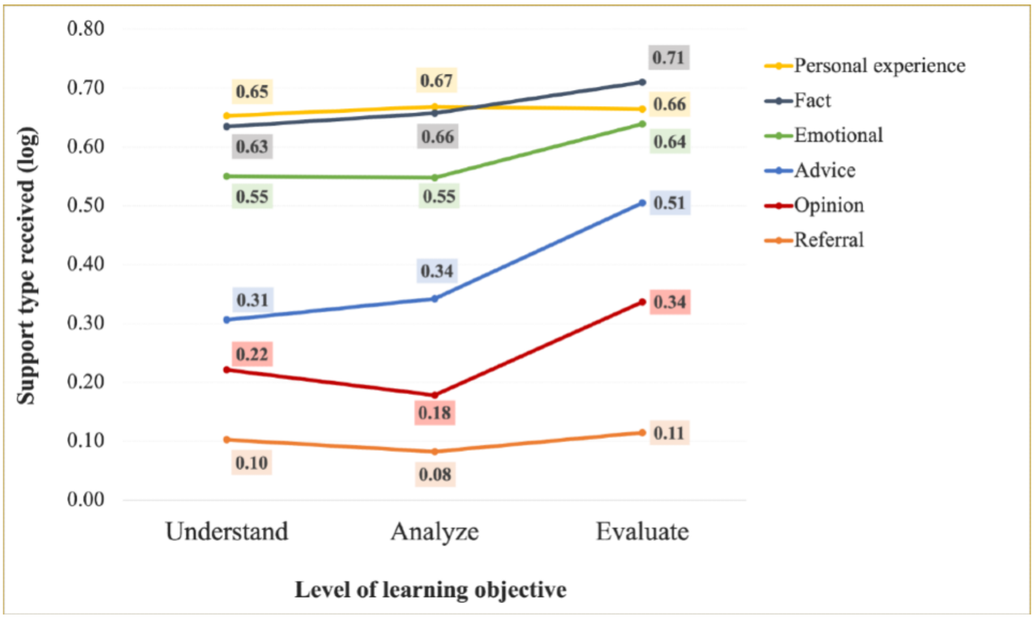
The 3642 comments providing support were grouped based on the learning objective in the post. Posts with the *understand* level were likely to receive the largest average number of comments from peers (N=7.68), followed by the *evaluate* (N=7.07) and *analyze* (N=5.63) levels. However, the results of the one-way ANOVA suggested no statistically significant difference between the average number of comments among the 3 levels of learning objectives ($F_{2451.295}$=2.712; *P*=.07).

Social Support Provided for Posts at Different Levels of Learning Objectives

The types and amount of social support provided by the repliers in each comment were aggregated by posts. Figure 7 shows the number of different types of support received in each post belonging to each learning objective. Log transformation is applied to the total number of each type of comment and plotted in the line chart. In general, the largest number of supportive replies was provided to posts with the evaluate-level learning objective, followed by the *understand* level, and it was the least for the *analyze*-level learning objective.

As determined by one-way ANOVA, significant differences among the 3 levels of learning objectives were found in *advice* ($F_{2437.84}$=9.69; *P*<.001), *opinion* ($F_{2418.18}$=11.56; *P*<.001), and *emotional support* ($F_{2395.88}$=3.24; *P*=.01) levels. A Games-Howell post hoc test revealed that posts seeking *analyze*-level knowledge received significantly less *opinion* support compared with *understand*-level (*P*=.002) and *evaluate*-level posts (*P*<.001). The amount of *advice* support at the *evaluate* level was significantly higher than that at the *analyze* (*P*<.001) and *understand* (*P*=.001) levels. For *emotionalsupport*, a significant result was found only between *analyze* and *evaluate* (*P*=.02) levels.

Figure 7. Type and amount of social support provided for questions at each learning objective level.



Influence of Social Support on Change in the Learning Objective (RQ3)

Overview

Because some users posted >1 posts with learning objectives in NOCC, this allowed the researcher to unveil how the learning objectives of the same user change over time. In total, 344 distinct users posted 560 posts with learning objectives. Most users (244/344, 70.9%) posted only 1 post, and 29.1% (100/344) of users posted multiple posts. Among the 100 users who posted >1 posts with learning objectives, 60, 17, 9, and 14 posted 2, 3, 4, and >5 posts, respectively, with learning objectives. These 100 users were further examined to uncover changes in their learning objectives in the NOCC and the influence of social support on the change.

The change in the learning objective is defined as the transition between the level of the learning objective in post P_i and post P_{i+1} for the same user U. The change in learning objectives was classified into 3 categories based on the transition from post P_i to P_{i+1}: knowledge increase, knowledge decrease, and no change. For example, if a user posted 3 initial posts (ie, P_1, P_2, and P_3) in the NOCC forum and the level of learning objective in them are P_1—*understand*, P_2—*analyze*, and P_3—*analyze*, then the change in learning objective from P_1 to P_2 is knowledge increase, and the change from P_2 to P_3 is no change. In total, 216 changes in learning objectives were identified from the 100 users who contributed multiple posts in the NOCC forum.

Change of Learning Objectives of the Same User

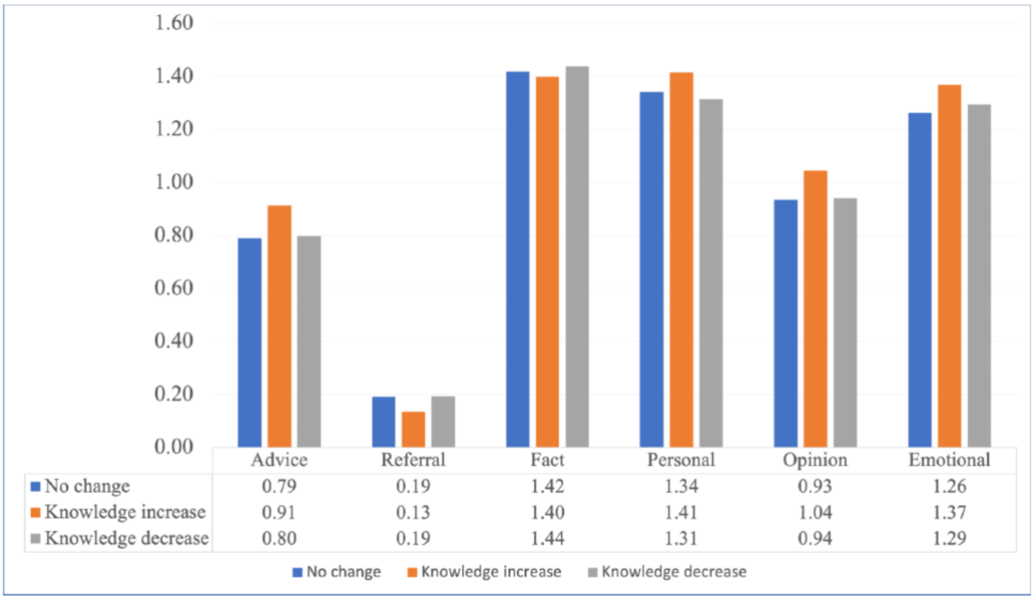
In general, 41.7% (90/216) of the pairs of 2 consecutive posts sought information on the same level of learning objectives, which resulted in *no change*. *Knowledge increase*, in which the learning objective in the subsequent post was higher than the previous one, was the second most frequent (70/216, 32.4%). The least frequent type of change was *knowledge decrease* (56/216, 25.9%). It can be inferred that NOCC users were more likely to increase or remain at the same level of learning objectives as they continued posting, asking questions, and acquiring knowledge in the same forum.

We also examined the specific types of transitions from different levels of learning objectives (eg, from *understand* to *understand*). This helped reveal how the current level of learning objective affected the subsequent post's learning objective. First, from *analyze* to *analyze* (A→A: 57/216, 26.4%) was the most common transition. The amount and ratio are also higher than those from *analyze* to *understand* (A→U: 22/216, 10.2%) and *analyze* to *evaluate* (A→E: 24/216, 11.2%), suggesting that *analyze*-level questions were likely to be followed by another *analyze*-level question than the increase or decrease in levels of learning objectives of the same user. Second, after asking an *understand*-level question, users tended to increase the level of learning objective and ask an *analyze*-level question (U→A: 36/216, 16.7%). This possibility is higher than asking another *understand*-level question (U→U: 27/216, 12.5%) or *evaluate*-level question (U→E: 10/216, 4.6%). This might be attributed to the fact that the *understand*-level learning objective was relatively easy to achieve, or the users' OvCa-related knowledge might evolve and increase over time, driving them to pursue a higher level of learning. Third, *evaluate*-level posts were mainly followed by *analyze*-level posts (E→A: 22/216, 10.2%) or *understand*-level posts (E→U: 12/216, 5.6%). Only rarely would users ask another *evaluate*-level question (E→E: 6/216, 2.8%). In addition, users were more likely to increase the learning objective by 1 level (ie, U→A: A→E) or decrease it by 1 level (ie, E→A: A→U) in 2 consecutive posts than to increase or decrease it by 2 levels (ie, U→E: E→U), indicating that the change in learning objectives was a gradually evolving process.

Social Support Received and Change of Learning Objective

Figure 8 shows how the type and amount of social support received for the current post influenced users' learning objectives in the next post. On average, for most types of social support, when users received more support, including *advice*, *personal experience*, *opinion*, and *emotional support*, they were more likely to increase their learning objective in the next post, rather than decrease or maintain the same level of learning objective. No statistically significant differences were found between the 3 types of changes.

Figure 8. Amount and type of social support received and change in the learning objective level.



Discussion

Overview

This study investigated knowledge acquisition by people with OvCa in an OHC. We borrowed three levels of learning objectives from the A&K taxonomy: *understand*, *analyze*, and *evaluate*. The results revealed (1) the distributions and topics of posts at different learning objective levels, (2) the type and amount of corresponding social support at each level, and (3) the influence of social support on changes in learning objectives. The principal findings, contributions, implications, and limitations of this study are discussed in the following sections.

Principal Findings

Our results showed that NOCC was mainly used by patients with OvCa and their caregivers to address information needs with low- to middle-level learning objectives. Of the questions, 82.3% (461/560) were either at the *understand* or *analyze* levels of cognitive complexity, in which the user initiates a post to pursue basic facts and concepts or connections and relationships among multiple concepts. Notably, only 17.7% (99/560) of the posts with questions were associated with an *evaluate*-level learning objective, in which the users asked other OHC members to help them make decisions or judgments based on their specific conditions. These results are partially different from the findings in [16], where >70% of the posted questions in the web-based discussion forums sought an opinion or evaluation of an issue, resembling an *evaluate*- or *analyze*-level question, whereas the need for factual and procedural information was less common. These conflicting results could be attributed to the different health conditions studied. In in the study by Savolainen [16], the topic of interest in the threads was depression, whereas in this study, it was OvCa, which is listed as a type of rare cancer by the National Institutes of Health [1]. Therefore, the general public lacks disease awareness and education regarding OvCa, and the information is complex and scattered. This might cause OHC users to seek basic facts and concepts at the *understand* level more often. In addition, the prevalence of *analyze*-level questions could be explained by the fact that OvCa is a complex disease. Because the diagnosis, staging, and treatment are complex, patients and caregivers have to learn and sort out which information applies to them and which does not. For example, on average, women with OvCa under treatment need to manage 12 concurrent symptoms [32].

Regarding OvCa-related topics, treatment is the most popular topic of interest among all the information needs, regardless of the level of learning objectives. This finding is in accordance with the results in the study by Madathil et al [19], in which treatment-related information was found to be the most sought-after information by patients (41.3%) compared with OvCa-specific and coping information. Data analyses were conducted at the Ovarian Cancer National Alliance, another OHC for OvCa. We identified 9 different topics by using our fine-grained topic classification framework, and the posts were classified in a nonmutually exclusive manner. Treatment was still found to be the most popular topic. This finding further underlines the high demand for treatment-related information and support among people with OvCa. It is also noteworthy that treatment decision accounted for a large share at the *evaluate* level despite the concern that an OHC might not be an appropriate resource to ask for treatment-related decisions. Such findings add to the demand for research efforts to assess the quality of treatment-related decisions shared by peers in OHCs.

In addition, we examined the type and amount of informational support in the comments, providing a means to study the quantity and quality of information that OHC users can acquire at different levels of knowledge acquisition. In general, users in the NOCC group received the largest number of comments for *understand*-level learning objective (N=7.68), followed by evaluate-level (N=7.07) and *analyze*-level (N=5.63) learning objectives. However, the number of comments itself was not enough to reflect the quality and quantity of social support in the OHC because a comment could provide 0, 1, or multiple types of social support; therefore, we classified the types of social support in the comment, especially informational support.

Descriptive results indicated that, in general, the total amount of social support of all types was the largest for evaluate-level learning, followed by *understand*-level learning, and it was the least for *analyze*-level learning. For each type of social support, *fact* was acquired the most compared with other types of support. This result is consistent with the results in the study by Chuang et al [17], which were based on a manual analysis of an alcoholism OHC. Regarding the effect of the learning objective, the results suggest that more *advice*, *opinions*, and *emotional support* were obtained for questions seeking *evaluate*-level learning. A possible explanation for this finding is that some subjective knowledge, to a certain extent, was needed to support people with OvCa's information needs of evaluate-level learning. As justified by the interviewees in the study by Harkin et al [2], practical advice shared by peers in OHCs was welcomed by many interviewees, as such information led them on a "journey to become informed." It is also notable that although the questions with the *analyze*-level learning objective were the most frequently posted in the OHC, they received the smallest number of average comments and the least amount of almost all types of social support in the comments. Measures beyond the number of comments and support are required to explore this finding in the future.

Finally, we examined multiple posts from the same user, and the results demonstrated that OvCa users' learning objectives changed during OHC use. This change was reflected by the transition from the current post's learning objective to the subsequent post's learning objective. Most of the users who posted >1 post with a learning objective in the NOCC tended to increase their learning objective (70/216, 32.4%) or remained at the same level of learning objective (90/216, 41.7%), as they continued posting and seeking information in the same forum. Furthermore, for users who increased their learning objective in the next post, a larger amount of support in *advice*, *personal experience*, *opinion*, and *emotional support* was observed in the current post (Figure 8). In other words, receiving more social support might drive the users to acquire higher-level knowledge in the same OHC. Although the result was not statistically significant, this finding adds to previous studies that have demonstrated the effect of social support on member retention and engagement [5,6,33] and contributes new evidence on the potential effects of social support on collaborative knowledge building and generation in web-based communities [13]. In-depth future research promises to investigate the relationship between receiving social support, especially informational support, and knowledge acquisition in OHCs.

Contributions and Implications

As one of the first studies to investigate users' knowledge acquisition in the context of OHCs, this study presents several contributions and implications to OHCs and the population of the OvCa community.

Implications for OHC

First, although there is an extensive body of literature investigating OHCs, and it has been proven that patients and their caregivers would use OHCs to post questions and acquire knowledge [12,15,17], little has been done to differentiate knowledge acquisition with different levels of learning objectives and the associated social support provided by peers in OHCs. Our study contributes empirical evidence and demonstrates that user interactions in OHCs can be described and studied from a knowledge acquisition perspective. Not all information needs regarding the underlying cognitive complexity of the learning objectives are identical. Our study also demonstrated that OHC is a promising resource for users to address information needs with different cognitive complexities and that OHCs can help users to improve knowledge if their information needs are well supported with informational and emotional support from peers.

Correspondingly, OHCs ought to recognize the cognitive complexity of the user's information needs and the underlying learning objective. Importantly, the quality and quantity of social support from peers are critical for users to address their information needs and seek higher-level knowledge. Enhancing patients' learning objectives is important because pursuing cognitively more complex learning objectives implies higher patient activation—informed and activated patients who actively engage in health care and decision-making. Higher patient activation is associated with better health-related outcomes [34,35]. Given the result that certain types of support were associated with an increase in learning objectives, algorithms or human moderators in OHCs are expected to match the level of learning objectives in the original post with the appropriate types of social support from active peers.

With their social features, OHCs amplify the benefits of a wealth of information as well as the negative emotions shared by peers. In addition, there are concerns about the quality of the narratives shared by patients in OHCs [36,37]. False information and rumors can cause false expectations [2]. To deal with the downside of OHCs, it is suggested that the content be carefully administered by moderators with professional backgrounds. Attention should be devoted to information-seeking posts with high cognitively complex learning objectives such as pursuing judgments and decisions from peers. In addition, some high-quality learning materials can be developed and disseminated via OHCs, as they have been proven to be an active informal learning platform.

Implications for OvCa Community

People with OvCa have exhibited constant and dynamic information needs, which changes based on the disease trajectory. Concurrently, their knowledge of the disease evolves gradually over the course of the disease trajectory. Most patients with OvCa have little to no knowledge of OvCa before their diagnosis due to a lack of disease awareness [26]. As the trajectory proceeds, they obtain information and gain knowledge through diverse sources, including OHCs [38]. However, the knowledge acquisition process could be extremely difficult because of the lack of OvCa-related knowledge, poor quality of some information available on the web, and inherent characteristics of OvCa [39]. The high prevalence of questions associated with low- to middle-level learning objectives found in this study further confirmed the public's lack of awareness of OvCa and the community's lack of disease knowledge.

By contrast, the findings highlighted the benefits of OHC in supporting the OvCa community. Patients with OvCa and caregivers address their assorted information needs in OHC and exchange information and emotional support in the community. In addition, the results based on the classification of OvCa-related topics provide insights into the information needs of people with OvCa, such as the high demand for treatment-related information and support. As there are multiple treatment options for OvCa, a more personalized search system will be beneficial for providing adjusted and dynamic treatment support. The findings provide implications for future health care providers, practitioners, researchers, and developers to design personalized health information systems that will enhance knowledge acquisition and satisfy the unmet needs of people with OvCa.

Methodological and Theoretical Implications

In addition to the empirical and practical implications of this study, there are several theoretical and methodological implications. First, this study adopted a mixed methods approach, which allowed us to examine both the quality and quantity of the OvCa community's knowledge acquisition in OHCs. Second, several coding frameworks originated from this study, such as the coding framework for OvCa-related topics and the coding framework for learning objectives. These frameworks can provide future researchers with an approach to unveil the complicated information requirements of the OvCa community.

Limitations and Future Directions

Regardless of its strengths, this study has several limitations. First, this study was conducted on the NOCC. Although it is a popular OHC for people with OvCa, the results of this study might be biased toward the site used to collect the data. Second, the measurement of users' learning objectives in this study was limited by the scope of the A&K taxonomy. Only 3 representative cognitive learning levels were selected. Such a design is based on the rationale explained in the Methods section, but we acknowledge that users' learning and knowledge evolution was oversimplified. Knowledge acquisition is confined to research settings. Little is known about how much the participants learned via other information sources beyond information seeking and support within the OHC. In the future, a complementary obtrusive approach, such as a questionnaire, would help measure patients' knowledge acquisition more comprehensively. Third, this study only captures OvCa-related topics based on the information needs of patients and caregivers. Other types of supportive care needs, such as interpersonal or intimacy and daily living needs, were not included in the analysis [40]. Finally, this study did not distinguish patients with OvCa according to their disease trajectory, given the scarce data in the NOCC. However, the literature suggests that the information needs of people with OvCa change with the disease trajectory [41,42]. It would be interesting to investigate whether there is a significant effect of disease trajectory on learning objectives and support in OHC. The answer to this question may help researchers and clinicians design interventions that better support patients with OvCa along their disease trajectory.

Conclusions

This work is one of the first to investigate users' participation in OHCs from a knowledge acquisition perspective through the analysis of a well-known OHC for OvCa. The results demonstrate that users use OHCs to address information needs with different levels of learning objectives, and simultaneously, they can acquire various types of information and emotional support in the comments from peers. Receiving support drives users to pursue higher levels of learning objectives. These findings contribute to improving OHC designs to support the OvCa community.

Acknowledgments

This study was supported by awards from the National Library of Medicine of the National Institutes of Health (R01-LM013038). The content is the sole responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. The authors would like to thank the National Ovarian Cancer Coalition for the approval of this project.

Conflicts of Interest

None declared.

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Abbreviations

A&K taxonomy: Anderson and Krathwohl taxonomy of learning
BERT: Bidirectional Encoder Representations from Transformers
NOCC: National Ovarian Cancer Coalition
OHC: online health community
OvCa: ovarian cancer
RQ: research question

Edited by A Mavragani; submitted 16.05.22; peer-reviewed by K Xing, R Pozzar; comments to author 20.06.22; revised version received 08.07.22; accepted 10.07.22; published 13.09.22.

Please cite as:
Chi Y, Thaker K, He D, Hui V, Donovan H, Brusilovsky P, Lee YJ
Knowledge Acquisition and Social Support in Online Health Communities: Analysis of an Online Ovarian Cancer Community
JMIR Cancer 2022;8(3):e39643
URL: https://cancer.jmir.org/2022/3/e39643
doi:10.2196/39643
PMID:36099015

Original Paper

Impact of a Personal Health Record Intervention Upon Surveillance Among Colorectal Cancer Survivors: Feasibility Study

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Abstract

Background: There are currently an estimated 1.5 million individuals living in the United States with colorectal cancer (CRC), and although the 5-year survival rate has increased, survivors are at risk for recurrence, particularly within the first 2-3 years after treatment. National guidelines recommend continued surveillance after resection to identify recurrence early on. Adherence among survivors ranges from 23% to 94%. Novel interventions are needed to increase CRC survivors' knowledge and confidence in managing their cancer and thus to increase adherence to follow-up surveillance.

Objective: The objective of this study is to develop and test the feasibility and efficacy of a stand-alone, web-based personal health record (PHR) to increase surveillance adherence among CRC survivors, with patient beliefs about surveillance as secondary outcomes.

Methods: A pre- and postintervention feasibility trial was conducted testing the efficacy of the colorectal cancer survivor (CRCS)–PHR, which had been previously developed using an iterative, user-centered design approach.

Results: The average age of the sample was 58 (SD 9.9) years, with 57% (16/28) male and the majority married (20/28, 71%) and employed full-time (15/28, 54%). We observed a significant increase in adherence to colonoscopy (before: 11/21, 52% vs after: 18/21, 86%; *P*=.005) and CEA (14/21, 67% vs 20/21, 95%; *P*=.01), as well as a slight increase in CT scans (14/21, 67% vs 18/21, 86%; *P*=.10). The only significant impact on secondary outcome (patient beliefs) was benefits of CEA test (*P*=.04), as most of the beliefs were high at baseline.

Conclusions: This feasibility study lays the groundwork for continued development of the CRCS-PHR to increase CRC surveillance. Patient-centered technologies, such as the CRCS-PHR, represent an important potential approach to improving the receipt of guideline-concordant care and follow-up surveillance, and not just for CRC survivors. Researchers should continue to develop patient-centered health technologies with clinician implementation in mind to increase patient self-efficacy and surveillance adherence.

(JMIR Cancer 2022;8(3):e34851) doi:10.2196/34851

KEYWORDS

personal health record; colorectal cancer survivors; surveillance; health record; survivor; cancer; oncology; colorectal; United States; North America; feasibility; web-based; patient belief; patient attitude; survival

Introduction

There are an estimated 1.5 million individuals living in the United States with colorectal cancer (CRC), and an estimated 150,000 new cases will be diagnosed during 2021 [1]. While the 5-year survival rate has increased to 65%, survivors are still at risk for cancer recurrence with >40% developing recurrent disease within 5 years, and 80% of recurrences happening within the first 2-3 years after treatment. National professional guidelines recommend follow-up or surveillance tests such as colonoscopy, carcinoembryonic antigen (CEA), and computed tomography (CT) scans at specific intervals after treatment [2-4]. Survivor adherence to recommended surveillance is often poor and ranges between 23% and 94% [5-11]. Novel interventions to increase guideline-concordant surveillance, thus, are needed to improve the quality of care and outcomes among cancer survivors. In the United States, national incentives for offering access to electronic personal health records (PHRs) have promoted patient engagement through information technology [12-17]. Patient-centered health-information technologies are potentially valuable tools for survivorship care planning to increase knowledge about surveillance tests, self-efficacy, and ultimately adherence to guideline-concordant surveillance [16-21].

Web-based technologies have the capacity to reach large numbers of patients efficiently. PHR use has expanded over time [22-25], with functions developed for individuals with various chronic diseases and across the lifespan [17,26-29]. These functions may vary widely depending on the context of PHR implementation. While there exists a variety of PHRs, there are three primary categories of PHRs, which are as follows: (1) stand-alone PHRs, which do not directly connect with any other electronic systems or networks; (2) tethered PHRs, often referred to as patient portals or web-based portals, which connect with the web-based network and electronic medical record of a specific institution; and (3) integrated PHRs, which are able to connect to multiple data networks and institutions [17,19,21]. While these different types of PHR categories describe general trends, there is a fair amount of overlap in terms of functionalities. PHRs have the potential to engage patients with cancer and cancer survivors to play a more active role in their surveillance care and to increase self-efficacy and knowledge about surveillance [16-21]. Providing patients access to their own health information, management strategies, web-based resources, and communication tools with providers can increase self-management and the quality of patient-provider communication, which lead to better patient outcomes [16,17,19,21]. However, PHRs tailored to the needs of cancer survivors have not been widely developed or tested for certain cancer site populations, including CRC. Among patients with cancer, PHRs have been mainly developed that target patients with breast and lung cancer as well as breast and lung cancer survivors [30,31]. Technology-based interventions have been limited in targeting CRC survivors who are at substantial risk for recurrent disease within the first couple of years after treatment and may benefit from the use of technology-based interventions. Given these issues, there is a considerable need for the development of technology-based interventions, such as PHRs, targeted toward patients with CRC, particularly to increase adherence to the recommended surveillance [16,17,19,21].

The purpose of this pilot trial was to test the feasibility and evaluate the effectiveness of a stand-alone PHR in increasing surveillance testing (colonoscopy, CEA, and CT scan) among CRC survivors. Moreover, the study assessed the impact of the PHR upon the secondary outcomes of patient self-efficacy, knowledge regarding surveillance, and CRC patients' perceptions of benefits and barriers to surveillance testing. The Colorectal Cancer Survivor (CRCS)–PHR was designed using open-source software to increase guideline-concordant CRC surveillance by delivering patients reminders and tracking tools regarding surveillance tests for which they were eligible. This work has the potential to benefit both researchers focused on developing technology-based interventions for patients, particularly cancer survivors, as well as clinicians who are working toward increasing adherence to guidelines.

Methods

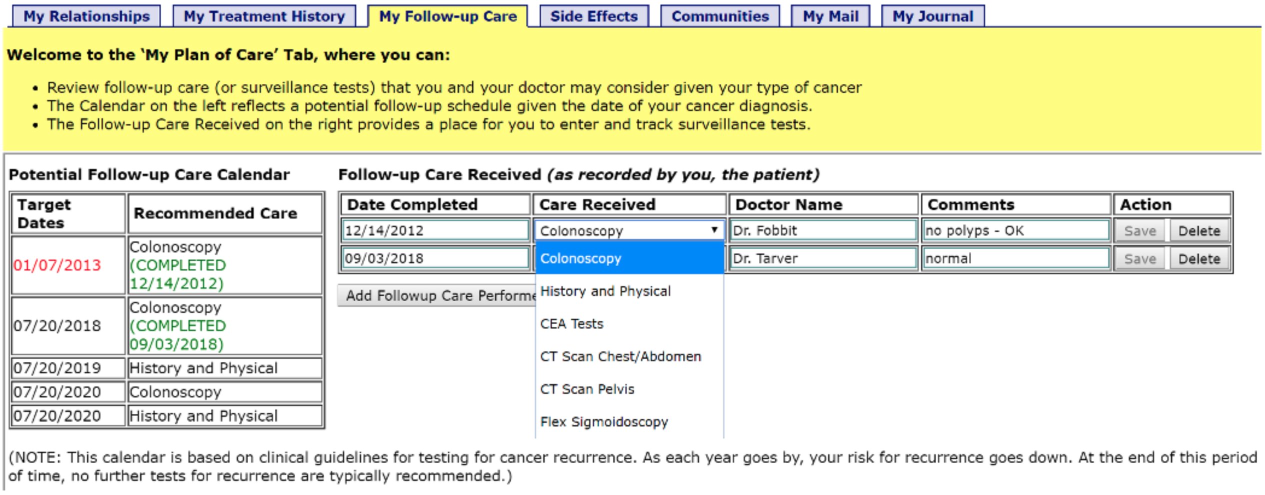
Colorectal Cancer Survivors' Personal Health Record

We developed the CRCS-PHR as a stand-alone, web-based tool for patient convenience, portability, and dissemination potential. An iterative, user-centered design approach was followed during development, including the creation of clinical content, program design, and web design usability testing. The design process began with the creation of content and technical parameters, culminating in a web-based interactive prototype. Product development included the application of established usability methods [32]. Stakeholders (consisting of patients, caregivers, and health care providers) were asked to participate in scenario-based evaluations with direct observation and debriefing interviews to gather data on user performance and preferences as described elsewhere [33]. Changes were not made in the web-based design until data from at least 4-6 stakeholders had been collected; consistent with previous work by Nielsen et al [34], a total of 17 stakeholders participated in data collection.

The CRCS-PHR includes the following clinical information: CRC surveillance guidelines, treatment received (surgery; adjuvant therapy; and lab, radiology, and procedure results), and potential future toxicities of the treatment received. The CRCS-PHR also had the ability to collect personal observations from the CRC survivor in an electronic journal or blog, relationships with providers and family members or friends, and communities with other CRC survivors.

Surveillance guidelines included information about guideline-concordant surveillance care, including bowel surveillance (colonoscopy), CEA tests, and CT scans [2], with reminders for individual surveillance tests based on individuals' needs. Recommendations for surveillance care were adapted from the guidelines of professional organizations [2]. Information about CRC surveillance guidelines were automatically tailored to the CRC survivor's disease stage (eg, CEA testing was not to be recommended for patients with stage I CRC). In the CRC-PHR, 2 tables related to surveillance care were delivered to the patient (Figure 1). First, a table was generated, which indicated what surveillance tests were appropriate for the patient and by what dates the tests should be performed. This informational table was designed to increase patient knowledge about surveillance and its benefits, as well as to prompt CRC survivors to seek the receipt of surveillance tests [35]. Second, a table was created wherein patients could self-enter information about the surveillance test received (date completed, type of test, and a brief description of results). This interactive table was designed both to enable the tracking of completed tests and to promote patient self-efficacy; interactivity is widely believed to enhance user involvement, commitment, and learning [36].

Figure 1. Screenshot of personal health record, “My Follow-up Care” Dashboard. CEA: carcinoembryonic antigen; CT: computed tomography.



Welcome to the ‘My Plan of Care’ Tab, where you can:

- Review follow-up care (or surveillance tests) that you and your doctor may consider given your type of cancer
- The Calendar on the left reflects a potential follow-up schedule given the date of your cancer diagnosis.
- The Follow-up Care Received on the right provides a place for you to enter and track surveillance tests.

Potential Follow-up Care Calendar

Target Dates	Recommended Care
01/07/2013	Colonoscopy (COMPLETED 12/14/2012)
07/20/2018	Colonoscopy (COMPLETED 09/03/2018)
07/20/2019	History and Physical
07/20/2020	Colonoscopy
07/20/2020	History and Physical

Follow-up Care Received *(as recorded by you, the patient)*

Date Completed	Care Received	Doctor Name	Comments	Action
12/14/2012	Colonoscopy ▾	Dr. Fobbit	no polyps - OK	Save Delete
09/03/2018	Colonoscopy	Dr. Tarver	normal	Save Delete

(NOTE: This calendar is based on clinical guidelines for testing for cancer recurrence. As each year goes by, your risk for recurrence goes down. At the end of this period of time, no further tests for recurrence are typically recommended.)

A 30-minute training session was developed to introduce patients to the content and functionality of the CRCS-PHR and was conducted in person by the research assistant at the time of recruitment. In addition, virtual training tools were embedded in the CRCS-PHR, including a 5-minute narrated training video and a detailed help section describing the purpose of all links, data-entry forms, and features of the tool.

Study Design

A pre- and posttest intervention trial was conducted to test the feasibility and to determine the ability of the targeted PHR intervention to increase patient knowledge, self-efficacy, beliefs, and receipt of surveillance tests among CRC survivors. Participants were recruited between March and October 2012, with the postintervention follow-up survey occurring 6 months after the baseline survey.

Sample and Recruitment

Patients with CRC were eligible to participate if they had received curative-intent therapy and had been diagnosed with American Joint Committee on Cancer Stage I-III adenocarcinoma at least 9 months (but no more than 24 months) earlier. Participants were excluded from the study if they had metastatic disease. We approached CRC survivors for recruitment at an academic medical center and the Veterans Affairs (VA) hospital in Indianapolis. At the academic medical center, patients were seen in surgery clinics led by CRC surgeons.

Data Collection and Measures

Data were collected via patient self-report. Self-reported data are a valid, widely accepted source about clinical service use due to cost and time efficiency, particularly for early-phase studies such as this feasibility study, as well as large-scale epidemiologic studies [37-40]. Presurvey measurements were collected by a research assistant at baseline immediately after the patient was provided with access to the CRCS-PHR. Postsurvey measurement was then collected 6 months after initial enrollment over the telephone, with a written survey being mailed beforehand to patients in order to facilitate answering the questions. In addition to the measures discussed below, participants were asked how they used the PHR and what features they found to be most and least useful after the intervention.

Measurements

Patient and Clinical Characteristics

Patient sociodemographic characteristics were collected during the baseline survey. Clinical characteristics regarding anatomic cancer site (colon or rectum), stage, and treatment (surgery, radiation treatment, and chemotherapy) were collected via medical record audit at the time of enrollment.

Patient-Centered Behavior Outcomes

Patient-centered behavior outcomes were all collected during the pre- and postintervention surveys. These outcomes included self-efficacy, perceived benefits of surveillance testing, barriers to adherence of surveillance testing, and knowledge of CRC surveillance testing. For self-efficacy, the General Self-Efficacy (GSE) scale was used, which consists of 10 items using a 4-point Likert scale (Multimedia Appendix 1) [41]. The GSE scale measures general self-efficacy and has been translated into more than 30 languages. The GSE scale had a Cronbach alpha of .86 in the current sample. For perceived benefits of CRC surveillance testing, a 5-item Likert scale was used, with the last 3 items each including a question dedicated to each of the 3 surveillance tests (colonoscopy, CEA test, and CT scan). For barriers to adherence to surveillance testing, a 3-item Likert scale was used. The items regarding perceived benefits and barriers were drawn from domains originally identified as being related to CRC screening by Rawl et al [42,43] among first-degree relatives of patients with CRC.

Surveillance Receipt

Adherence to surveillance testing was captured via patient report during both the pre- and postintervention surveys. Patients were asked yes or no if they had undergone each of the following tests since having CRC surgery: colonoscopy, CEA test, and CT scan.

Patient Knowledge

Patient knowledge regarding follow-up surveillance tests and visits was assessed by asking participants how often they believe each surveillance test (colonoscopy, CEA test, CT scan, and physical examination) should be performed. Participants were given various time frame categories to choose from. The guideline-concordant test frequency is as follows: physical exam, 3-6 months; CEA test, 3-4 months; colonoscopy, 2-3 years; and CT scan, annually [2]. For each participant, the number of items answered correctly was summed to generate the knowledge score (0-4). Patient knowledge was assessed at both baseline and after the intervention.

Statistical Analysis

Frequencies and measures of central tendency were calculated for patient sociodemographic variables. Descriptive statistics were calculated for sociodemographics, patients' beliefs about surveillance tests categories (knowledge, self-efficacy, barriers, and benefits), and receipt of surveillance tests (colonoscopy, CEA test, and CT scan). Paired *t* test (2-tailed) was used to examine the differences in patient-centered behavior outcomes pre- and postintervention delivery. To examine the differences in surveillance receipt before and after the intervention, McNemar test was used. Patients who did not complete the follow-up survey were excluded from the primary analysis. The excluded participants were compared to those who completed both surveys in terms of sociodemographic and clinical characteristics; no differences were found. Data were analyzed using STATA 16.1 (StataCorp).

Ethical Considerations

Approval for this study was obtained by the Indiana University Institutional Review Board (1201007805), as well as the Indianapolis VA Research & Development committee. The procedures used in this study adhere to the guidelines of the World Medical Association Declaration of Helsinki. Prior to enrollment in the study, the purpose of the study and each participant's role were explained. Written consent was obtained from everyone who participated.

Results

Patient Characteristics

A total of 28 patients with CRC completed the baseline survey, with 22 patients completing the follow-up survey at 6 months after the intervention. The majority of the sample was recruited at Indiana University Health (25/28, 89%), with 3 patients being recruited through the Indianapolis VA Medical Center. Table 1 describes the patient sociodemographics. The average age of the sample was 58 (SD 9.9) years. Two-thirds (18/28, 64%) of the patients had rectal cancer vs colon cancer (9/28, 33%). The majority of the patients were male (16/28, 57%), married (20/28, 71%), and were employed full-time (15/28, 54%); they also had an annual household income of >US $60,000 (16/28, 57%). Slightly less than half of patients (13/28, 46%) had a college education or greater.

Table 1. Demographic characteristics (N=28).

Characteristics	Values
Age (years), mean (SD)	58 (10)
Sex, n (%)	
Male	16 (57)
Female	12 (43)
Cancer type, n (%)	
Colon	9 (32)
Rectal	18 (64)
Unknown	1 (4)
Education, n (%)	
High school	8 (29)
Some college or trade school	7 (25)
Associate or bachelor's degree	7 (25)
Some or complete graduate school	6 (21)
Current marital status, n (%)	
Married (or long-term commitment)	20 (71)
Not Married	8 (29)
Employment status, n (%)	
Full-time	15 (54)
Part-time	1 (4)
Unemployed	3 (11)
Retired	7 (25)
Unable to work	2 (7)
Income (US$), n (%)	
<30,000	5 (18)
30,001-59,999	7 (25)
>60,000	16 (57)

Patient-Centered Behavior Outcomes

Descriptive statistics and paired *t* test results for the 4 categories of behavior outcomes, including self-efficacy, perceived benefit, perceived barriers, and patient knowledge, both before and after the intervention are reported in Table 2, while Tables 3-5 provide a more in-depth view of how patients answered the baseline questions for the 3 categories of knowledge, barriers, and benefits. For knowledge, patients were asked about the correct intervals of recommended follow-up times for various surveillance tests (physical exam, CEA test, colonoscopy, and CT scan). Out of the 4 knowledge questions, patients answered on average just under 2 of the 4 correctly, with no change in knowledge between the two surveys (*P*=.69). Self-efficacy (range 10-40) saw little change between pre- (32.2) and postintervention surveys (31.8; *P*=.66). Patients rated barriers (range 3-15) at both intervals fairly low, with 4.7 before the intervention and 4.9 at after the intervention *P*=.81). Benefits (range 5-25) is the only beliefs category in which we saw a significant change, and this was only benefits for CEA test, as benefits for all tests were rated fairly high. For colonoscopy, patients rated benefits before the intervention at 22.6, with no change after the intervention at 22.8 (*P*=.75). CEA test was rated as 20.9 before the intervention, with 22.0 after the intervention (*P*=.04). CT scan saw little change with preintervention rating at 21.6 and postintervention rating at 22.1 (*P*=.45).

Table 2. Patients' beliefs about surveillance tests (n=22).

Patients' beliefs	Before intervention, mean (SD)	After intervention, mean (SD)	*P* value
Knowledge (range: 0-4)	1.7 (1.1)	1.7 (1.1)	.69
Self-efficacy (range: 10-40)	32.2 (3.6)	31.8 (3.4)	.66
Barriers (range: 3-15)	4.7 (2.2)	4.9 (1.9)	.81
Benefits (range: 5-25)			
Colonoscopy	22.6 (2.6)	22.8 (2.3)	.75
CEA[a] test	20.9 (3.3)	22.0 (2.9)	*.04*[c]
CT[b] scan	21.6 (2.7)	22.1 (2.6)	.45

[a] CEA: carcinoembryonic antigen.

[b] CT: computed tomography.

[c] Italicized *P* values indicate significant value at the .05 level.

Table 3. Response frequency for benefits and barriers of surveillance at baseline.

Questions and responses	Strongly disagree	Disagree	Neither	Agree	Strongly agree
Benefits					
Finding the recurrence of CRC[a] early will save your life.	0 (0)	0 (0)	0 (0)	7 (25)	21 (75)
The treatment for the recurrence of CRC may not be as bad if the cancer is found early.	0 (0)	2 (7)	0 (0)	11 (39)	15 (54)
The following tests will help find the recurrence of CRC early:					
Colonoscopy	0 (0)	0 (0)	0 (0)	6 (21)	22 (79)
CEA[b] test	0 (0)	1 (4)	6 (21)	11 (39)	10 (36)
CT[c] scan	0 (0)	0 (0)	2 (7)	14 (50)	12 (43)
The following tests will decrease your chances of dying from the recurrence of CRC:					
Colonoscopy	1 (4)	1 (4)	1 (4)	8 (28)	17 (60)
CEA test	1 (4)	0 (0)	8 (29)	10 (36)	9 (32)
CT scan	1 (4)	0 (0)	2 (7)	14 (50)	11 (39)
The following tests will help you not worry as much about the recurrence of CRC:					
Colonoscopy	2 (7)	1 (4)	0 (0)	7 (25)	18 (64)
CEA test	2 (7)	0 (0)	6 (21)	11 (39)	9 (32)
CT scan	2 (7)	0 (0)	1 (4)	13 (46)	12 (43)
Barriers					
You feel anxious about having follow-up tests because you don't really understand what will be done.	16 (57)	9 (32)	0 (0)	3 (11)	0 (0)
The cost would keep you from having follow-up tests.	12 (43)	14 (50)	0 (0)	1 (4)	1 (4)
Transportation problems would keep you from having follow-up tests.	15 (54)	10 (36)	1 (4)	2 (7)	0 (0)

[a] CRC: colorectal cancer.

[b] CEA: carcinoembryonic antigen.

[c] CT: computed tomography.

Table 4. Response frequency for knowledge about surveillance at baseline[a].

Questions and responses	3-4 Months	6 Months	Yearly	Never	Don't know
Knowledge					
How often do you believe the following cancer surveillance tests should be performed for a colon cancer survivor similar to yourself?					
Physical examination	*14 (50)*	*7 (25)*	0 (0)	6 (21)	1 (4)
CEA[b] test	*14 (50)*	7 (25)	0 (0)	1 (4)	6 (21)

[a] Italicized responses are the correct answers to the frequency for each surveillance test.

[b] CEA: carcinoembryonic antigen.

Table 5. Response frequency for knowledge about surveillance at baseline (continued)[a].

Questions and responses	Yearly	2-3 Years	4-5 Years	Never	Don't know
Knowledge					
How often do you believe the following cancer surveillance tests should be performed for a colon cancer survivor similar to yourself?					
Colonoscopy	20 (71)	*5 (18)*	2 (7)	0 (0)	1 (4)
CT[b] scan	*16 (57)*	3 (11)	2 (7)	0 (0)	7 (25)

[a] Italicized responses are the correct answers to the frequency for each surveillance test.

[b] CT: computed tomography.

Receipt of Surveillance Testing

Table 6 reports the prevalence and comparison (paired *t* test) for each of the 3 primary surveillance tests at each time point. Since having surgery, only 52% had a colonoscopy since their CRC surgery, while that number increased to 86% (18/21) after the intervention (*P*=.005). Similarly, 67% (14/21) had a CEA test from the time of their surgery prior to the preintervention survey, while the proportion increased to 95% (20/21) after the intervention (*P*=.01). CT scan was the only surveillance test in which we did not see a significant uptick, with 67% (14/21) reporting having had a CT scan at the beginning of the study and 86% (18/21) having had one after the intervention (*P*=.10).

Table 6. Receipt of surveillance tests (n=21).

Tests	Preintervention, n (%)	Postintervention, n (%)	*P* value
Colonoscopy	11 (52)	18 (86)	*.005*[c]
CEA[b] test	14 (67)	20 (95)	*.01*
CT[c] scan	14 (67)	18 (86)	.10

[a] Italicized *P* values indicate significant value at the .05 level.

[b] CEA: carcinoembryonic antigen.

[c] CT: computed tomography.

Discussion

Overview

The purpose of our study was to test the feasibility of a stand-alone PHR for CRC survivors' post resection and examine its impact upon receipt of recommended surveillance testing and behavior outcomes. CRC survivors are at an increased risk of recurrence, especially within the first 2-3 years after treatment. Interventions targeted toward increasing surveillance rates for CRC survivors would help to detect signs of recurrence early in its progression, and thus potentially decrease morbidity and mortality.

Principal Findings

For our primary outcome, we found an overall significant impact on receipt of CRC surveillance tests. From baseline to the 6-month postintervention follow-up, we saw a significant impact for both colonoscopy (*P*=.005) and CEA testing (*P*=.01). There was no significant increase in CT scans between before and after the intervention, although we did observe an increase from 67% (14/21) at baseline to 86% (18/21) of the sample receiving a CT scan at 6 months. The effect of CRC surveillance tests is commonly clinically approached as a bundle of care, that is, recommending the combination of colonoscopy, CEA testing, and imaging [44]. At baseline, only 42% (12/28) of participants reported having received all 3 tests, with 29% (8/28) not having received any. Whereas, at the 6-month follow-up, 77% (16/21) had received all 3 surveillance tests, and all patients had received at least one. Both CEA testing and CT scans have been associated with increased rates of surgical treatment of recurrence, suggesting that increases in either type of surveillance testing may be associated with more salvage surgery with curative intent [45].

Comparison With Prior Work

Existing frameworks provide some guidance about what behavioral mechanisms may explain these main effects. The Health Belief Model [46] posits that self-efficacy, perceived barriers, and perceived benefits (ie, belief about the effectiveness of surveillance in reducing risk) mediate changes in the health behavior of individuals. Further, other investigators have postulated that patient-centered portals, with many features in common with personal health records, will have a positive effect upon patient self-efficacy [47-49]. In addition, Lo et al [50] found screening knowledge, perceived barriers to care, and social norms to be significant mediators of sociodemographic differences in the uptake of CRC screening. The CRCS-PHR may act through similar mechanisms. Our patient-centered technology had design features intended to increase screening knowledge and the perceived benefit of surveillance, including both clinical reminders to the patients about the next surveillance test due and web-based educational materials to explain the nature and purpose of each test. Participants found the summary and schedules of their cancer treatment and follow-up appointments to be the most useful in the PHR, along with side effects of treatment and community resources [31,47].

Due to the conceptual and empiric importance of patient knowledge, perceived benefits and barriers, as well as self-efficacy to the uptake of CRC screening [51], we explored the effect of the CRCS-PHR upon these secondary outcomes. Many patients did not know the answer to individual knowledge questions (Table 3); the proportion varied by test, from 25% (7/28) to 75% (21/28) for physical exam to colonoscopy, respectively. These findings suggest that patient-centered technologies have the potential to increase patient knowledge but can be further tailored to tests about which patient have the least awareness (eg, colonoscopy or CT scans). Nonetheless, patient knowledge is commonly not associated with changes in patient screening behavior [52]; our observations that surveillance test use increased, whereas knowledge about the tests often did not, reinforced this weak association.

Overall, patients largely agreed about the benefits of CRC surveillance, with the proportion who reported individual tests (colonoscopy, CEA test, or CT scan) as beneficial ranging from 75% to 100% (find recurrence early); from 68% to 88% (decrease chance of dying from recurrence); and from 71% to 89% (help you not to worry). With patient beliefs, the only domain that significantly increased was the perceived benefits of CEA testing, as most were quite high at baseline. These relatively high proportions are similar to the perceived benefit of CRC screening tests among a general population not already diagnosed with cancer [43]. High perceived benefit limited the potential for improvement in these perceptions among the CRC survivors enrolled in our trial. Conversely, low perceived barriers to care at baseline likely limited the potential for improvement in these domains. Moreover, the potential barriers of cost and transportation are challenging to address [53-58], and our CRCS-PHR implementation needs to be accompanied by changes in the health care systems, and policy needs to be adequately addressed.

We found no significant differences in patient self-efficacy. Systematic reviews conducted by Han et al [47] and Lancaster et al [48] found that eHealth tools such as provider-patient communication functionalities, case management, and other forms of clinical support may increase self-efficacy and self-management. Empiric findings from previous studies have been mixed. Secure messaging had a positive impact upon medication self-efficacy among patients with diabetes [59,60], but other studies have shown no association [60]. These mixed findings suggest that the influence of patient portals upon self-efficacy may vary depending upon both the functions used and the populations targeted.

Future studies in the field of cancer control should assess new populations of patients with cancer, including prostate, ovarian, and skin cancers, as they are underrepresented in this area of the literature and patient-centered technology [31]. However, with differences across sites of cancer, and more specifically, across the cancer continuum, patient-centered technology interventions will need to be targeted toward specific sites and continuum levels as efficacy and effectiveness may vary [31]. This may be due in part to the complexity of cancer care across the care trajectory versus other chronic disease management, as well as the need for tailored functionalities by cancer type. Treatment plans and surveillance testing will likely differ for each cancer type in terms of the tests and intervals recommended. Future studies should also consider what types of recruitment strategies may be optimal in this type of research, such as recruitment through clinicians versus registry-based outreach. We employed a recruitment strategy involving clinician engagement to recruit individuals, as we felt this approach would better identify eligible patients and decrease attrition over time due to ongoing engagement with their clinicians. Testing this type of engagement was important to assess initial intervention feasibility. However, there are advantages to registry-based recruitment, which is more likely to lead to increased access to a larger number of potential participants. Researchers should weigh the advantages and disadvantages of different recruitment strategies in relation to the specific needs of their studies.

Limitations

While this work provides strong insights and evidence to inform the development of the CRCS-PHR, our work is not without its limitations. First, without a control group not exposed to the CRCS-PHR, we are limited in our ability to make inferences of the intervention effect. Additionally, the pre- and posttest design has the potential for a temporal effect on the patient beliefs and surveillance receipt over time, which is important to note. With feasibility established, future studies should use a randomized controlled trial design, which will account for the potential of a temporal effect and increase the strength of our causal inferences with the introduction of a control group. The relatively small sample size of our feasibility study also limits our ability to test mediation pathways. Our sample was primarily White, younger on average compared with the national CRC population (58 years versus 66 years old) [1], and more highly educated than the population of Indiana and that of the United States (13/28, 46% of the sample having college degree). The young age and higher education of our sample is not unusual among early adopters of new patient technologies and cancer survivors recruited at academic medical centers [60-62]; however, the results are not directly generalizable to other populations, including patients treated in community-based oncology clinics. Future work needs to continue to focus upon how best to engage CRC survivors who tend to be older adults in use of these new technologies. While our sample had a majority of rectal patients, nearly an inverse of the US CRC survivor population (70% of national CRC survivors being colon), we believe it is important to understand the use of this technology among both rectal and colon cancer survivors, and do not have a reason to believe its use would differ between these closely related cancer types. The higher proportion of rectal to colon patients in the sample was due in part to the local expertise in rectal cancer surgery at one of the academic sites.

Conclusions

Patient-centered technologies such as the CRCS-PHR represent an important potential approach to improving the receipt of guideline-concordant care such as surveillance tests among cancer survivors. In assessing these rapidly emerging technologies, we encourage investigators and evaluators to continue measuring behavioral constructs that might serve as plausible mechanisms to explain observed effects. With this approach, we can grow to understand not only if new technologies improve the quality of care but how this improvement takes place. Future research in this area should also assess the effect of personal health records with quasi-experimental and randomized controlled study designs when possible. Finally, survivors of different types of cancers should be enrolled in future research, given that the clinical and supportive care needs of patients may vary widely among different populations.

Acknowledgments

Funding for this project was provided by the Livestrong Foundation and the US Department of Veterans Affairs, Veterans Health Administration, Office of Research and Development, Health Services Research and Development Project #CDA 07-016 (DAH). Funding was also provided by the National Institutes of Health/National Cancer Institute Training Grant T32CA117865 (EV).

The views expressed in this article are those of the authors and do not necessarily reflect the position or policy of the Department of Veterans Affairs or the United States government.

Conflicts of Interest

None declared.

Multimedia Appendix 1
General self-efficacy measure.
[DOCX File , 14 KB - cancer_v8i3e34851_app1.docx]

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Abbreviations

CEA: carcinoembryonic antigen
CRC: colorectal cancer
CRCS: colorectal cancer survivors
CRCS-PHR: Colorectal Cancer Survivor Personal Health Record
CT: computed tomography
GSE: General Self-Efficacy
PHR: personal health record
VA: Veterans Affairs

Edited by A Mavragani; submitted 07.12.21; peer-reviewed by C Smith, S Choemprayong, M Mansourzadeh; comments to author 17.05.22; revised version received 07.07.22; accepted 20.07.22; published 11.08.22.

Please cite as:
Vachon E, Robb BW, Haggstrom DA
Impact of a Personal Health Record Intervention Upon Surveillance Among Colorectal Cancer Survivors: Feasibility Study
JMIR Cancer 2022;8(3):e34851
URL: https://cancer.jmir.org/2022/3/e34851
doi:10.2196/34851
PMID:35969424

Original Paper

The Achieving Self-directed Integrated Cancer Aftercare Intervention for Detection of Recurrent and Second Primary Melanoma in Survivors of Melanoma: Pilot Randomized Controlled Trial

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Abstract

Background: Melanoma is common with increasing incidence. Guidelines recommend monthly total skin self-examinations (TSSEs) by survivors to detect recurrent and new primary melanomas. TSSE is underperformed despite evidence of benefit.

Objective: This study compares the effect on psychological well-being and TSSE practice of a self-directed digital intervention with treatment as usual in patients treated for a first stage 0 to IIC primary cutaneous melanoma within the preceding 60 months.

Methods: This randomized clinical trial was conducted at 2 UK National Health Service hospitals (Aberdeen Royal Infirmary, Grampian, and Addenbrooke's, Cambridge). Adults (≥18 years) diagnosed with a first 0 to IIC primary cutaneous melanoma were randomized to receive Achieving Self-directed Integrated Cancer Aftercare (ASICA), a tablet-based intervention prompting and supporting TSSE in survivors of melanoma, or to usual care. The hypothesis was that ASICA would increase TSSE practice in users affected by melanoma and compared with controls without affecting psychological well-being. The main primary outcomes were melanoma worry (Melanoma Worry Scale), anxiety and depression (Hospital Anxiety and Depression Scale), and quality of life (EQ-5D-5L) as well as secondary outcomes collected using postal questionnaires 3, 6, and 12 months following randomization.

Results: A total of 240 recruits were randomized (1:1) into the ASICA (n=121, 50.4%) or control (n=119, 49.6%) groups. There were no significant differences between groups for melanoma worry at 12 months (mean difference: 0.12, 95% CI −0.6 to 0.84; *P*=.74), 3 months (0.23, 95% CI −0.31 to 0.78; *P*=.40), or 6 months (−0.1, 95% CI −0.7 to 0.51; *P*=.76). The ASICA group had lower anxiety scores at 12 months (−0.54, 95% CI −1.31 to 0.230; *P*=.17), 3 months (−0.13, 95% CI −0.79 to 0.54; *P*=.71), and significantly at 6 months (−1.00, 95% CI −1.74 to −0.26; *P*=.009). Depression scores were similar, being lower at 12 months

(−0.44, 95% CI −1.11 to 0.23; *P*=.20) and 3 months (−0.24, 95% CI −0.84 to 0.35; *P*=.42) but only significantly lower at 6 months (−0.77, 95% CI −1.41 to −0.12; *P*=.02). The ASICA group had significantly higher quality of life scores at 12 months (0.044, 95% CI 0.003-0.085; *P*=.04) and 6 months (0.070, 95% CI 0.032-0.107; *P*<.001) and nonsignificantly at 3 months (0.024, 95% CI −0.006 to 0.054; *P*=.11). ASICA users reported significantly more regular (>5) TSSEs during the study year and significantly higher levels of self-efficacy in conducting TSSE. They also reported significantly higher levels of planning and intention to perform TSSE in the future.

Conclusions: Using ASICA for 12 months does not increase melanoma worry, can reduce anxiety and depression, and may improve quality of life. ASICA has the potential to improve the well-being and vigilance of survivors of melanoma and enable the benefits of regular TSSE.

Trial Registration: ClinicalTrials.gov NCT03328247; https://clinicaltrials.gov/ct2/show/NCT03328247

International Registered Report Identifier (IRRID): RR2-10.1186/s13063-019-3453-x

(JMIR Cancer 2022;8(3):e37539) doi:10.2196/37539

KEYWORDS

primary care; melanoma; cancer; randomized controlled trial; survivorship; self-directed care; eHealth; Achieving Self-directed Integrated Cancer Aftercare; ASICA; well-being; quality of life; mobile phone

Introduction

Background

The COVID-19 pandemic has seen the rapid deployment of digital technologies to manage both acute and scheduled health care with apparent success [1]. In the United Kingdom and elsewhere, digital technology has been deployed widely to manage triage and direct care to appropriate places and times [1]. Although demonstrating the great potential of digital health care across the National Health Service (NHS), uncertainties about the true impact on patients' well-being and outcomes remain, and the rigorous development and evaluation of digital technologies has never been more urgent [2]. A particular area where digital technology could have much to offer is secondary prevention of cutaneous melanoma [3].

Melanoma is common, with approximately 16,200 people in the United Kingdom diagnosed each year, and its incidence has increased 5-fold in 30 years [4]. The UK guidelines recommend that patients treated for cutaneous melanoma receive extended hospital follow-up to detect recurrence or new primaries [5]. However, delivering melanoma follow-up to the growing population of survivors is burdensome for both individuals and health services [6]. Nevertheless, follow-up is important as approximately 20% of patients with early-stage melanoma experience a recurrence, and 4% to 8% develop a new primary, the risk of both being highest in the first 5 years [7-10]. Melanoma recurrence can present locally, regionally, or with distant metastases, and new primaries can occur anywhere [11]. Successful treatment of recurrent melanoma with targeted and immunological treatments is leading to significant improvements in survival even in advanced melanoma [12].

Therefore, it is important to detect new primary and recurrent melanomas in a timely way. Most recurrences and new primaries are detected by patients between scheduled follow-up visits [5]. Thus, guidelines recommend that patients conduct monthly total skin self-examinations (TSSEs; thorough checks of the total surface of the skin) during follow-up. A randomized trial in the United States showed that increasing TSSE practice for 6 months in the short term resulted in significantly more detection of potential melanoma in people with increased melanoma risk [13]. There is evidence from the United Kingdom and elsewhere that TSSE practice in people with melanoma is suboptimal and not practiced monthly as recommended [14,15]. Barriers to initiating and maintaining TSSE include lack of initial training, declining motivation, and insufficient time [16]. There are good reasons to believe that these barriers could be tackled by digital technology [15]. However, it is also important to ensure that interventions to increase TSSE do not have the unintended consequence of negatively affecting patient well-being. It has been shown that long-term survivors of cancer have increased rates of anxiety compared with controls [17]. Furthermore, there is evidence of increasing anxiety in the days and weeks preceding a scheduled follow-up appointment for many survivors of melanoma [18]. As such, it is possible that more frequent prompts to check the skin between scheduled follow-ups will exacerbate patient anxiety and adversely affect well-being.

This Study

The aim of this pilot study was to evaluate the Achieving Self-directed Integrated Cancer Aftercare (ASICA) self-directed digital intervention in a patient-focused randomized controlled trial among those treated for a first stage 0 to IIC primary cutaneous melanoma within the preceding 60 months. The primary objective of the pilot study was to determine the impact of using ASICA on patients' melanoma worry, anxiety and depression, and quality of life. The secondary objective was to provide information on the feasibility of the processes for a full-scale national trial of the ASICA intervention.

Methods

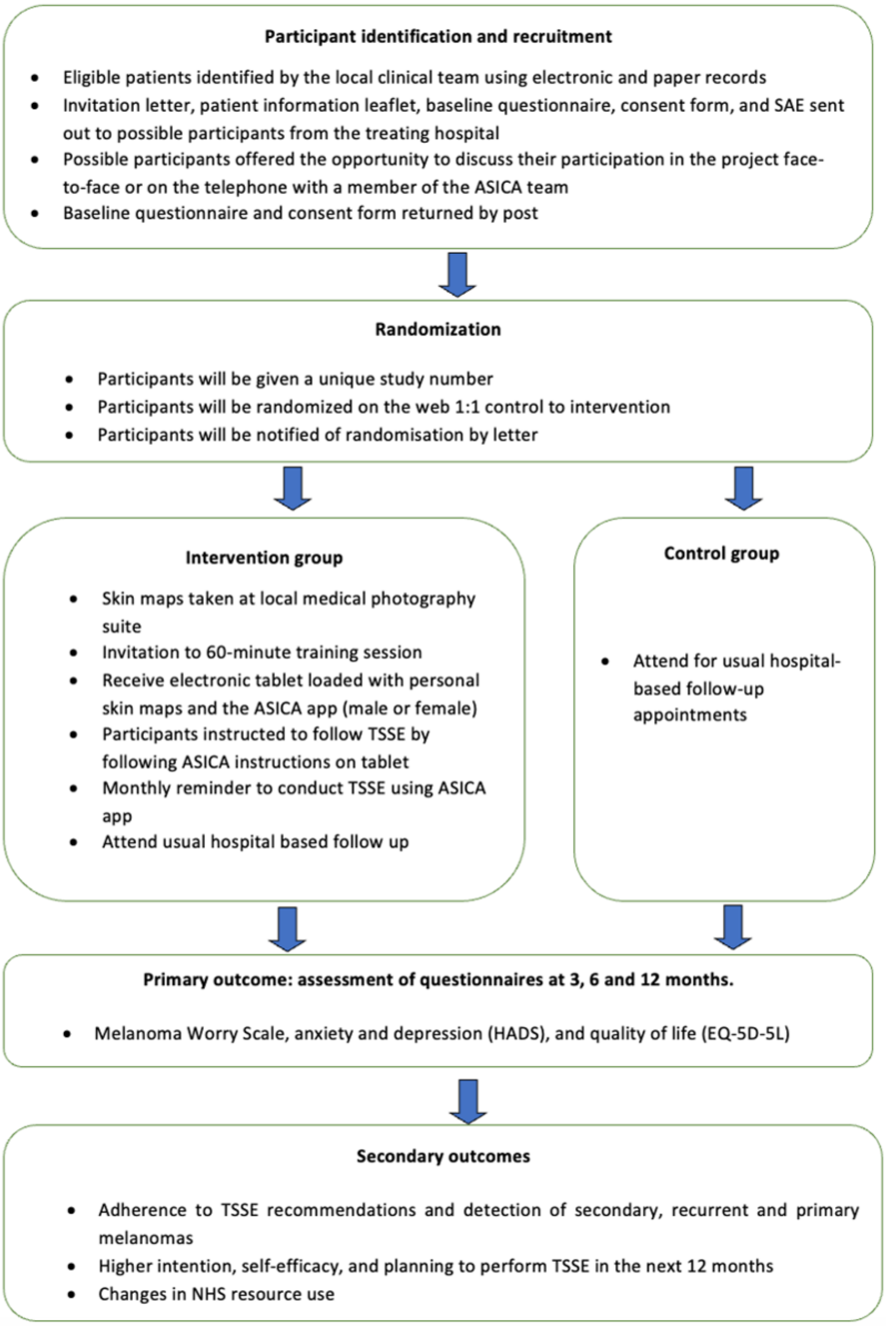
Study Protocol

The trial protocol has been published and is available as a web-based supplement [19]. The methods are described briefly in the following sections according to the CONSORT (Consolidated Standards of Reporting Trials) guidelines.

Study Design and Participants

ASICA was a 2-arm, open, 2-center randomized controlled pilot trial comparing the ASICA digital intervention with a control group receiving usual follow-up only (Figure 1 [20,21]). The study sites were the Aberdeen Royal Infirmary and Addenbrooke's Hospital, Cambridge. Adults (aged ≥18 years) treated within the preceding 60 months for a previous stage 0 to IIC primary cutaneous melanoma were sent information about the study, a consent form, and a baseline questionnaire by post. Individuals diagnosed with stage III and IV melanoma or recurrent melanoma within the last 60 months or unable to consent or complete the questionnaires were excluded. Those interested in participating in the study were contacted by the recruiting site for further discussion. The participants were randomized after informed written consent had been obtained.

Figure 1. Flow diagram of the study design and schedule. Reproduced from Murchie et al [20]. This paper is distributed under the terms of the Creative Commons Attribution 4.0 International License, which permits unrestricted use, distribution, and reproduction in any medium provided appropriate credit is given to the original authors and source, a link to the Creative Commons license is provided, and it is indicated if changes were made. The Creative Commons Public Domain Dedication waiver [30] applies to the data made available in this paper unless otherwise stated. ASICA: Achieving Self-directed Integrated Cancer Aftercare; HADS: Hospital Anxiety and Depression Scale; NHS: National Health Service; SAE: self-addressed envelope; TSSE: total skin self-examination.



Participant identification and recruitment

- Eligible patients identified by the local clinical team using electronic and paper records
- Invitation letter, patient information leaflet, baseline questionnaire, consent form, and SAE sent out to possible participants from the treating hospital
- Possible participants offered the opportunity to discuss their participation in the project face-to-face or on the telephone with a member of the ASICA team
- Baseline questionnaire and consent form returned by post

Randomization

- Participants will be given a unique study number
- Participants will be randomized on the web 1:1 control to intervention
- Participants will be notified of randomisation by letter

Intervention group

- Skin maps taken at local medical photography suite
- Invitation to 60-minute training session
- Receive electronic tablet loaded with personal skin maps and the ASICA app (male or female)
- Participants instructed to follow TSSE by following ASICA instructions on tablet
- Monthly reminder to conduct TSSE using ASICA app
- Attend usual hospital based follow up

Control group

- Attend for usual hospital-based follow-up appointments

Primary outcome: assessment of questionnaires at 3, 6 and 12 months.

- Melanoma Worry Scale, anxiety and depression (HADS), and quality of life (EQ-5D-5L)

Secondary outcomes

- Adherence to TSSE recommendations and detection of secondary, recurrent and primary melanomas
- Higher intention, self-efficacy, and planning to perform TSSE in the next 12 months
- Changes in NHS resource use

Intervention and Control

The intervention group received the ASICA digital tablet-based intervention, which is designed to support TSSE in those with cutaneous melanoma and enables appropriate and timely clinical responses when concerns are raised. It has been rigorously developed and is theoretically based, using specified behavior change techniques to prompt users to perform regular TSSE [20].

Briefly, the intervention group participants attended a 30-minute training session in which they were provided with a 7-inch Samsung Galaxy tablet and given instructions on the intervention and how the tablet-based app should be used to support them in conducting a thorough, full-body TSSE in response to a monthly SMS text message reminder sent from the trial team. The nurse demonstrated the function of the app and answered any questions about the TSSE or the intervention. The app included information about the importance of monthly TSSE; instructional videos demonstrating how to perform a TSSE and take good photographs of skin lesions; a digital map of the patient's own skin; a structured checkbox list of body parts to check; prompts for the patient to plan their next TSSE; and the capability to take photographs of suspicious skin lesions and send them to a dermatology nurse practitioner for review along with a text-based report of the TSSE outcomes, including a description of any concerns. All participants who submitted text-based reports of any skin concerns were followed up with by the dermatology nurse practitioner. The monthly prompt was sent on a single occasion, and no reminders were sent to individuals who did not complete the TSSE that month, but they would continue to be reminded on each subsequent month. The control group also completed the baseline questionnaire. All participants (intervention and control) continued to attend their usual structured melanoma follow-up as determined by local guidelines.

Randomization and Blinding

Participants were randomized 1:1 to intervention or control using a remote automated computer-allocated application hosted at the Centre for Healthcare Randomised Trials in Aberdeen, United Kingdom. An algorithm minimized the imbalance in sex and center between the groups [22]. Owing to the nature of the intervention, both participants and researchers were not blinded to the randomized allocation.

Outcomes and Ascertainment

Baseline data were collected from secondary care records by a research nurse at each site before randomization. The coprimary outcomes were the Melanoma Worry Scale, anxiety and depression (Hospital Anxiety and Depression Scale), and quality of life (EQ-5D-5L) [19]. The secondary outcomes were adherence to TSSE recommendations, self-efficacy, and future intention and planning to perform TSSE [23]. Primary and secondary outcomes were collected using postal questionnaires at baseline and 3, 6, and 12 months after randomization. Tertiary outcomes were new primary and recurrent melanomas and patterns of skin-related NHS resource use. These were collected 12 months after randomization from secondary care records by research nurses blinded to allocation.

Sample Size

There was no formal power calculation to derive sample size. The decision to conduct a relatively large pilot randomized controlled trial of 240 participants was influenced by several factors. Our previous nonrandomized feasibility study recruited 19 patients to provide information on recruitment, acceptability, compliance, and retention at 1 site [19]. Hospital Anxiety and Depression Scale scores at the 6-month follow-up exhibited high variability in both magnitude and direction of the effect at follow-up. This raised the possibility of a bidirectional effect on psychological outcomes (ie, some individuals were made more and some less anxious by the intervention). Another possible explanation was, of course, a small, unrepresentative sample. This required further exploration in a sample of sufficient size and representativeness before proceeding to a trial powered on clinical outcomes. A sample size of 240 was a pragmatic choice to provide a sufficiently diverse group of participants (with respect to age, sex, geographical location, and socioeconomic status) to assess this.

Statistical Analysis

A comprehensive statistical analysis plan was agreed upon with the trial steering committee before any analysis and is available upon request from the corresponding author. The analysis was based on the intention-to-treat principle. No interim analyses were planned or conducted. Baseline characteristics and follow-up data were described using summary statistics (mean and SD or median and IQR for continuous variables dependent on distribution and number and percentage for categorical variables). Treatment effects are presented with 95% CIs. There were no adjustments to the secondary outcome CIs for multiple testing.

A linear mixed effects, repeated-measure model was used for the analysis of the coprimary outcomes. The treatment group (ASICA or control), time point (3, 6, and 12 months), trial center (Aberdeen or Cambridge), and baseline value for the outcome variable were included as fixed effects. A treatment-by-time interaction was included to estimate the treatment effect at each time point. A random effect was included for participants. Other covariates in the model were age and time since diagnosis (years) as continuous variables and fixed effects for sex, deprivation (decile), rurality (urban vs rural), site (head and neck, upper body, upper limb, and lower limbs), and stage (0, IA, IB, and II) of melanoma at baseline as categorical variables.

TSSE question scores were aggregated to obtain domain scores for intentions, self-efficacy and planning to conduct TSSE. TSSE practice at 12 months was compared between the groups by calculating the difference in proportions with 95% CIs with continuity correction between trial groups. A stringent definition of TSSE practice as described by Janda et al [23] was used as an outcome compared between the trial groups. For a participant to be considered to have performed a TSSE, they must also report that they used a mirror or asked for help from someone else to examine difficult-to-see areas of their skin. A logistic regression model was then used to analyze this, adjusted for similarly defined baseline TSSE. The difference in mean scores between the groups was estimated for TSSE self-efficacy, intention, and planning using analysis of covariance controlling for baseline values of these same outcomes (TSSE self-efficacy, intention, and planning).

Negative binomial regression was used to estimate the incidence rate ratios (IRRs) of the ASICA group compared with the control group with respect to the use of resources, as evidenced by skin-related general practitioner (GP) appointments, hospital appointments, and hospital admissions. The models were adjusted for baseline age, sex, deprivation, rurality, time since diagnosis, site, and stage of melanoma. A negative binomial regression model was also used for intention to conduct TSSE at the 12-month follow-up (the number of times the patient planned to conduct TSSE in the following 12 months) controlling for baseline intentions.

Ethical Considerations

This project received full approval from the North of Scotland Research Ethics Committee on April 28, 2017 (17/NS/0040). Written informed consent was obtained from all study participants. The trial was conducted according to the principles of good clinical practice provided by the Research Governance Guidelines. Consent for publication did not apply.

Patient and Public Involvement

A detailed pilot study was conducted during the development of the ASICA project to ascertain patients' priorities, experiences, and preferences. Interviews were conducted with 19 potential recipients of the ASICA intervention, and these interviews informed the development of the study research questions and the selection of outcome measures. Patients were not directly involved in the design of the study but did inform the design via participation in the pilot study interviews. The burden of the ASICA intervention was assessed by patients in a qualitative substudy. A total of 2 patient representatives sat on the trial steering committee feeding into plans for recruitment and dissemination. The results of the project will be disseminated to all participants (except for those who opted out) via a postal newsletter.

Trial Status

Participant recruitment began in January 2018 and finished in March 2019. The first participant was randomized on January 24, 2018. Currently approved protocol: version 3, May 1, 2020.

Results

Overview

Between January 24, 2018, and March 8, 2019, a total of 240 participants were randomized (n=121, 50.4% to the ASICA intervention and n=119, 49.6% to usual care). A total of 264 participants from the 2 centers were assessed for eligibility for the trial (n=188, 71.2% at the Aberdeen Royal Infirmary and n=76, 28.8% at the Addenbrooke's Hospital, Cambridge). Of these 264 participants, 19 (7.2%) declined participation, 1 (0.4%) did not meet the inclusion criteria, and 4 (1.5%) had other reasons. At 12 months, 67.8% (82/121) of the participants in the ASICA group returned patient questionnaires, whereas 72.3% (86/119) of the participants in the usual follow-up group returned completed questionnaires (Figure 2). The baseline demographic and clinical characteristics were balanced between the 2 trial groups (Table 1).

Figure 2. Flow diagram of participants through the Achieving Self-directed Integrated Cancer Aftercare (ASICA) trial.

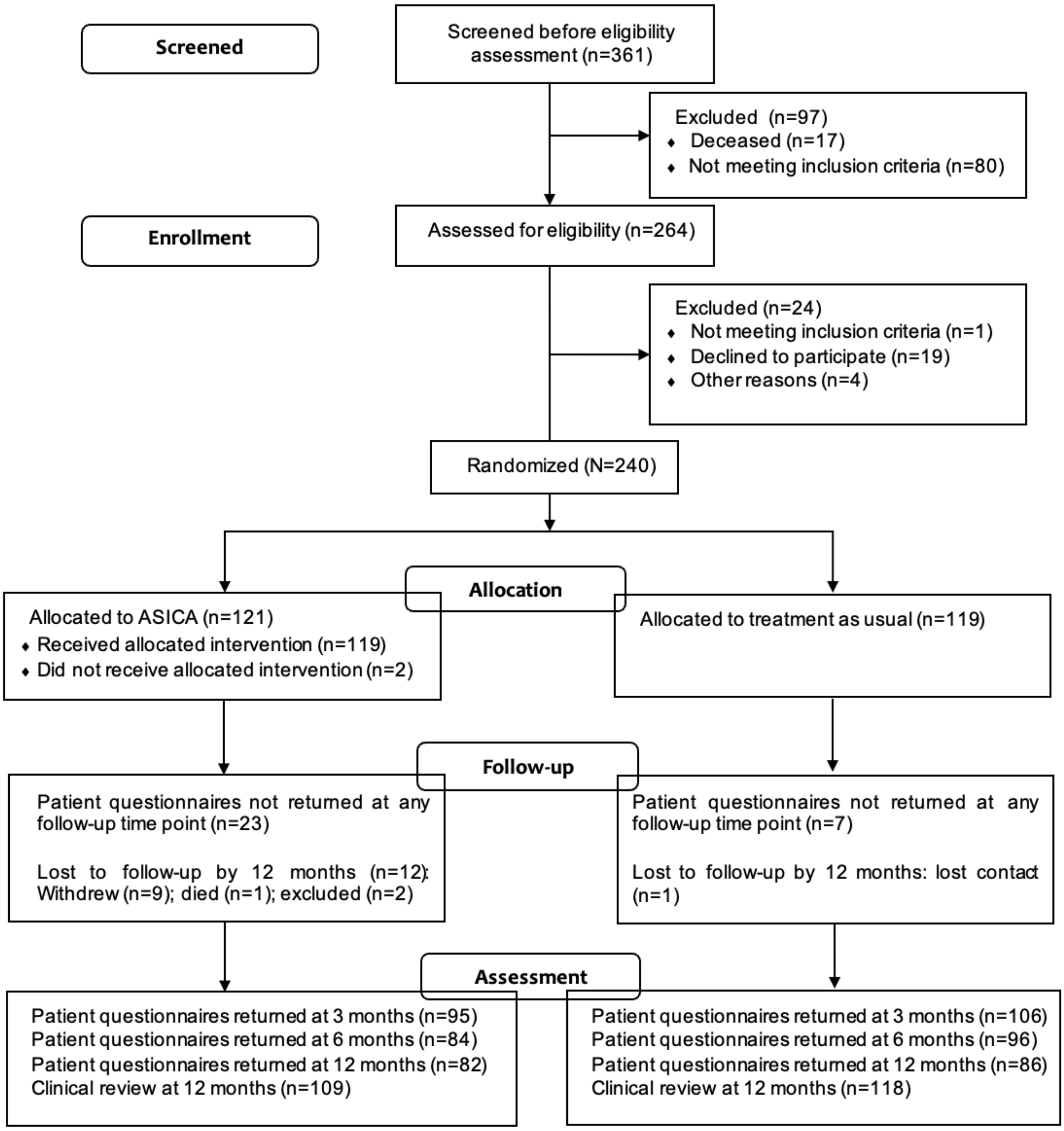


Table 1. Baseline demographic and clinical characteristics and outcome measures for the trial participants (N=240).

	ASICA[a] (n=121)	Control group (n=119)
Characteristics		
Sex (male), n (%)	55 (45.5)	53 (44.5)
Age (years), mean (SD)	59.1 (14.1)	57.6 (13.7)
Time since diagnosis (years), mean (SD)	2 (1.3)	1.9 (1.3)
Deprivation decile, n (%)		
1 (most deprived)	0 (0)[b]	0 (0)[c]
2	2 (1.7)[b]	2 (1.7)[c]
3	4 (3.4)[b]	3 (2.5)[c]
4	0 (0)[b]	7 (5.9)[c]
5	4 (3.4)[b]	9 (7.6)[c]
6	17 (14.5)[b]	12 (10.2)[c]
7	16 (13.7)[b]	13 (11)[c]
8	18 (15.4)[b]	20 (16.9)[c]
9	28 (23.9)[b]	22 (18.6)[c]
10 (least deprived)	28 (23.9)[b]	30 (25.4)[c]
Rurality, n (%)		
Urban	72 (59.5)	78 (65.5)
Rural	49 (40.5)	41 (34.5)
Clinical characteristics		
Site of first primary melanoma, n (%)		
Head and neck	22 (18.2)	22 (18.5)
Upper body	46 (38)	51 (42.9)
Upper limbs	21 (17.4)	21 (17.6)
Lower limbs	32 (26.4)	25 (21)
Subtype of melanoma at diagnosis, n (%)		
Superficial spreading	86 (72.3)[d]	88 (75.9)[e]
Nodular	10 (8.4)[d]	3 (2.6)[e]
Amelanotic	1 (0.8)[d]	0 (0)[e]
Lentigo maligna	8 (6.7)[d]	13 (11.2)[e]
Acral	1 (0.8)[d]	1 (0.9)[e]
Other	13 (10.9)[d]	11 (9.5)[e]
Stage of melanoma diagnosis, n (%)		
0 and IA	57 (47.1)	65 (54.6)
IB	43 (35.5)	39 (32.8)
IIA, IIB, and IIC	21 (17.4)	15 (12.6)
Breslow depth (mm), median (IQR)	0.9 (0.5-1.6)	0.6 (0.5-1.1)
Clark level, n (%)		
1	0 (0)[f]	0 (0)[g]

	ASICA[a] (n=121)	Control group (n=119)
2	15 (31.9)[f]	13 (29.5)[g]
3	10 (21.3)[f]	12 (27.3)[g]
4	21 (44.7)[f]	19 (43.2)[g]
5	1 (2.1)[f]	0 (0)[g]
Mode of detection, n (%)		
Patient-detected	27 (69.2)[h]	36 (100)[i]
Detected at hospital	5 (12.8)[h]	0 (0)[i]
Detected by GP[j]	1 (2.6)[h]	0 (0)[i]
Other	6 (15.4)[h]	0 (0)[i]
Type of melanoma treatment, n (%)		
Surgery	120 (99.2)	118 (99.2)
Immunotherapy	0 (0)	0 (0)
Radiotherapy	1 (0.8)	0 (0)
Chemotherapy	1 (0.8)	0 (0)
Outcome measures		
Melanoma Worry Scale, mean (SD)	8.5 (3.5)[k]	8.8 (3.1)[e]
HADS[l], mean (SD)		
Anxiety	5 (4.1)[c]	5.1 (3.5)[b]
Depression	2.8 (2.9)[c]	2.8 (2.6)[e]
Quality of life (EQ-5D-5L), mean (SD)	0.871 (0.148)[b]	0.863 (0.158)[b]
Resource use in preceding 2 years, median (IQR)[m]		
Melanoma follow-up appointments	4 (2-5.3)	3 (2-5)
Skin-related hospital appointments	2 (1-3)	1 (1-2)
Skin-related hospital admissions	1 (1-2)	1.5 (1-2)
Reported practicing TSSE[n] in previous 12 months, n (%)	60 (63.2)[o]	73 (74.5)[p]

[a] ASICA: Achieving Self-directed Integrated Cancer Aftercare.

[b] N=117.

[c] N=118.

[d] N=119.

[e] N=116.

[f] N=47.

[g] N=44.

[h] N=39.

[i] N=36.

[j] GP: general practitioner.

[k] N=115.

[l] HADS: Hospital Anxiety and Depression Scale.

[m] Of those who used these resources.

[n] TSSE: total skin self-examination (defined as having used a mirror or asked for help to view difficult-to-see areas of the skin).

[o] N=95.

[p] N=98.

Melanoma Worry

The difference between the groups for melanoma worry score was close to 0 at all time points (Table 2), and the narrow CI bands indicated that ASICA did not increase melanoma worry among the intervention group at any point at which it was measured during the trial.

Table 2. Estimates for mean differences at each time point for the primary outcomes (N=240).

Outcome, subscale, and time point	ASICA[a] (n=121), mean (SD)	Control group (n=119), mean (SD)	Adjusted mean difference[b] (95% CI)	*P* value
MWS[c]				
3 months	8.47 (3.03)[d]	8.48 (2.93)[e]	0.23 (–0.31 to 0.78)	.40
6 months	7.65 (2.71)[f]	7.97 (3.13)[g]	–0.1 (–0.70 to 0.51)	.76
12 months	7.94 (3.20)[f]	7.93 (3.06)[h]	0.12 (–0.60 to 0.84)	.74
HADS[i]				
Anxiety				
3 months	4.17 (3.6)[j]	4.57 (3.78)[d]	–0.13 (–0.79 to 0.54)	.71
6 months	3.55 (3.25)[k]	4.71 (4.28)[l]	–1.00 (–1.74 to –0.26)	.01
12 months	3.77 (3.41)[k]	4.38 (3.95)[m]	–0.54 (–1.31 to 0.23)	.17
Depression				
3 months	2.33 (2.35)[l]	2.79 (3.19)[n]	–0.24 (–0.84 to 0.35)	.42
6 months	2.05 (2.43)[k]	3.18 (3.35)[j]	–0.77 (–1.41 to –0.12)	<.001
12 months	2.28 (2.69)[o]	2.82 (3.35)[p]	–0.44 (–1.11 to 0.23)	.20
Quality of life (EQ-5D- 5L)				
3 months	0.877 (0.137)[q]	0.864 (0.169)[e]	0.024 (–0.006 to 0.054)	.11
6 months	0.911 (0.129)[r]	0.853 (0.19)[d]	0.070 (0.032 to 0.107)	<.001
12 months	0.891 (0.136)[f]	0.859 (0.177)[h]	0.044 (0.003 to 0.085)	.04

[a] ASICA: Achieving Self-directed Integrated Cancer Aftercare.

[b] Adjusted for baseline scores, age, sex, deprivation, rurality, time since diagnosis, site, and stage of melanoma.

[c] MWS: Melanoma Worry Scale.

[d] N=92.

[e] N=102.

[f] N=80.

[g] N=93.

[h] N=84.

[i] HADS: Hospital Anxiety and Depression Scale.

[j] N=90.

[k] N=75.

[l] N=89.

[m] N=73.

[n] N=95.

[o] N=76.

[p] N=77.

[q] N=94.

[r] N=83.

Anxiety and Depression

The ASICA group had lower anxiety scores at each time point compared with the control group, but these differences were small, and CIs showed that larger differences were not compatible with the data (Table 2). At 12 months, the difference was –0.54 (95% CI –1.31 to 0.23; *P*=.17). This pattern was similar for depression; at 12 months, the mean difference was –0.44 (95% CI –1.11 to 0.23; *P*=.20).

Quality of Life

The EQ-5D-5L also favored ASICA at each time point (Table 2). At 12 months, it was higher in the ASICA group, with a mean difference of 0.044 (95% CI 0.003-0.085; *P*=.04).

Secondary Outcomes

Self-reported TSSE Adherence

Table 3 reports between-group comparisons of secondary outcomes of any TSSE practice, resource use, TSSE intentions, TSSE self-efficacy, and TSSE planning during the study year. Table 4 provides more details from questionnaire responses about self-reported TSSE practice during the study year.

Table 3. Estimates for secondary outcomes at the 12-month follow-up.

Outcome and subcategory	ASICA[a]	Control group	Effect estimates (95% CI)	*P* value
Self-reported TSSE[b] at 12 months[c]—Yes, n (%)	58 (76)[d]	47 (73)[e]	2.45 (0.76 to 7.90)	.13
Resource use, median (IQR); mean (SD)				
Skin-related GP[f] appointments[g]	0 (0-0); 0.27 (0.79)[h]	0 (0-0); 0.13 (0.46)[i]	2.64 (1.1 to 6.33)	.03
Skin-related hospital appointments[g]	0 (0-1); 0.66 (1.35)[j]	0 (0-1); 0.49 (0.95)[k]	1.14 (0.71 to 1.85)	.59
Skin-related hospital admissions[g]	0 (0-1); 0.53 (0.92)[l]	0 (0-0); 0.28 (0.58)[m]	1.94 (1.17 to 3.2)	.01
TSSE, mean (SD)				
Intentions about TSSE[n]	11.9 (8.9)[o]	8.3 (14.5)[p]	1.44 (0.97 to 2.13)	.07
Self-efficacy about TSSE[q]	33.5 (6.0)[r]	29.9 (6.9)[s]	3.8 (2.0 to 5.6)	<.001
Planning about TSSE				
Action planning	7.3 (2.1)[t]	5.9 (2.2)[u]	1.3 (0.6 to 1.1)	<.001
Coping planning	4.22 (0.77)[t]	3.96 (0.79)[v]	0.24 (–0.01 to 0.50)	.06

[a] ASICA: Achieving Self-directed Integrated Cancer Aftercare.

[b] TSSE: total skin self-examination.

[c] Self-reported TSSE defined as having used a mirror or asked for help to view difficult-to-see areas of the skin. The effect estimate is the odds ratio adjusted for baseline self-reported TSSE.

[d] N=76.

[e] N=64.

[f] GP: general practitioner.

[g] The effect estimates are incidence rate ratios adjusted for center, age at randomization, sex, deprivation decile, rurality, time since diagnosis, site of melanoma, and stage of melanoma.

[h] N=82.

[i] N=86.

[j] N=92.

[k] N=91.

[l] N=89.

[m] N=90.

[n] The effect estimate is the incidence rate ratio adjusted for baseline intentions.

[o] N=56.

[p] N=55.

[q] The effect estimates are the differences in means adjusted for the baseline outcome score.

[r] N=74.

[s] N=72.

[t] N=73.

[u] N=70.

[v] N=67.

Table 4. Total skin self-examination practice at 12 months.

Question	ASICA[a], n (%)	Control group, n (%)	Difference in proportion (95% CI)	*P* value
Have you or someone who is not a doctor or nurse, such as your spouse or partner, ever deliberately checked any part of your skin for early signs of skin cancer?—Yes	64 (88)[b]	62 (82)[c]	6.1 (–6.8 to 19.0)	.42
In the past 12 months, have you or someone who is not a doctor or nurse, such as your spouse or partner, deliberately checked any part of your skin for early signs of skin cancer?—Yes	63 (95)[d]	58 (89)[e]	6.3 (–4.4 to 16.8)	.31
In the past 12 months, how often have you or someone who is not a doctor or nurse checked any part of your skin for early signs of skin cancer?—≥5 times	45 (68)[d]	25 (42)[f]	26.5 (8.1 to 44.9)	.005
And just thinking about the past 6 months, how often have you or someone who is not a doctor or nurse checked any part of your skin for early signs of skin cancer?—≥5 times	35 (53)[d]	17 (29)[g]	24.2 (5.9 to 42.5)	.01
During your last check, did you use a handheld mirror or full-sized mirror to check difficult-to-see areas of your skin such as your back?—Yes	50 (74)[h]	31 (48)[i]	25.1 (9.0 to 41.2)	.005
During your last check, did you have someone to help you see difficult-to-see areas; for example, your wife, partner, or another relative?—Yes	36 (53)[h]	38 (60)[j]	–7.4 (–25.8 to 11.1)	.50

[a] ASICA: Achieving Self-directed Integrated Cancer Aftercare.

[b] N=73.

[c] N=76.

[d] N=66.

[e] N=65.

[f] N=60.

[g] N=59.

[h] N=68.

[i] N=64.

[j] N=63.

A higher proportion of the ASICA group (58/76, 76%) than of the control group (47/64, 73%) reported having conducted at least one TSSE during the study year, but the difference was nonsignificant (*P*=.13). However, a significantly higher proportion of the ASICA group reported checking their skin 5 or more times over the 12 months of follow-up compared with the control group (45/66, 68% vs 25/60, 42%; between-group difference: 26.5, 95% CI 8.1-44.9; *P*=.005). A significantly greater proportion in the ASICA group than in the control group reported having used a mirror to check difficult-to-see areas of their skin (50/68, 74% vs 31/64, 48%; between-group difference: 25.1, 95% CI 9.0-41.2; *P*=.005). Details of the difference in the proportion of actual TSSE practice at 12 months are reported in Table 4. When using the stringent TSSE practice definition, there were higher but nonsignificant odds of reporting having carried out TSSE in the ASICA arm than in the usual follow-up arm (odds ratio 2.45, 95% CI 0.76-7.90; *P*=.13) allowing for baseline self-reported TSSE.

Intention, Self-efficacy, and Planning to Conduct TSSE

Table 3 reports the effect estimates for participants' intentions, self-efficacy, and planning to conduct TSSE. Participants' intentions to check their skin for early signs of cancer were similar in the 2 groups, as were the intentions to contact a health professional if they found something of concern during TSSE. Participants in the ASICA group reported having a significantly higher level of confidence (self-efficacy) about checking their skin correctly than the usual care group (mean difference: 3.8, 95% CI 2.0-5.6; *P*<.001). The ASICA group also had clearer plans about when and where they would conduct TSSE (action planning; mean difference: 1.3, 95% CI 0.6-1.1; *P*<.001).

Patterns of NHS Resource Use

The rate of skin-related GP appointments reported by participants was significantly higher in the ASICA group than in the control group (adjusted IRR: 2.64, 95% CI 1.1-6.33; *P*=.03). In addition, the rate of melanoma-related hospital admissions was higher in the ASICA group than in the control group (IRR: 1.94, 95% CI 1.17-3.2; *P*=.01); however, there was no difference in the rate of skin-related hospital appointments between the groups (IRR: 1.14, 95% CI 0.71-1.85; *P*=.59).

Recurrences and New Primaries

There were 4.1% (5/121) of recurrences or new primaries reported in the ASICA group compared with 9.2% (11/119) in the control group (odds ratio 0.42, 95% CI 0.14-1.26; *P*=.18).

Discussion

Summary of Principal Findings

This pilot study succeeded in recruiting 241 survivors of melanoma. Overall, the results demonstrate that ASICA is a feasible and acceptable means of supporting TSSE practice in survivors of melanoma. In the pilot study, using ASICA did not increase melanoma worry and led to a significant reduction in anxiety and depression scores at 6 months but not at 12 months. ASICA users reported a significantly higher quality of life at 6 and 12 months. These results provide an important signal suggesting that widespread ASICA use by survivors of melanoma would have no adverse psychological effects and may improve quality of life. Furthermore, during the study year, ASICA users reported checking their skin more frequently and thoroughly than the control participants. ASICA users also reported that they were more confident in their ability to check their skin and had clearer plans regarding when and where they would perform the checks. Furthermore, ASICA users had significantly more skin-related GP appointments and hospital admissions.

Strengths and Limitations

This study is timely given the growing interest in and research activity on digital health care interventions in modern health services. Good quality evidence to inform policy and best practices in the field is needed. Our trial implemented and evaluated a rigorously developed and theoretically based digital intervention with real potential to improve patient outcomes and the efficiency of services. The trial was sufficiently large to provide strong signals about the likely impact of using the ASICA intervention on participants' psychological well-being and quality of life, although a larger trial with a sample size calculation informed by these results will be needed to provide definitive evidence of psychological benefit. Furthermore, the trial was designed to capture how well potential recipients of a digital intervention actually used it. The trial also measured the psychological variables (self-efficacy, intention, and planning) that are most predictive of continuing behavior change [19].

The trial has informed on the overall feasibility of ASICA being used by survivors of melanoma. It has also provided useful information about trial procedures and crucially enabled insight into practical issues relating to the use of ASICA from the perspective of the different population groups that could take part in a definitive trial powered on clinical outcomes and among whom the intervention would ultimately be implemented. The use of the 2 study sites has provided confidence that individuals in remote locations can be monitored successfully by an appropriately skilled dermatology nurse practitioner.

Less affluent individuals were underrepresented in the participants. In some ways, this reflects the demographic profile of melanoma in the United Kingdom and, therefore, the likely future users of ASICA. By contrast, it emphasizes that it is challenging to recruit those of lower economic status to clinical trials, with the resultant effect of increasing "health data poverty" regarding how those with lower economic status engage with technology to manage their health [24]. Specifically, in this trial, it means that we lack definitive detailed knowledge of how effectively deprived individuals could or would use the ASICA intervention, which may hinder future optimization of the intervention and its wider implementation. However, it may be that future development of ASICA could include a web-accessible demonstration that might be disseminated using social media, and this could enable us to reach groups that are harder to recruit to trials using traditional recruitment mechanisms [25]. However, this is an important point and emphasizes the importance of considering methods to increase demographic equity of recruitment in digital health care trials going forward [25]. A further point to note is that there were differing degrees of adherence to the intervention displayed by the intervention group. Although adherence was not a prespecified outcome for this study, data on adherence patterns were collected and will be reported separately.

ASICA represents a complex intervention consisting of 3 interconnecting components: a prompt to conduct a TSSE, an app to support the conduction and reporting of a monthly TSSE, and a clinical response where concerns were raised. The challenges of evaluating complex interventions and of being certain of how the complex components have achieved any observed effects are well described. To provide the best opportunity to understand how our intervention worked, we first developed it carefully and sequentially with potential users in a series of developmental steps [19]. Second, we measured our primary and secondary outcomes using established and validated instruments [20]. Third, we conducted parallel qualitative interviews with a sample of participants to obtain a clearer understanding of how ASICA operates in the field. These data are beyond the scope of this paper but will be reported separately. However, there remains the challenge inherent in all evaluations of being certain of how intervention components have operated together to produce the apparent effects reported in this paper.

Context With Other Literature

Evidence for the place of digital technology to support those at high risk of melanoma as well as survivors of melanoma is accumulating. A trial in the East of England randomized 119 of 238 people at high risk of melanoma to use a smartphone skin self-monitoring app for 12 months. The study found no increase in skin self-monitoring behavior or skin consultation in the intervention group but, equally, found no evidence of increased melanoma worry. This adds to our finding that digitally supported skin self-monitoring is not psychologically harmful [26]. ASICA users also reported having checked their skin more regularly and thoroughly during the study year, and this seems to have resulted in a greater number of subsequent GP appointments and skin-related hospital admissions. This is consistent with an earlier study in which recipients of an educational program to increase TSSE were found to have increased rates of skin surgery [13]. It could be that increased TSSE practice does make individuals more vigilant and more inclined to seek medical advice for concerning skin lesions, with a corresponding increase in biopsies to establish a definitive diagnosis.

A possible limitation of the ASICA intervention is that it is relatively "low-tech" and does not use the latest technologies, such as teledermoscopy or artificial intelligence. A study in Queensland, Australia, randomized half of 234 participants with at least two risk factors for melanoma to use a smartphone-based dermatoscope for skin self-monitoring, with the control being naked-eye skin self-monitoring for 2 months. Mobile teledermoscopy did not increase sensitivity for detection of skin cancers [27]. In terms of artificial intelligence, a recent review including 9 studies of 6 different algorithm-based smartphone apps concluded that the apps could not be relied upon to detect melanoma or other skin cancers. The reviewers suggested that test performance is likely to be poorer than reported if the apps are used in clinically relevant populations and by their intended users [28]. In light of the data presented here, it appears that our approach has the potential to offer efficient and effective digital survivorship care for patients with melanoma in the short to medium term.

Adding human support is also known to promote engagement in many interventions [29]. A key feature of our intervention compared with similar interventions for skin cancer was that it enabled participants who had raised concerns to interact via telephone and the internet to receive support and guidance from a dermatology nurse practitioner. The beneficial role of a human guide in promoting engagement with digital interventions has been noted previously; for example, by a systematic review of 14 studies of internet-based mental health interventions [30].

Conclusions and Implications

Using ASICA did not worsen psychological well-being and appeared to reduce anxiety and depression and improve quality of life in this demographically diverse group of survivors of melanoma. ASICA users also reported performing more regular TSSE and having greater confidence in conducting and planning it. Overall, these findings reinforce the potential for ASICA to support survivors of melanoma in the future. Further work could focus on incorporating elements of artificial intelligence and automation to increase efficiency and improve adherence [29].

Acknowledgments

The authors gratefully acknowledge Joanna Kaniewska, Anne Duncan, and Alison MacDonald (trial management) for their contributions to the protocol and management of the study and Andrea Fraser for secretarial support and data coordination. They also acknowledge Bolanle Birkinns and Susie Hall, who were the research nurses who trained participants and collected case note data at the Aberdeen and Cambridge sites, respectively. The authors thank Mr Mark Forrest and Mr Michael Chung for supporting the digital aspects of the intervention and data collection. They also thank Ms Ilja De Vries and her team from Medical Illustration for providing digital skin maps at the Aberdeen site and Mr Mark Bartley and the Medical Photography team at Addenbrooke's Media Studio for providing skin maps for the Cambridge participants. The authors also thank Dr Aileen Neilson, who provided advice on collecting data about service use. They also wish to acknowledge the contribution of Rebecca Woods, Patricia Fairbrother, and Dr Doug Smith, who were members of the trial steering committee. The authors also acknowledge the 19 people affected by melanoma who participated in their early feasibility study. This study was supported by a grant from a Cancer Research UK Population Research Committee project award (C10673/A21685). The views and opinions expressed herein are those of the authors and do not necessarily reflect those of Cancer Research UK. The funder (through their peer review and funding board review process) approved the study proposal but had no role in the collection, analysis, or interpretation of the data; the writing of the report; or the decision to submit this paper for publication. The Health Services Research Unit, University of Aberdeen, receives core funding from the Chief Scientist Office of the Scottish Government Health Directorates.

Data Availability

The intellectual property of the Achieving Self-directed Integrated Cancer Aftercare intervention is held by the University of Aberdeen. Regulatory approval and ethical approval received from the participants makes it possible for data collected during this study (including anonymized individual patient data) and a data dictionary defining each field within the data set to be made available to other bona fide researchers subject to regulatory approvals and the agreement of the principal investigator (PM). Other related documents (including the study protocol, statistical analysis plan, study questionnaires, case report forms, consent forms, and invitation letters) are available from the corresponding author upon request. Data will be made available from publications through application to the corresponding author. The participants have been assured that no data that could personally identify them will be shared in any circumstance, and that any data shared will be the minimum required to address the needs of the applicant. Data-sharing requests should be made to the principal investigator and will be granted only upon careful consideration of the specific case made for why the data are to be shared, how they are to be used, and the likely outcome of their use. Decisions to share data will only be made in light of advice from the regulatory bodies approving the study and from Research and Innovation, University of Aberdeen. Where a decision is made to share data, we will ensure that secure transfer protocols are used and that optimal security is used by the data recipient. Upon application to the corresponding author, we will also provide copies of the study protocol, statistical analysis plan, and other relevant study documentation such as informed consent forms. Data are available for sharing from June 23, 2021. The data will be made available by the corresponding author (PM).

Authors' Contributions

PM conceived the study with intellectual input from JM, JA, MJ, SH, and WB. ST, GM, and AL contributed advice on intervention design, study design, power calculations, and statistical analysis. ST, LC, and GM provided advice on trial design. FW, KR, CP, AD, WB, and NB provided advice on clinical aspects. DA conducted the study analysis with direction from AL, GM, and PM. PM and DA verified the study data. PM wrote the manuscript with comments from all authors. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
CONSORT eHEALTH Checklist (V 1.6.2).
[PDF File (Adobe PDF File), 88 KB - cancer_v8i3e37539_app1.pdf]

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Abbreviations

ASICA: Achieving Self-directed Integrated Cancer Aftercare
CONSORT: Consolidated Standards of Reporting Trials
GP: general practitioner
IRR: incidence rate ratio
NHS: National Health Service
TSSE: total skin self-examination

Edited by A Mavragani; submitted 25.02.22; peer-reviewed by G Black, R Zhao, C Fleming; comments to author 24.06.22; revised version received 06.07.22; accepted 11.07.22; published 08.09.22.

Please cite as:
Murchie P, Constable L, Hall S, Brant W, Allan J, Johnston M, Masthoff J, Lee A, Treweek S, Ayansina D, Proby C, Rahman K, Walter F, Burrows N, Durrani A, Maclennan G
The Achieving Self-directed Integrated Cancer Aftercare Intervention for Detection of Recurrent and Second Primary Melanoma in Survivors of Melanoma: Pilot Randomized Controlled Trial
JMIR Cancer 2022;8(3):e37539
URL: https://cancer.jmir.org/2022/3/e37539
doi:10.2196/37539
PMID:36074560

Original Paper

Characteristics of Users of the Cook for Your Life Website, an Online Nutrition Resource for Persons Affected by Cancer: Descriptive Study

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Abstract

Background: Accessible nutrition resources tailored to patients with cancer, caregivers of cancer survivors, and people interested in cancer prevention are limited. Cook for Your Life is a bilingual (ie, English and Spanish) website providing science-based, nutrition information for people affected by cancer.

Objective: The aim of this study was to describe the characteristics of Cook for Your Life website users.

Methods: In December 2020, Cook for Your Life website visitors at least 18 years old were invited to participate in an online English-language survey. A Spanish version was offered in April 2021. Demographic, health, and cooking characteristics were collected. Persons with a cancer history were asked about treatment and side effects. Data were analyzed through December 2021 on those completing over half of the survey. Three groups were compared: people with a history of cancer diagnosis, caregivers of cancer survivors, and the general public (ie, people without a cancer history). Website use data were also compared.

Results: Among English-language respondents, 3346 initiated the survey and 2665 (79.65%) completed over half of the questions. Of these, 54.82% (n=1461) had a cancer diagnosis, 8.26% (n=220) were caregivers, and 36.92% (n=984) were from the general public. English-language respondents were US residents (n=2054, 77.07%), with some from Europe (n=285, 10.69%) and Canada (n=170, 6.38%). Cancer survivors were most likely 55 years of age or older, female, non-Hispanic White, with incomes over US $100,000, and college educated. Caregivers and the general public were younger and more racially and geographically diverse. The most common cancer malignancies among English-language cancer survivors were breast (629/1394, 45.12%) and gastrointestinal (209/1394, 14.99%). For Spanish-language respondents, 942 initiated the survey; of these, 681 (72.3%) were analyzed. Of the 681 analyzed, 13.5% (n=92) were cancer survivors, 6.8% (n=46) were caregivers, and 79.7% (n=543) were from the general public. Spanish-language respondents were also more likely to be female and highly educated, but were younger, were from South or Latin America, and had incomes less than US $30,000. Among Spanish-language cancer survivors, breast cancer (27/81, 33%) and gastrointestinal cancer (15/81, 19%) were the most common diagnoses. Website use data on over 2.2 million users from December 2020 to December 2021 showed that 52.29% of traffic was in English and 43.44% was in Spanish. Compared to survey respondents, a higher proportion of website users were male, younger, and from South or Central America and Europe.

Conclusions: Cook for Your Life website users were demographically, socioeconomically, and geographically diverse, especially English-language respondents without a cancer history and all Spanish-language respondents. Improvements on website user diversity and reach for all patients with cancer and research on effective strategies for using this digital platform to support cancer prevention, treatment, and survivorship will continue.

Trial Registration: ClinicalTrials.gov NCT04200482; https://www.clinicaltrials.gov/ct2/show/NCT04200482

(JMIR Cancer 2022;8(3):e37212) doi:10.2196/37212

KEYWORDS

oncology nutrition; eHealth; website use; bilingual

Introduction

Access to science-based nutrition information is vital for all persons affected by cancer, which includes those with a cancer diagnosis, caregivers of patients with cancer and survivors, and those interested in improving their diets for cancer prevention. For patients with cancer who are undergoing treatment, healthy nutrition is an important factor for maintaining energy, improving treatment tolerance and response, reducing cancer symptoms, and addressing the side effects of cancer treatments [1-5]. For cancer survivors, eating a nutritious diet may lower the risk of cancer recurrence and the development of other comorbid diseases, and may help to improve and maintain a high quality of life [6,7]. Patients with cancer and their caregivers have expressed the need to improve their nutrition knowledge, increase self-efficacy about optimal nutrition care, and have greater access to nutrition support [8-10]. Generally, most people are motivated to eat a nutritious diet to reduce the risk of developing many chronic diseases, including cancer, and to improve their overall health.

However, accessible, evidence-based dietary and nutrition resources tailored to the needs of people affected by cancer are limited [11,12]. Indeed, a national survey of 1073 cancer survivors reported that 98% of respondents rated nutrition as important for their cancer care, but only 39% had interacted with a registered dietician [13]. Additionally, a cross-sectional survey conducted among 315 breast cancer survivors reported that 75% used internet searches as their primary source of nutrition advice [14]. This indicates the need for, and importance of, providing clear, relevant, and practical online nutrition education that is backed by sound scientific research.

Cook for Your Life [15] is a website with a broad focus of providing science-based nutrition and culinary education for cancer prevention and for support during cancer treatment and survivorship. Cook for Your Life was acquired by the Fred Hutchinson Cancer Center (Fred Hutch) in 2019 (Textbox 1 [16-18]) and was relaunched in December 2020 with updated features, such as the delivery of bilingual (ie, Spanish and English) videos, recipes, and nutrition education content. Cook for Your Life is funded by Fred Hutch and scientific research grants and does not accept money for advertising or from private or for-profit corporations. Furthermore, all of the Cook for Your Life website content is approved by a board-certified, registered dietician specializing in oncology nutrition, who ensures that all information posted follows the Oncology Nutrition for Clinical Practice guidelines [19].

When the website was relaunched in December 2020, a survey on the English language site was offered to visitors of the website. In April 2021, a Spanish version of the survey was added. The objective of this paper is to describe overall website use and findings from the English and Spanish online user surveys. Improving our knowledge about Cook for Your Life website users is key to understanding how and who uses the website and to determine how effectively we are reaching patients with cancer and survivors, caregivers, and the general population interested in cancer nutrition. With this information, we will be better able to adapt the website content to meet users' needs and appropriately use the website as a resource and tool in the development of new health interventions to improve cancer prevention, treatment, and survivorship.

Textbox 1. History of the Cook for Your Life website.

- Cook for Your Life was a nonprofit organization founded in New York City in 2007 by AOG, a three-time cancer survivor. Recognizing that her culinary knowledge helped her better manage the side effects of her chemotherapy treatment, AOG began sharing cooking tips and recipes with other patients with cancer undergoing treatment. These efforts ultimately resulted in free, in-person cooking classes focused on healthy nutrition for patients with cancer and survivors, which were offered through New York City–based cancer centers and community organizations. One of the classes, "Cocinando Saludable, Viviendo Saludable: Promoviendo las compras, el concinar y comer saludable en los que han sobrevivido el cáncer de seno (Healthy Cooking, Healthy Life: Promoting ways to shop, cook and eat healthy foods among breast cancer survivors)," was tailored for Latina breast cancer survivors.
- In 2009, AOG met HG, a cancer epidemiologist and cancer prevention scientist, when she was a faculty member at Columbia University's Mailman School of Public Health. With funding from the National Cancer Institute (NCI), they developed AOG's program into a formal curriculum and tested it in the Cocinar Para Su Salud (Cook for Your Health) study (ClinicalTrials.gov NCT01414062) [16,17]. In 2012, AOG founded the Cook for Your Life website [15], recognizing that sharing tips and recipes online could broaden the reach to patients with cancer and survivors worldwide. Using findings from the Cocinar Para Su Salud study, additional NCI funding was obtained to further develop and test the program and include an online component using the Cook for Your Life website in the Mi Vida Saludable (My Healthy Life) trial (ClinicalTrials.gov NCT02780271) [18]. The website became bilingual (ie, English and Spanish) in 2016.
- In 2017, HG moved her research program to the Fred Hutchinson Cancer Center (formerly, the Fred Hutchinson Cancer Research Center) in Seattle, and upon AOG's retirement in 2019, the Cook for Your Life website was acquired by the Fred Hutchinson Cancer Center. The website has subsequently been used as a nutrition tool and resource for new trials testing digital mobile health interventions to improve lifestyle behaviors among cancer survivors and individuals at risk of developing cancer, with a focus on underserved communities (ClinicalTrials.gov NCT04081298; ClinicalTrials.gov NCT04200482).

Methods

Website Analytics

The Cook for Your Life website was built on a WordPress platform and is hosted on Amazon Web Services servers. Web traffic and use data are available from Google Analytics. Traffic data includes the number of new and returning users and number of page views. Web use data on all users includes metrics such as demographic characteristics, behavior on the site, country of residence, and type of device used (eg, mobile or desktop). Web analytics data can be viewed in real time or over specified date ranges.

Survey Design and Administration

An online survey with questions about demographic characteristics, health and cooking behaviors, and cancer history was created. Usability testing by study staff was conducted to check the survey branching logic and gauge length of time to complete. The English-language version of the survey was released on December 10, 2020, the same day the Cook for Your Life website was relaunched by Fred Hutch. The survey was released in Spanish on April 15, 2021. As an incentive, survey respondents received a customized, downloadable nutrition e-book upon survey completion, either in English or Spanish. Respondents were required to self-report being at least 18 years of age to participate. The Spanish version of the survey was identical to the English version in content and recruitment for participation.

Public-facing visitors to the website were invited to complete the survey through three routes. The first was via a “Volunteer to participate in a research study” link on the home page, the second was a “Get Involved” link in the global navigation at the top, and the third was through a pop-up window appearing to new visitors after 45 seconds on the website. The pop-up window invited users to click a link to participate in a short survey. In addition, the online survey and the request for volunteers was promoted weekly in the website’s digital newsletter, which has a mailing list of approximately 15,000 individuals.

Ethical Considerations

A waiver of consent was submitted and approved (IRB file number 10567) by the Fred Hutch Institutional Review Board. The survey is administered using the Qualtrics Health Insurance Portability and Accountability Act–secure platform. The survey was completely voluntary. Although lengthy, respondents always had the option to stop answering survey questions at any time by closing the online window. This study was registered at ClinicalTrials.gov (NCT04200482).

Measures

Web traffic information over time was measured using number of page views per month. Website use data included number of users to the site and users’ gender, age range, and country of residence.

The online survey included questions about demographics, health status and behaviors, diet preferences, and cooking behaviors. Demographic characteristics included age group, gender, country of residence, race and ethnicity, education, household income, number of people living in their household, and whether they live in an urban, suburban, or rural area. Health status and behaviors included presence of noncancer medical conditions, smoking and drinking behavior, height and weight, frequency of fruit and vegetable consumption, and frequency of physical activity. Cooking questions included dietary preference, self-evaluation of cooking ability, frequency of cooking and eating out, and challenges of cooking. Survey respondents with a history of cancer were asked a subset of cancer-related questions, including cancer type, age at diagnosis, treatments received, and side effects of treatment.

Statistical Analysis

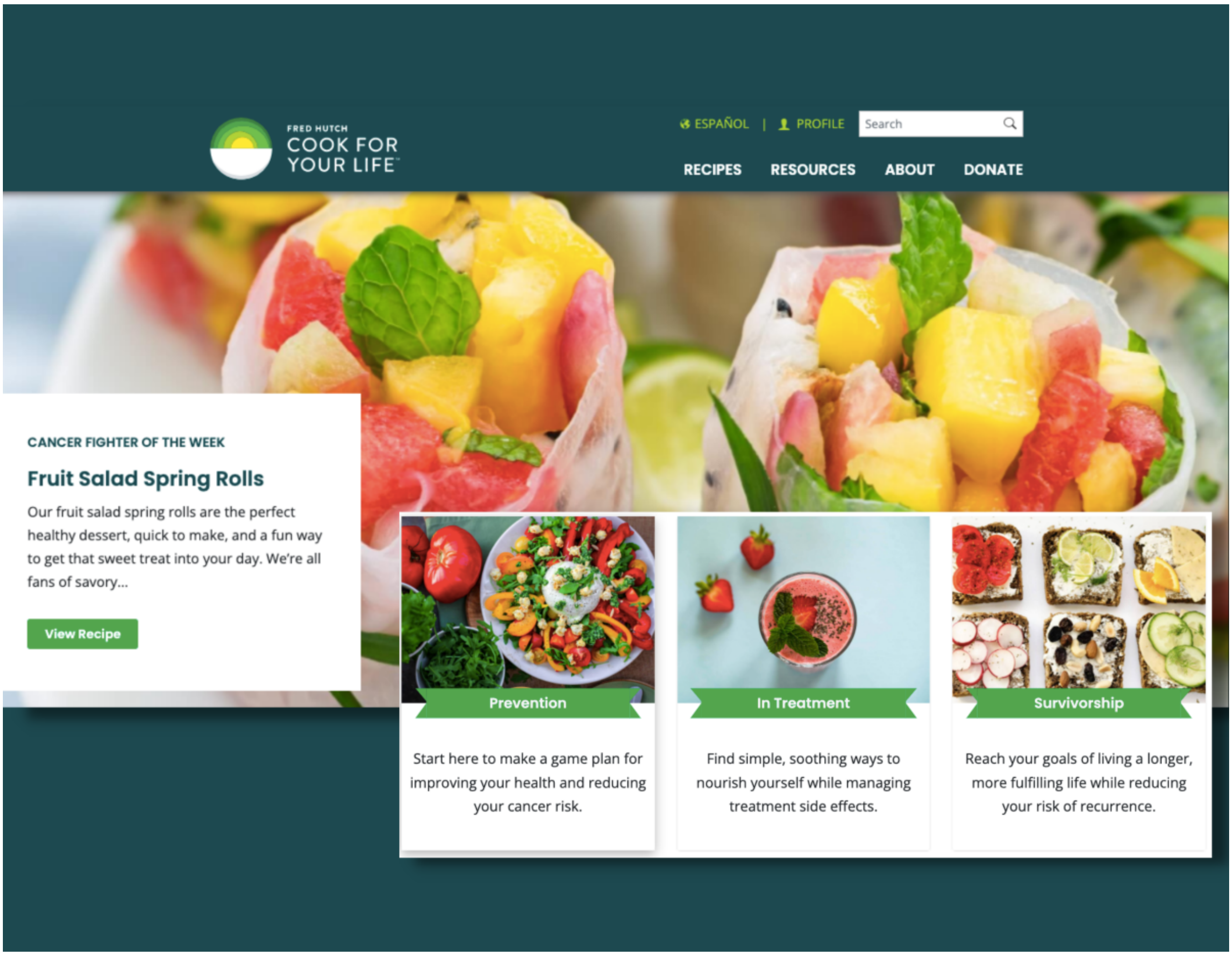
Website data from Google Analytics were reviewed for the period from December 10, 2020, to December 13, 2021, to align with the same window of time that the English-language survey data were analyzed. The Spanish-language survey data were analyzed from users who participated in the survey from April 15 to December 13, 2021. Frequencies by gender, age range, and country of residence from the web use data were compared to the survey respondents.

Respondents completing at least 50% of the survey were included in the analysis. Three mutually exclusive groups were created: (1) cancer survivors, including patients undergoing active treatment; (2) primary caregivers of a patient with cancer or a survivor; and (3) members of the general public interested in cancer prevention. Frequency distributions in the characteristics were calculated across these three groups for the total sample and were stratified by gender. Statistically significant differences comparing cancer survivors to primary caregivers and the general public were tested using the Pearson chi-square test. Distributions of cancer-related characteristics among cancer survivor survey respondents stratified by gender were also estimated.

Results

From December 10, 2020, to December 13, 2021, a total of 2.08 million unique users visited the Cook for Your Life website (Figure 1). Over this time, there were a total of 3.63 million page views. Monthly total page views for all users and among the English and Spanish sites showed that engagement decreased in the winter months, but increased in spring, stayed level over summer, and began to decrease again by the end of fall (Figure 2). On average, the number of users that visited the site every month was 165,917 (SD 19,668), with the highest number of total users visiting in October 2021 (184,835 users). Use statistics showed that 71.18% of users were female, 38.72% were between 18 and 34 years of age, and 33.15% were between 35 and 54 years of age. Only 12.53% of users were 65 years of age and older. Overall, 30.88% of users were from the United States, 27.07% were from South America, 20.91% were from Europe, and 8.80% were from Central America. Among 1.16 million users who visited the English-language version of the website, most were from the United States (51.63%), the United Kingdom (21.29%), and Canada (9.87%). On the Spanish-language version of the website, out of 1.08 million users, most were from Argentina (25.12%), Spain (14.24%), and Mexico (12.61%).

Figure 1. Screenshot of the Cook for Your Life website.



CANCER FIGHTER OF THE WEEK

Fruit Salad Spring Rolls

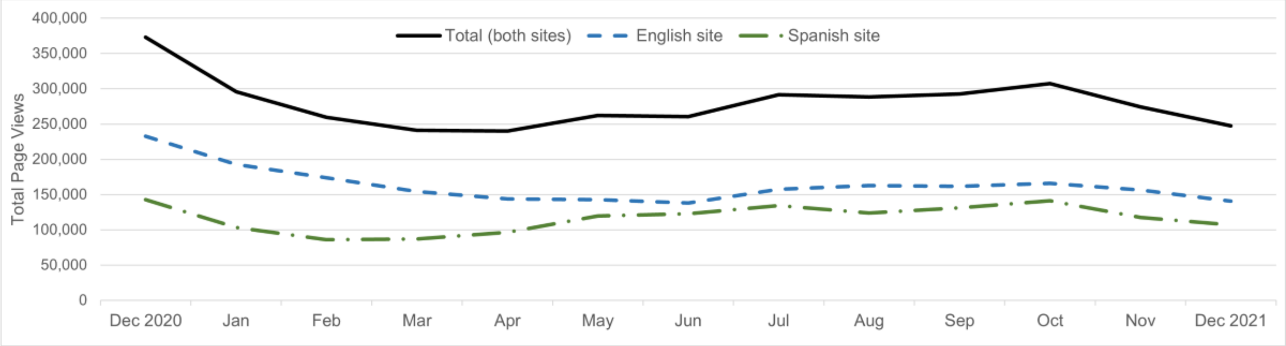
Our fruit salad spring rolls are the perfect healthy dessert, quick to make, and a fun way to get that sweet treat into your day. We're all fans of savory...

Start here to make a game plan for improving your health and reducing your cancer risk.

Find simple, soothing ways to nourish yourself while managing treatment side effects.

Reach your goals of living a longer, more fulfilling life while reducing your risk of recurrence.

Figure 2. Cook for Your Life website total page views, and page views by English- and Spanish-language website users from December 2020 to December 2021.



After 1 year of data collection, 3346 website visitors initiated the English-language survey and, of these, 2665 (79.65%) completed at least 50% the survey. For the Spanish-language survey, 942 visitors initiated the survey, of whom 681 (72.3%) completed at least 50% of the survey. Among all 3346 respondents in either language, 82.79% (n=2770) reported being female, 78.48% (n=2626) were college educated, 78.75% (n=2635) were omnivores, 70.56% (n=2361) rated their cooking skills as intermediate, 62.67% (n=2097) cooked five or more times per week, and 69.04% (n=2310) ate out zero times or one time per week. English-language compared to Spanish-language respondents were more likely to report being a US resident (77.1% vs 11.9%), over 65 years of age (38.3% vs 18.5%), White (80.9% vs 38.0%), non-Hispanic (83.4% vs 5.7%), a nonsmoker (95.7% vs 89.3%), in a household with income over US $60,000 (45.0% vs 13.5%), and engaging in moderate-to-vigorous physical activity (84.9% vs 73.7%). English-language respondents from outside the United States were mainly from Europe (46.6%) or Canada (27.8%), while Spanish-language respondents were more likely to report living in South or Latin America (79.4%).

Characteristics comparing cancer survivors, primary caregivers, and the general public are provided in Tables 1 and 2. The distributions by group for English-language respondents (n=2665) were as follows: 1461 (54.82%) cancer survivors, 220 (8.26%) primary caregivers, and 984 (36.92%) members of the general public. Among English-language respondents overall, cancer survivors compared to either caregivers or the general public were more likely to be US residents, over 65 years of age, non-Hispanic, and nonsmokers, as well as to report eating fruit every day. By gender, demographic characteristics of cancer survivors, caregivers, and the general public for males only and females only were similar in distribution to the overall sample (Tables S1 and S2 in Multimedia Appendix 1). For health characteristics, male cancer survivors were less likely to drink alcohol and to eat over 1 cup of vegetables compared to male caregivers and males from the general public (Table S3 in Multimedia Appendix 1). Female cancer survivors were less likely to be smokers and more likely to eat fruit every day compared to female caregivers and females from the general public (Table S4 in Multimedia Appendix 1).

Of the 681 Spanish-language respondents analyzed, 92 (13.5%) were cancer survivors, 46 (6.8%) were primary caregivers, and 543 (79.7%) were members of the general public. For Spanish-language respondents overall, cancer survivors were more likely to be over 65 years of age and nondrinkers relative to caregivers and members of the general public, but they were generally similar in all other characteristics. By gender, demographic and health characteristics for males across all three groups were similar in distribution to the overall sample of Spanish-language respondents (Tables S1 and S3 in Multimedia Appendix 1). For females, cancer survivors compared to members of the general public were more likely to be over 65 years of age, nonresidents of South or Latin America, hypertensive, and nondrinkers (Tables S2 and S4 in Multimedia Appendix 1).

Clinical characteristics of cancer survivors by gender are shown in Table 3. Among 201 male English-language respondents, the most reported malignancies were gastrointestinal (31.8%) and genitourinary (28.4%). The majority (52.2%) of male patients with cancer were diagnosed after 65 years of age. Over half (n=111) reported being in active cancer treatment, with chemotherapy as the most frequent type of treatment (n=78, 70.3%). Of male patients with cancer in treatment, 87.4% (97/111) reported experiencing side effects in the previous week, the most common being fatigue (72/111, 64.9%), decreased appetite (39/111, 35.1%), and sad feelings (35/111, 31.5%). Among 1177 female English-language respondents, breast cancer was the most reported cancer diagnosis (n=624, 53.02%), followed by gastrointestinal (n=142, 12.06%) and gynecologic (n=124, 10.54%) malignancies. Most (n=477, 40.53%) were diagnosed from 36 to 55 years of age. About half (n=581, 49.36%) reported being in active cancer treatment, with most undergoing chemotherapy (274/581, 47.2%) and endocrine therapy (183/581, 31.5%), and 80.4% (467/581) having had surgery. Of female patients with cancer in treatment, 91.7% (533/581) reported experiencing side effects in the previous week, with the most common being fatigue (373/581, 64.2%), anxiety (201/581, 34.6%), and insomnia (190/581, 32.7%). Among 13 male Spanish-language respondents, the two most common malignancies were gastrointestinal and genitourinary (both 4/13, 31%). Nearly half (6/13, 46%) were diagnosed between 36 and 55 years of age. The majority (11/13, 85%) were in active treatment, and the most common side effects reported in the previous week were anxiety, sad feelings, and general pain (all 4/13, 36%). For the 67 female Spanish-language respondents with cancer history, 40% (27/64) were diagnosed with breast cancer and 48% (32/67) were diagnosed between 36 and 55 years of age. Less than 40% (26/67) were in active treatment, with the most common side effects reported in the past week being fatigue (13/26, 50%), nausea (12/26, 46%), and insomnia (12/26, 46%).

Table 1. Frequency of demographic characteristics of Cook for Your Life English- and Spanish-language respondents who completed at least 50% of the online survey.

Characteristic	English respondents (n=2665), n (%)			Spanish respondents (n=681), n (%)		
	Cancer survivors	Primary caregivers	General public	Cancer survivors	Primary caregivers	General public
Respondents by group	1461 (54.8)	220 (8.3)	984 (36.9)	92 (13.5)	46 (6.8)	543 (79.7)
Gender[a,b]						
Male	214 (14.7)	18 (8.2)	175 (17.8)	15 (16.3)	11 (23.9)	100 (18.4)
Female	1230 (84.2)	200 (90.9)	795 (80.8)	76 (82.6)	34 (73.9)	435 (80.1)
Region of residence[a,b,c]						
United States	1206 (82.7)	159 (72.3)	689 (70.2)	15 (16.5)	5 (10.9)	61 (11.3)
Africa	13 (0.9)	1 (0.5)	12 (1.2)	0 (0)	0 (0)	0 (0)
Asia or Pacific Islands	42 (2.9)	11 (5.0)	30 (3.1)	1 (1.1)	0 (0)	0 (0)
Europe	95 (6.5)	23 (10.5)	167 (17.0)	13 (14.3)	5 (10.9)	35 (6.5)
Middle East	2 (0.1)	1 (0.5)	3 (0.3)	0 (0)	0 (0)	0 (0)
Canada	84 (5.8)	15 (6.8)	71 (7.2)	0 (0)	0 (0)	3 (0.6)
South or Latin America	17 (1.2)	10 (4.6)	10 (1.0)	62 (68.1)	36 (78.3)	443 (81.9)
Age (years)[a,b,c]						
18-35	30 (2.1)	19 (8.6)	105 (10.7)	6 (6.5)	8 (17.4)	99 (18.2)
36-55	391 (26.8)	79 (35.9)	276 (28.1)	35 (38.0)	20 (43.5)	223 (41.1)
56-65	407 (27.9)	64 (29.1)	273 (27.7)	25 (27.2)	9 (19.6)	130 (23.9)
66-75	436 (29.8)	49 (22.3)	242 (24.6)	22 (23.9)	7 (15.2)	71 (13.1)
≥76	197 (13.5)	9 (4.1)	88 (8.9)	4 (4.4)	2 (4.4)	20 (3.7)
Race[a]						
American Indian	9 (0.6)	3 (1.4)	6 (0.6)	2 (2.2)	2 (4.4)	2 (0.4)
Asian, Native Hawaiian, or Pacific Islander	46 (3.2)	15 (6.8)	37 (3.8)	1 (1.1)	0 (0)	3 (0.6)
Black or African American	49 (3.4)	10 (4.6)	48 (4.9)	2 (2.2)	0 (0)	5 (0.9)
White	1216 (83.2)	164 (74.6)	775 (78.8)	37 (40.2)	21 (45.7)	201 (37.0)
Mixed race	85 (5.8)	17 (7.7)	71 (7.2)	31 (33.7)	17 (37.0)	234 (43.1)
Other	18 (1.2)	4 (1.8)	14 (1.4)	8 (8.7)	2 (4.4)	45 (8.3)
Prefer not to say	38 (2.6)	7 (3.2)	33 (3.4)	11 (12.0)	4 (8.7)	53 (9.8)
Ethnicity[a,b,c]						
Hispanic	81 (5.5)	21 (9.6)	60 (6.1)	73 (79.4)	40 (87.0)	480 (88.4)
Non-Hispanic	1258 (86.1)	177 (80.5)	787 (80.0)	11 (12.0)	2 (4.4)	26 (4.4)
Prefer not to say	122 (8.4)	22 (10.0)	137 (13.9)	8 (8.7)	4 (8.7)	37 (8.7)
Education[b]						
Less than high school	22 (1.5)	6 (2.7)	35 (3.6)	6 (6.5)	5 (10.9)	40 (7.4)
High school graduate or GED[d]	111 (7.6)	13 (5.9)	80 (8.1)	13 (14.1)	3 (6.5)	51 (9.4)
Trade school or associate’s degree	127 (8.7)	21 (9.6)	105 (10.7)	11 (12.0)	5 (10.9)	51 (9.4)
Some college but not a graduate	211 (14.4)	32 (14.6)	150 (15.2)	14 (15.2)	10 (21.7)	102 (18.8)
College degree or more	985 (67.4)	147 (66.8)	610 (62.0)	48 (52.2)	23 (50.0)	294 (54.1)
Other	5 (0.3)	1 (0.5)	4 (0.4)	0 (0)	0 (0)	5 (0.9)
Household income (US $)[b]						

Characteristic	English respondents (n=2665), n (%)			Spanish respondents (n=681), n (%)		
	Cancer survivors	Primary caregivers	General public	Cancer survivors	Primary caregivers	General public
0-30,000	183 (12.5)	38 (17.3)	169 (17.2)	38 (41.3)	21 (45.7)	208 (38.3)
30,001-60,000	227 (15.5)	38 (17.3)	171 (17.4)	16 (17.4)	5 (10.9)	48 (8.8)
60,001-100,000	294 (20.1)	44 (20.0)	189 (19.2)	4 (4.4)	3 (6.5)	37 (6.8)
>$100,000	399 (27.3)	47 (21.4)	225 (22.9)	5 (5.4)	3 (6.5)	40 (7.4)
Prefer not to say	358 (24.5)	53 (24.1)	230 (23.4)	29 (31.5)	14 (30.4)	210 (38.7)
Number of people in household[a,b]						
1	297 (20.3)	23 (10.5)	232 (23.6)	9 (9.8)	7 (15.2)	60 (11.1)
2	762 (52.2)	108 (49.1)	428 (43.5)	29 (31.5)	9 (19.6)	155 (28.6)
3	183 (12.5)	42 (19.1)	125 (12.7)	19 (20.7)	11 (23.9)	124 (22.8)
≥4	219 (15.0)	47 (21.4)	199 (20.2)	35 (38.0)	19 (41.3)	204 (37.6)
Area of residence						
Urban	455 (31.1)	78 (35.5)	351 (35.7)	64 (69.6)	34 (73.9)	425 (78.3)
Suburban	691 (47.3)	100 (45.5)	429 (43.6)	22 (23.9)	7 (15.2)	78 (14.4)
Rural	315 (21.6)	42 (19.1)	204 (20.7)	6 (6.5)	5 (10.9)	40 (7.4)

[a] *P*≤.05 comparing patients with cancer and primary caregivers among English-language survey respondents.

[b] *P*≤.05 comparing patients with cancer and general public among English-language survey respondents.

[c] *P*≤.05 comparing patients with cancer and general public among Spanish-language survey respondents.

[d] GED: General Education Diploma.

Table 2. Frequency of health characteristics of Cook for Your Life English- and Spanish-language respondents who completed at least 50% of the online survey.

Characteristic	English respondents (n=2665), n (%)			Spanish respondents (n=681), n (%)		
	Cancer survivors	Primary caregivers	General public	Cancer survivors	Primary caregivers	General public
Cardiometabolic condition[a]						
Chest pain	30 (2.4)	7 (3.4)	23 (2.4)	2 (2.3)	1 (2.4)	20 (3.8)
Diabetes or prediabetes	200 (14.3)	29 (13.9)	153 (16.0)	16 (18.2)	7 (16.7)	78 (14.8)
Hypertension	338 (24.2)	55 (26.4)	250 (26.2)	26 (29.6)	9 (21.4)	116 (22.1)
High cholesterol	290 (20.7)	45 (21.6)	215 (22.5)	18 (20.5)	14 (33.3)	90 (17.1)
Heart disease	66 (4.7)	10 (4.8)	45 (4.7)	2 (2.3)	3 (7.1)	19 (3.6)
Vascular disease	37 (2.6)	7 (3.4)	27 (2.8)	2 (2.3)	1 (2.4)	6 (1.1)
Current smoker[a,b]	35 (2.5)	11 (5.3)	64 (6.7)	8 (9.1)	7 (16.7)	55 (10.5)
Drinks alcohol[b,c,d]	625 (45.5)	88 (45.4)	540 (59.0)	22 (25.3)	20 (48.8)	199 (39.2)
Number of alcoholic drinks[a,b] (out of those who drink alcohol, as reflected in "Total" row)						
Total	619 (100)	86 (100)	535 (100)	22 (100)	20 (100)	195 (100)
1-2 per week	320 (51.7)	43 (50.0)	204 (38.1)	14 (63.6)	12 (60.0)	133 (68.2)
3-6 per week	191 (30.9)	23 (26.7)	187 (35.0)	6 (27.3)	6 (30.0)	43 (22.1)
Every day	57 (9.2)	4 (4.7)	56 (10.5)	1 (4.6)	1 (5.0)	9 (4.6)
≥2 per day	51 (8.2)	16 (18.6)	88 (16.5)	1 (4.6)	1 (5.0)	10 (5.1)
Days per week that fruit is eaten[a,b]						
None	36 (2.7)	6 (3.1)	37 (4.1)	3 (3.5)	1 (2.4)	16 (3.2)
1-3 days	255 (18.7)	53 (27.8)	234 (25.8)	24 (27.6)	10 (24.4)	169 (33.6)
4-6 days	417 (30.6)	64 (33.5)	276 (30.4)	31 (35.6)	17 (41.5)	149 (29.6)
Every day	653 (48.0)	68 (35.6)	360 (39.7)	29 (33.3)	13 (31.7)	169 (33.6)
Amount of fruit when eating (out of those who eat fruit, as reflected in "Total" row)						
Total	1318 (100)	184 (100)	860 (100)	83 (100)	40 (100)	483 (100)
<1 cup	853 (64.7)	116 (63.0)	548 (63.7)	50 (60.2)	18 (45.0)	234 (48.5)
1-2 cups	355 (26.9)	50 (27.2)	235 (27.3)	23 (27.7)	15 (37.5)	176 (36.4)
>2 cups	110 (8.4)	18 (9.8)	77 (9.0)	10 (12.1)	7 (17.5)	73 (15.1)
Days per week that vegetables are eaten						
None	12 (0.9)	0 (0)	9 (1.0)	2 (2.3)	0 (0)	5 (1.0)
1-3 days	138 (10.2)	20 (10.5)	103 (11.5)	22 (25.6)	10 (24.4)	123 (24.7)
4-6 days	420 (31.0)	70 (36.8)	288 (32.1)	32 (37.2)	15 (36.6)	190 (38.1)
Every day	784 (57.9)	100 (52.6)	497 (55.4)	30 (34.9)	16 (39.0)	181 (36.3)
Amount of vegetables when eating[a,b] (out of those who eat vegetables, as reflected in "Total" row)						
Total	1321 (100)	184 (100)	849 (100)	84 (100)	41 (100)	473 (100)
<1 cup	775 (58.7)	95 (51.6)	442 (52.1)	48 (57.1)	23 (56.1)	225 (47.6)
1-2 cups	437 (33.1)	65 (35.3)	308 (36.3)	27 (32.1)	14 (34.2)	173 (36.6)
>2 cups	109 (8.3)	24 (13.0)	99 (11.7)	9 (10.7)	4 (9.8)	75 (15.9)
Days per week of MVPA[e]						
None	208 (15.6)	28 (15.2)	123 (14.4)	25 (29.4)	7 (17.1)	127 (26.6)
1-3 days	475 (35.7)	74 (40.2)	319 (37.3)	35 (41.2)	22 (53.7)	208 (43.5)

Characteristic	English respondents (n=2665), n (%)			Spanish respondents (n=681), n (%)		
	Cancer survivors	Primary caregivers	General public	Cancer survivors	Primary caregivers	General public
4-6 days	487 (36.6)	62 (33.7)	302 (35.3)	18 (21.2)	11 (26.8)	109 (22.8)
Every day	162 (12.2)	20 (10.9)	112 (13.1)	7 (8.2)	1 (2.4)	34 (7.1)
Minutes per day of MVPA[e]						
0 to <10	220 (16.5)	31 (16.9)	134 (15.7)	24 (28.2)	6 (14.6)	134 (28.0)
10 to <30	352 (26.4)	56 (30.4)	214 (25.0)	25 (29.4)	17 (41.5)	110 (23.0)
30 to <40	296 (22.2)	37 (20.1)	185 (21.6)	17 (20.0)	6 (14.6)	77 (16.1)
40 to <60	321 (24.1)	41 (22.3)	208 (24.3)	14 (16.5)	9 (22.0)	101 (21.1)
≥60	143 (10.7)	19 (10.3)	115 (13.4)	5 (5.9)	3 (7.3)	56 (11.7)

[a] *P*≤.05 comparing patients with cancer and primary caregivers among English-language survey respondents.

[b] *P*≤.05 comparing patients with cancer and general public among English-language survey respondents.

[c] *P*≤.05 comparing patients with cancer and primary caregivers among Spanish-language survey respondents.

[d] *P*≤.05 comparing patients with cancer and general public among Spanish-language survey respondents.

[e] MVPA: moderate-to-vigorous physical activity.

Table 3. Frequency of cancer-related characteristics of English- and Spanish-language patients with cancer and survivors responding to at least 50% of the Cook for Your Life website survey stratified by gender.

Characteristic	English respondents (n=1394), n (%)		Spanish respondents (n=81), n (%)	
	Male (n=201)	Female (n=1177)	Male (n=13)	Female (n=67)
Primary cancer site				
Breast	0 (0)	624 (53.0)	0 (0)	27 (40.3)
Gastrointestinal region	64 (31.8)	142 (12.1)	4 (30.8)	11 (16.4)
Gynecologic region	N/A[a]	124 (10.5)	N/A[a]	10 (14.9)
Hematologic region	24 (11.9)	102 (8.7)	0 (0)	1 (1.5)
Genitourinary region	57 (28.4)	26 (2.2)	4 (30.8)	3 (4.5)
Respiratory region (lung)	10 (5.0)	29 (2.5)	1 (7.7)	3 (4.5)
Skin	6 (3.0)	24 (2.0)	1 (7.7)	2 (3.0)
Endocrine region (thyroid)	1 (0.5)	20 (1.7)	3 (23.1)	3 (4.5)
Other	39 (19.4)	86 (7.3)	0 (0)	7 (10.5)
Age at diagnosis (years)				
18-35	8 (4.0)	62 (5.3)	1 (7.7)	10 (14.9)
36-55	38 (18.9)	477 (40.5)	6 (46.2)	32 (47.8)
56-65	50 (24.9)	355 (30.2)	2 (15.4)	16 (23.9)
>65	105 (52.2)	283 (24.0)	4 (30.8)	9 (13.4)
Undergoing treatment	111 (55.2)	581 (49.4)	11 (84.6)	26 (38.8)
Type of treatment (out of those undergoing treatment, as reflected in "Total" row)				
Total	111 (100)	581 (100)	11 (100)	26 (100)
Chemotherapy	78 (70.3)	274 (47.2)	4 (36.4)	13 (50.0)
Radiation therapy	24 (21.6)	102 (17.6)	3 (27.3)	5 (19.2)
Endocrine therapy	9 (8.1)	183 (31.5)	4 (36.4)	7 (26.9)
Targeted therapy or immunotherapy	18 (16.2)	125 (21.5)	0 (0)	2 (7.7)
Surgery	64 (57.7)	467 (80.4)	11 (100)	12 (46.2)
Side effects in past 7 days[b] (out of those with side effects, as reflected in "Total" row)				
Total	111 (100)	581 (100)	11 (100)	26 (100)
Fatigue	72 (64.9)	373 (64.2)	3 (27.3)	13 (50.0)
Anxiety	27 (24.3)	201 (34.6)	4 (36.4)	10 (38.5)
Insomnia	20 (18.0)	190 (32.7)	2 (18.2)	12 (46.2)
Sad feelings	35 (31.5)	169 (29.1)	4 (36.4)	11 (42.3)
Nausea	33 (29.7)	159 (27.4)	3 (27.3)	12 (46.2)
Dry mouth	24 (21.6)	165 (28.4)	1 (9.1)	9 (34.6)
Hot flashes	7 (6.3)	181 (31.2)	2 (18.2)	11 (42.3)
Decreased appetite	39 (35.1)	146 (25.1)	3 (27.3)	9 (34.6)
General pain	22 (19.8)	151 (26.0)	4 (36.4)	7 (26.9)
Taste changes	30 (27.0)	142 (24.4)	1 (9.1)	8 (30.8)
Constipation	23 (20.7)	143 (24.6)	2 (18.2)	8 (30.8)
Diarrhea	23 (20.7)	130 (22.4)	2 (18.2)	2 (7.7)
Mouth sores	6 (5.4)	62 (10.7)	1 (9.1)	3 (11.5)
Difficulty swallowing	16 (14.4)	40 (6.9)	1 (9.1)	5 (19.2)
Vomiting	9 (8.1)	34 (5.9)	0 (0)	4 (15.4)

[a] N/A: not applicable for men.

[b] Multiple responses possible.

Discussion

Principal Findings

The Cook for Your Life website is a bilingual science-based culinary and nutrition resource for persons affected by cancer, broadly defined as cancer survivors, caregivers of patients with cancer, and people interested in cancer prevention. An important goal of the website is to provide accessible diet and nutrition information to a wide and diverse range of people, including those from underserved populations. To improve our understanding of the website's reach, we administered a volunteer-based, nonprobability survey on the site. Analysis of these survey data indicated that survey respondents, cancer survivors in particular, were primarily living in the United States and were primarily White, non-Hispanic females who were about 55 years of age or older, highly educated, and of high socioeconomic status. This finding suggests the need to improve the reach and diversity of the Cook for Your Life website user base, especially among patients with cancer and survivors.

Further evaluation of the survey respondents showed that characteristics differed according to whether the survey was taken in English or Spanish. English-language respondents were mainly White, non-Hispanic females with high household incomes and living in the United States. English-language cancer survivors were most likely to fit this description, and most reported having breast cancer. In the United States, breast cancer is the most common malignancy among women, and incidence rates are highest among non-Hispanic White people over 60 years of age [20], which aligns with our own survey respondent profile. Furthermore, a study of nutrition needs among cancer survivors reported that breast cancer survivors expressed the most interest in receiving additional nutrition support [13], while another study found that a large proportion of breast cancer survivors seek nutrition advice online [14]. Motivators for responding to surveys, including online surveys, are knowing who is administering it, the topic area, and the length of time to finish [21]. Referrals to the Cook for Your Life website were primarily from social media or from a doctor or dietician (data not shown), so it is also possible that more women were motivated to respond because of Cook for Your Life's partnership with Fred Hutch, a well-respected and renowned cancer research organization, along with their own self-interests about cancer and nutrition.

Although cancer survivors were less diverse, English-language respondents without a history of cancer showed more gender, international, racial, and socioeconomic diversity. Spanish-language respondents were also more demographically diverse, including among those reporting a history of cancer. Website use data indicated that Cook for Your Life visitors, in general, included higher proportions of men, were younger (ie, 18-44 years old), and were more globally represented than those who responded to the survey. Furthermore, examination of the cooking questions indicated that many survey respondents cooked for themselves often and regarded their cooking skills to be intermediate, indicating that the Cook for Your Life website is attracting people with already-strong culinary interests. These findings suggest that the content and topic areas of the Cook for Your Life website are appealing to a wide range of people without a history of cancer, and the focus on reach and diversity should be concentrated mainly among patients with cancer and survivors.

While our analysis indicated acceptable demographic, socioeconomic, and geographic diversity and reach among our general users without a history of cancer, the Cook for Your Life website also aims to support nutrition needs of patients with cancer and survivors as well as cancer caregivers. Previous studies have reported that both patients with cancer and their caregivers do not receive adequate nutrition education despite expressing a desire and need for more nutrition support and information [10,11,13]. One of Cook for Your Life's goals is to be a nutrition resource for patients with cancer and caregivers of patients with cancer undergoing treatment. The literature supports the notion that a healthy diet can improve cancer therapy response and reduce side effects, such as nausea and vomiting, in patients with cancer [1-5]. The survey indicated that most patients with cancer undergoing therapy experienced side effects, which might be improved with nutrition information provided on the Cook for Your Life website. The Cook for Your Life website also serves as a resource and tool for intervention studies aimed at improving health behaviors in patients with cancer and survivors, with a specific focus on underserved populations. This emphasizes the need to ensure that website users with a cancer history are being reached. Therefore, in-depth evaluations focusing on a sampling frame of patients with cancer and survivors may be required to address specific issues, such as content appeal, accessibility, applicability, and usability.

Limitations

We acknowledge that the survey data represented only those who were agreeable to participating in an online survey and then, among those, who completed at least half of the survey. Web surveys are prone to increased error associated with coverage, sampling, and nonresponse, and those limitations apply to this analysis as well [21,22]. Compared to the respondents of the Spanish-language survey, respondents of the English-language survey were more likely to complete 50% or more of the survey. Also, a higher proportion of patients with cancer and survivors completed the English-language version, and it is likely that their health status was a stronger motivator for greater engagement in the survey. However, it is difficult to know what bias might be introduced in the findings without knowledge about the nonresponders, noncompleters, and those generally not interested in participating in surveys. For web surveys without a clear sampling frame, information about nonresponders and noncompleters cannot be obtained [22]. Coverage error (ie, internet access) is also a study limitation, and studies show that lack of coverage is more likely among non-White racial groups and those of lower socioeconomic status [23], which are the demographic groups that we most need to reach. Lastly, analysis of the race and ethnicity variables indicated that these were US-based constructs, and a large proportion of international respondents were unable to provide answers to these questions. Similarly, the household income response categories were applicable to US respondents and were likely not specific enough for international respondents from countries whose definition of "high" socioeconomic status may be at a cutoff value much lower than that of the United States.

Comparison With Prior Work

There have been a handful of science-based websites also focused on providing nutrition education and support to patients with cancer and led by cancer research or academic institutions. A publication from a research team in the Netherlands described their process of developing a website titled "Voeding en kanker info" (Nutrition and cancer info) [24], which provides nutrition education for cancer prevention as well as during and after treatment [12]. In addition to their development process, user statistics for the year after their launch (ie, May 2014-May 2015), including total page views, total visitors, and region of user's residence, were reported; however, details such as demographic, health behavior, and clinical characteristics about their users were not described [12]. A similar project of developing a web-based cookbook for pediatric patients with cancer, undertaken by the MD Anderson Cancer Center in Texas, has also been described [25] and compared to two other science-based cancer and nutrition websites, including Cook for Your Life [26]; however, information about the characteristics of their users was not provided.

Conclusions

Analysis of users who visited the Cook for Your Life website indicated acceptable demographic, socioeconomic, and geographic reach and diversity for users without a history of cancer in particular. Research to improve our knowledge about the website's user base, including understanding how people learn and apply knowledge from the website, use of specific website content, and information about website functionality, access, and application, more broadly, will continue. Work focused on improving diversity and reach among patients with cancer and survivors is needed and should include targeting patients with cancer with a clear sampling frame and through various modes of data collection.

Acknowledgments

This work was supported by funding from the Fred Hutchinson Cancer Center and the National Cancer Institute (grant R01CA186080).

Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary tables.
[DOCX File , 65 KB - cancer_v8i3e37212_app1.docx]

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Abbreviations

Fred Hutch: Fred Hutchinson Cancer Center.

Edited by A Mavragani; submitted 10.02.22; peer-reviewed by K Balter, R Choudhury; comments to author 19.04.22; revised version received 20.05.22; accepted 05.06.22; published 05.07.22.

Please cite as:
Rillamas-Sun E, Schattenkerk L, Cobos S, Ueland K, Gaffney AO, Greenlee H
Characteristics of Users of the Cook for Your Life Website, an Online Nutrition Resource for Persons Affected by Cancer: Descriptive Study
JMIR Cancer 2022;8(3):e37212
URL: https://cancer.jmir.org/2022/3/e37212
doi:10.2196/37212
PMID:35788100

Original Paper

A Digital Educational Intervention With Wearable Activity Trackers to Support Health Behaviors Among Childhood Cancer Survivors: Pilot Feasibility and Acceptability Study

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Abstract

Background: Childhood cancer survivors are at increased risk of cardiometabolic complications that are exacerbated by poor health behaviors. Critically, many survivors do not meet physical activity guidelines.

Objective: The primary aim was to evaluate the feasibility and acceptability of *iBounce*, a digital health intervention for educating and engaging survivors in physical activity. Our secondary aims were to assess the change in survivors' physical activity levels and behaviors, aerobic fitness, and health-related quality of life (HRQoL) after participating in the iBounce program.

Methods: We recruited survivors aged 8 to 13 years who were ≥12 months post cancer treatment completion. The app-based program involved 10 educational modules, goal setting, and home-based physical activities monitored using an activity tracker. We assessed objective physical activity levels and behaviors using cluster analysis, aerobic fitness, and HRQoL at baseline and after the intervention (week 12). Parents were trained to reassess aerobic fitness at home at follow-up (week 24).

Results: In total, 30 participants opted in, of whom 27 (90%) completed baseline assessments, and 23 (77%) commenced iBounce. Our opt-in rate was 59% (30/51), and most (19/23, 83%) of the survivors completed the intervention. More than half (13/23, 57%) of the survivors completed all 10 modules (median 10, IQR 4-10). We achieved a high retention rate (19/27, 70%) and activity tracker compliance (15/19, 79%), and there were no intervention-related adverse events. Survivors reported high satisfaction with iBounce (median enjoyment score 75%; ease-of-use score 86%), but lower satisfaction with the activity tracker (median enjoyment score 60%). Parents reported the program activities to be acceptable (median score 70%), and their overall satisfaction was 60%, potentially because of technological difficulties that resulted in the program becoming disjointed. We did not observe any significant changes in physical activity levels or HRQoL at week 12. Our subgroup analysis for changes in physical activity behaviors in participants (n=11) revealed five cluster groups: *most active*, *active*, *moderately active*, *occasionally active*, and *least active.* Of these 11 survivors, 3 (27%) moved to a more active cluster group, highlighting their engagement in more frequent and sustained bouts of moderate-to-vigorous physical activity; 6 (56%) stayed in the same cluster; and 2 (18%) moved to a less active cluster. The survivors' mean aerobic fitness percentiles increased after completing iBounce (change +17, 95% CI 1.7-32.1; *P*=.03) but not at follow-up (*P*=.39).

Conclusions: We demonstrated iBounce to be feasible for delivery and acceptable among survivors, despite some technical difficulties. The distance-delivered format provides an opportunity to engage survivors in physical activity at home and may address barriers to care, particularly for regional or remote families. We will use these pilot findings to evaluate an updated version of iBounce.

Trial Registration: Australian New Zealand Clinical Trials Registry ACTRN12621000259842; https://anzctr.org.au/Trial/Registration/TrialReview.aspx?ACTRN=ACTRN12621000259842

(JMIR Cancer 2022;8(3):e38367) doi:10.2196/38367

KEYWORDS

childhood cancer; survivorship; physical activity; exercise; activity tracker; eHealth; education; behavior change

Introduction

Background

Advances in childhood cancer treatments have led to significant improvements in survival rates globally [1,2]. Despite improvements in survival rates, many childhood cancer survivors (henceforth called *survivors*) are at increased risk of developing late effects and chronic diseases such as cardiovascular disease, metabolic syndrome, and obesity [3,4]. Health behavior interventions, including physical activity promotion and engagement, are crucial for preventing or minimizing the impact of these late effects [5,6]. In addition, physical activity may have a positive influence on survivors' health-related quality of life (HRQoL) [7]. Nevertheless, many survivors do not engage in sufficient levels of physical activity [8], have poor perceptions of their activity levels [9], and have below-average fitness levels [10].

When surveyed, 60% of the survivors expressed a need for age-appropriate exercise information, and 79% reported a desire for exercise guidance [11]. A major burden for many survivors and families, especially for the 45% of this population living in rural or regional areas in Australia, is the tyranny of distance, compounded by the financial burden of travel and accommodation [12]. As a result, families from rural and regional areas have less access to supportive care, experience greater cancer-related financial hardship in survivorship than metropolitan families, and are therefore at highest risk of poor health outcomes [13,14]. Consequently, the delivery of health behavior interventions using distance-delivered technologies is a growing field to address physical inactivity and low fitness levels, as well as to improve access to services among this population [15-17].

Objectives

This study aimed to pilot *iBounce*, a distance-delivered health education intervention for fostering health behaviors (ie, physical activity to improve fitness levels) among survivors of childhood cancer. iBounce uses a slightly modified version of iEngage (BePatient), an evidence-based health education program that provides children without chronic disease with health knowledge and practical skills to improve their physical activity behaviors and strive toward achieving recommended moderate-to-vigorous physical activity (MVPA) levels. iEngage uses a digital app on a tablet connected to wearable activity trackers that record physical activity continuously and support experiential learning [18,19]. We adapted iEngage to create the home-based iBounce intervention by modifying physical activities, educational content, and readability of the program, as well as incorporating direct parent involvement in the intervention and creating a messaging platform for participants to contact the study coordinator for technical assistance or general inquiries.

Our primary aim was to evaluate the feasibility and acceptability to survivors of using iBounce at home. Our secondary aims were to assess the impact of the iBounce intervention on survivors' physical activity levels and behaviors, aerobic fitness, and HRQoL.

Methods

Participants

Our eligibility criteria included participants who (1) were aged 8 to 13 years, (2) had been diagnosed with childhood cancer, (3) were at least 12 months post cancer treatment completion or undergoing maintenance chemotherapy, (4) were able to communicate in English, and (5) had internet access at home. Participants were excluded if they (1) had cancer relapse after recruitment, (2) had a medical condition that would prohibit exercise, (3) were participating in another research study that would affect this study's primary and secondary outcomes, or (4) had previously completed a research study <4 weeks prior. We recruited participants from Sydney Children's Hospital in Randwick, New South Wales, Australia, between May 2019 and May 2021. Study recruitment was affected from March 2020 to May 2021 because of the COVID-19 pandemic, limiting face-to-face consultations and reducing opportunities for face-to-face communication with families.

Ethical Considerations

Nursing staff identified eligible participants through hospital clinic lists with approval from treating oncologists. The study coordinator (LH) telephoned eligible parents or carers of survivors (henceforth called *parents*) to discuss the study, with the study invitation package sent through email or post. An initial consultation was organized with consenting parents and survivors, and study equipment was provided for participants. After written informed consent was provided by parents, survivors were enrolled in the study and provided with account log-in details for the program. The study received ethics approval through the Sydney Children's Hospital Network Human Research Ethics Committee (HREC/18/SCHN/471), and we retrospectively registered the intervention on the

Australian New Zealand Clinical Trials Registry (ANZCTN12621000259842).

Intervention

The iBounce program uses iEngage [18-20], which includes a digital app on a tablet connected to wearable activity trackers that record physical activity continuously and support experiential learning. The iEngage digital app includes animated animal characters who guide the child through 10 self-paced educational modules that focus on different health topics, including physical activity, muscular strength, sedentary behaviors, and fitness (refer to Multimedia Appendix 1 [19] for a summary of the module topics). There is also a focus on health literacy throughout the program, which involves teaching participants to define and classify physical activity intensities (light, moderate, and vigorous), self-ratings of perceived effort during exercise, recommended guidelines relating to physical activity, sedentary behaviors, fitness, well-being (physical, mental, and social), screen-based behaviors, and sugar intake. iEngage was built for schoolchildren aged 10 to 12 years without a chronic disease; it was piloted in a rural school in New Caledonia [18] and trialed in 2 primary schools in Sydney, New South Wales, Australia, in 2017 and 2018 [19,21]. Caillaud et al [19] and Diaz et al [21] have detailed the iEngage program.

For this study, we adapted iEngage by (1) modifying the activities so that they were suitable for completion in a home setting, (2) modifying the module contents to encourage participation with family and friends, (3) expanding readability to ensure that younger children could understand the content, (4) including a messaging platform for participants to contact the study coordinator for technical assistance or general inquiries, and (5) educating parents on how to assess and administer an aerobic fitness test for their child. We aimed to target children aged 8 to 13 years because this is a critical life period for a child, when they are learning habits and becoming more independent [22]. We recommended to the participants that they complete the modules once or twice per week and synchronize their activity tracker to the program when completing each module.

Outcome Measures

Overview

Survivors and parents completed questionnaires at baseline and after the intervention (week 12). We assessed survivors' objective physical activity levels and aerobic fitness assessments at baseline and after completing the iBounce intervention. Aerobic fitness was assessed by parents at home at follow-up (week 24).

Feasibility

We calculated (1) opt-in rates (percentage of participants who opted into the study), (2) retention rates (percentage of participants who completed the intervention), (3) proportion of program modules completed (10 in total), and (4) activity tracker adherence (number of modules for which activity trackers were synchronized with the app) to determine feasibility. On the basis of previous similar childhood cancer physical activity interventions [8,23], we decided on opt-in and retention rates of 70% as our feasibility targets. In addition, we evaluated the feasibility of the intervention by assessing adverse events, defined as any detrimental health- or medical-related event that occurred during, or as a direct result of, exercise. Participants self-reported adverse events, which was based on the Common Terminology Criteria for Adverse Events (version 5.0) guideline [24]. The study coordinator (LH) also noted any technical difficulties experienced by participants and how they were resolved.

Acceptability

At 12 weeks after the intervention, the survivors completed an acceptability questionnaire that included items adapted from the Youth Satisfaction Questionnaire [25] in addition to 4 purposely designed items to measure survivors' enjoyment and satisfaction with the iBounce program using a scale ranging from 0 to 100 (0=not at all, 100=enjoyed lots), as well as open-text fields to assess reasons for their satisfaction rating. Other acceptability questions included the following:

- Would you encourage other children to be a part of the iBounce study?
- Would you be happy to keep using the activity tracker in the future?
- Did you learn anything from using the program?

The survivors could respond *Yes*, *Unsure*, or *No* and provide reasons in open-text responses. We also asked the survivors to report on what they thought could be improved using an open-text field. In addition, we assessed parent-reported acceptability of the iBounce program using questions that were identical to those answered by the survivors and 2 additional items to assess whether their child's participation in the iBounce study was beneficial or burdensome to them, using a 5-point Likert scale (1=*not at all*, 5=*very much so*). We decided on a rate of 70% as our acceptability target, similarly reported in previous childhood cancer physical activity interventions [8,23].

Physical Activity

We objectively assessed physical activity levels using the GENEActiv accelerometer (Activinsights) at baseline and after the intervention [26]. We instructed participants to wear the accelerometer on their nondominant hand for 7 consecutive days, including at night. The GENEActiv accelerometer is a research-grade waterproof wrist accelerometer that records continuous daily activity and captures acceleration along three axes (x, y, and z) with a sample frequency of 60 Hz. It shows good validity and accuracy at both wrist locations (right: r=0.90, left: r=0.91) [27]. After 7 consecutive days of wear time, participants returned the accelerometer in a prepaid-postage envelope. Once the study coordinator (LH) received the tracker, the raw data were downloaded to a computer, generating 1 data set per survivor.

To ensure that the accelerometer data were comparable for each participant, we excluded days with missing data or noncompliance. Our exclusion criteria for noncompliance were guided by the protocol described by Mattocks et al [28]: (1) an *invalid* day had <10 hours of data, (2) *nonwear* time within 1 day contained >80% of sedentary behavior from 6 AM to 9 PM (excluding sleep time), and (3) *number of valid days* was <3 days. Possible valid reasons for which data were missing include children taking the accelerometer off for certain sports that do not allow watches to be worn (eg, netball).

Aerobic Fitness

We assessed the survivors' aerobic fitness using the 6-minute walk test (6MWT) at baseline, after the intervention (week 12), and at follow-up (week 24). The 6MWT has previously been used in childhood cancer survivors and is a good predictor of aerobic fitness [9,10]. Before and after the intervention, the 6MWT was administered by an accredited exercise physiologist (LH), in accordance with the American Thoracic Society recommendations [29]. During the assessment, the accredited exercise physiologist educated and demonstrated to the parent how to administer the test. Participants were encouraged to walk as fast as they could without running within 6 minutes around a 30-m track. We provided a 30-m–long rope and cones for participants to distinguish a 30-m track. Participants were instructed to walk around the rope, aiming for as many laps as they could without running. After the test, participants rated the intensity of the test using the Borg Rating of Perceived Exertion scale, which runs from 0 to 10 (0=rest, 10=maximal effort) [30]. At the week-24 follow-up period, the survivors were assessed on the 6MWT again by their parent at home using written instructions and equipment that was provided to them in their study equipment pack.

HRQoL Assessment

We used the EQ-5D Youth 5-Level Questionnaire (EQ-5D-Y-5L) to assess self-reported HRQoL in the survivors at baseline and 12 weeks after the intervention [31]. The questionnaire uses appropriate and child-friendly wording and comprises five dimensions—(1) mobility; (2) looking after myself; (3) doing usual activities; (4) having pain or discomfort; and (5) feeling worried, sad, or unhappy—answered on a 5-level Likert scale ranging from 1=*no problems* to 5=*I am unable to*. The EuroQoL Group's visual analog scale accompanies the EQ-5D-Y-5L, where participants self-report their health on a scale ranging from 0 to 100 (0=*the worst health you can imagine*, 100=*the best health you can imagine*). The EQ-5D-Y-5L has been validated in children aged 8 to 16 years with pediatric conditions, including childhood cancer, with a test-retest reliability of 0.84 [32].

Statistical Analyses

This pilot study primarily aimed to assess feasibility and acceptability; therefore, there was no initial power analysis to calculate a required sample size [8]. We aimed to enroll a sample size of up to 30 participants, which was considered sufficient for the purpose of providing initial feedback data to improve the intervention, testing the planned recruitment method, and assessing the acceptability of the intervention from the perspective of survivors and parents [33].

We analyzed data using SPSS software (version 26.0; IBM Corp) and used descriptive statistics to describe participant characteristics and evaluate the feasibility and acceptability of iBounce. We calculated the opt-in rate by dividing the total number of participants who opted into the study by the total number of invited participants (excluding participants who were unreachable or ineligible). For qualitative acceptability data, we used content analysis to interpret the meaning from the context of the text data [34]. We used the Accessibility and Remoteness Index of Australia to assess the rurality of participants' residence according to their distance from Australian service centers [35].

This pilot was purposely not powered to evaluate the efficacy of iBounce. However, we conducted preliminary analyses to evaluate the impact of iBounce on the survivors' physical activity levels, aerobic fitness levels, and HRQoL. On the basis of intention-to-treat principles, we used mixed effects models accounting for missing-at-random data and with participant-specific random intercepts to assess the change in (1) physical activity levels (minutes per day) and sedentary behavior (hours per day) using two time points (baseline vs after the intervention), (2) aerobic fitness levels using three time points (baseline vs after the intervention vs follow-up), and (3) HRQoL scales using two time points (baseline vs after the intervention).

We calculated means and SDs of daily time spent in sedentary behavior and MVPA using the minimum bout-filtered daily accumulated data (≥60-second bouts for sedentary behavior and ≥3-second bouts for MVPA) [36]. We compared the survivors' daily physical activity levels with the Australian 24-Hour Movement Guidelines for children and adolescents aged 5 to 17 years [37]. The physical activity guidelines recommend that children accumulate at least 60 minutes of MVPA per day.

We performed our cluster analysis using R (RStudio), published in Open Science Framework. We processed the raw data into 1-second epoch signal vector magnitude data points of activity between 7 AM and 10 PM and then classified each second into a physical activity intensity level (sedentary, light, and MVPA) using activity cut points validated for children aged 8 to 14 years [27]. Our cluster analysis grouped participants according to the similarity of their mean daily physical activity and sedentary behaviors to characterize each cluster before and after the intervention. We used principal component analysis to maximize the variance of our accelerometer data and the elbow method for the total within-cluster sum of squares to confirm the number of acceptable clusters. All participants' daily physical activity was clustered by eight factors: total time spent in MVPA of ≥3-second bouts and ≥30-second bouts, total time spent in sedentary behavior of ≥60-second bouts and ≥300-second bouts, frequency of ≥3-second and ≥30-second MVPA bouts, and frequency of ≥60-second and ≥300-second sedentary bouts. Informed by the studies by Diaz et al [21] and Schaefer et al [38], we selected 3-second–bout lengths to represent short MVPA bouts because activity recorded in <3 seconds typically represents agitation of the GENEActiv activity tracker or *noise*, rather than meaningful physical activity. We used bout lengths of at least 30 seconds to represent sustained MVPA. Likewise, for sedentary behavior, we used bout lengths of at least 60 seconds to represent short duration activity and bout lengths of at least 300 seconds to represent sustained activity. Next, we compared the survivors' cluster group at baseline and after the intervention to ascertain whether they had moved to a more active cluster after the intervention, suggesting behavior change.

In addition to quantifying daily time spent in various physical activity intensities before and after the intervention, we used unsupervised data mining methods to further understand physical activity behaviors. We sought to assess behaviors defined by how the survivors' sedentary behavior and MVPA levels were distributed throughout the day and how these levels evolved with regard to intensity, duration, and frequency of physical activity bouts. Exploring various physical activity bouts plays an important role in understanding how survivors accumulate their physical activity; for example, whether survivors engage in frequent and short bouts of MVPA or less frequent and long bouts of MVPA. To capture these various physical activity intensities, durations, frequencies, and bouts, we used the cluster analysis method proposed in earlier work [21] to analyze the impact of iBounce on the survivors' physical activity behaviors.

For aerobic fitness, we converted the survivors' 6MWT distance results to age- and sex-specific percentiles [39]. To assess the frequencies of self-reported HRQoL problems, we dichotomized the five levels into *no problems* (level 1) and *any problems* (levels 2, 3, 4, and 5). We analyzed the five dimensions (mobility; looking after myself; doing usual activities; having pain or discomfort; and feeling worried, sad, or unhappy) individually and determined a quality-of-life index value ranging from 0 to 1 (0=death, 1=perfect health) according to the developer's instructions [40].

Results

Overview

Of 165 childhood cancer survivors screened for eligibility, 93 (56.4%) did not meet the inclusion criteria (refer to Figure 1 for details). We invited the remaining (72/165, 43.6%) childhood cancer survivors to enroll in our study. Of these 72 survivors, 21 (29%) actively refused (n=14, 67%, were not interested; n=5, 24%, were too busy; and n=2, 9%, were unable to travel for assessments), and 21 (29%) could not be contacted (ie, there was no response after 2 telephone calls and a voicemail). Thus, of the 72 survivors invited to enroll in our study, 30 (42%) opted into the study. The mean age of the participants was 10.2 (SD 1.5) years, 44% (12/27) were female survivors, and they were on average 5.0 (SD 3.1) years from cancer treatment completion. Participant demographic and clinical characteristics are described in Table 1.

Figure 1. Recruitment flowchart.

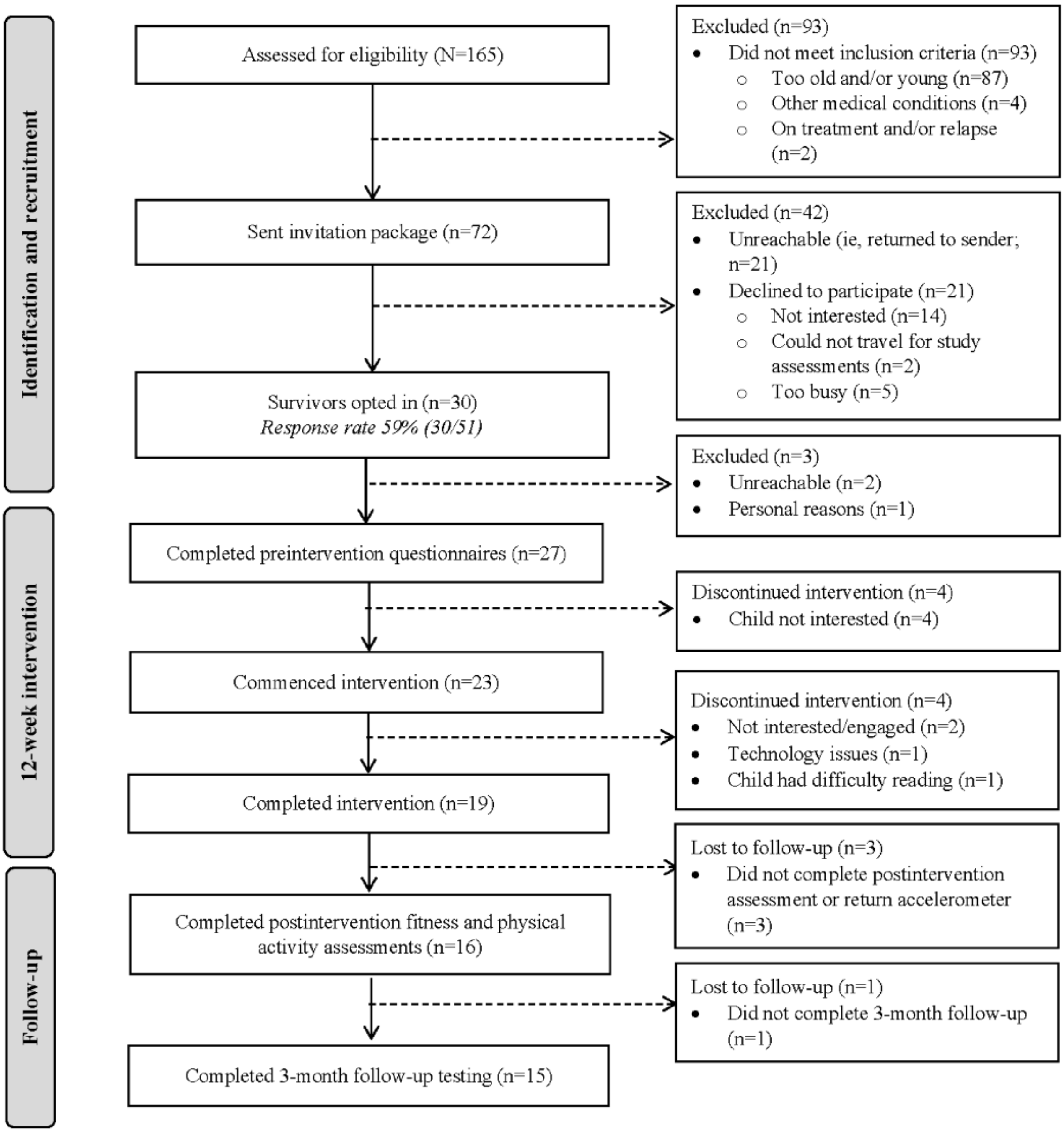


Table 1. Participant baseline demographic and clinical characteristics (N=27).

Characteristics	Values
Sex (female), n (%)	12 (44)
Age during study (years), mean (SD)	10 (1.5)
Time since treatment completion (years), mean (SD)[a]	5 (3.1)
Cancer diagnosis, n (%)	
Acute lymphoblastic leukemia	15 (56)
Neuroblastoma	4 (15)
Burkitt lymphoma	3 (11)
Other malignancies[b]	5 (18)
Treatment received, n (%)[c]	
Chemotherapy	26 (96)
Surgery	17 (63)
Radiotherapy	4 (15)
Bone marrow transplant or stem cell transplant	4 (15)
Rurality, n (%)[d]	
Major city	23 (85)
Regional	4 (15)
Parent education, n (%)	
High school	3 (11)
Certificate, diploma, or apprenticeship	10 (37)
University degree	10 (37)
Postgraduate degree	4 (15)

[a] The data of 2 participants were missing.

[b] Other malignancies include hepatoblastoma, non-Hodgkin lymphoma, Wilms tumor, and germ cell tumor.

[c] Participants may have had >1 treatment.

[d] According to the Accessibility and Remoteness Index of Australia, which categorizes regions according to their accessibility to services.

Feasibility

The opt-in rate was 59% (30/51; of the 72 participants who were sent the invitation package, 21, 29% were unreachable). Of the 30 participants who verbally opted into the study, 2 (7%) could not be contacted, and 1 (3%) decided to withdraw from the study for personal reasons; the remaining 27 (90%) participants completed baseline assessments. However, of these 27 participants, 3 (11%) withdrew after completing baseline assessments, and 1 (4%) withdrew after completing only the fitness assessment, primarily because of lack of interest. Of the 3 participants who withdrew after completing baseline assessments, 1 (33%) male participant aged 13 years expressed that he felt too old for the program. Of the 30 participants who verbally opted into the study, 23 (77%) commenced the iBounce program. Of these 23 participants, 4 (17%) withdrew after commencing iBounce because of lack of engagement (n=2, 50%), technology issues (n=1, 25%), and difficulty reading (n=1, 25%), resulting in a 70% (19/27) retention rate. Of the 23 participants who commenced iBounce, 19 (83%) completed the intervention. There were no intervention-related adverse events reported, although we recorded a nonserious adverse event where a participant fractured their arm in an incident unrelated to the intervention, and they were still able to continue.

Of the 23 participants who commenced the program, 13 (57%) completed all 10 modules (median 10, IQR 4-10). Activity tracker engagement was high, with 79% (15/19) of the participants synchronizing their activity tracker to the program for ≥7 iBounce modules. The median number of modules that activity trackers were worn for, and synchronized to, was 9 (IQR 2-10).

In total, 70% (16/23) of the survivors completed the postintervention fitness test and returned their accelerometers, and 65% (15/23) completed the week-24 follow-up assessment.

Technical Difficulties

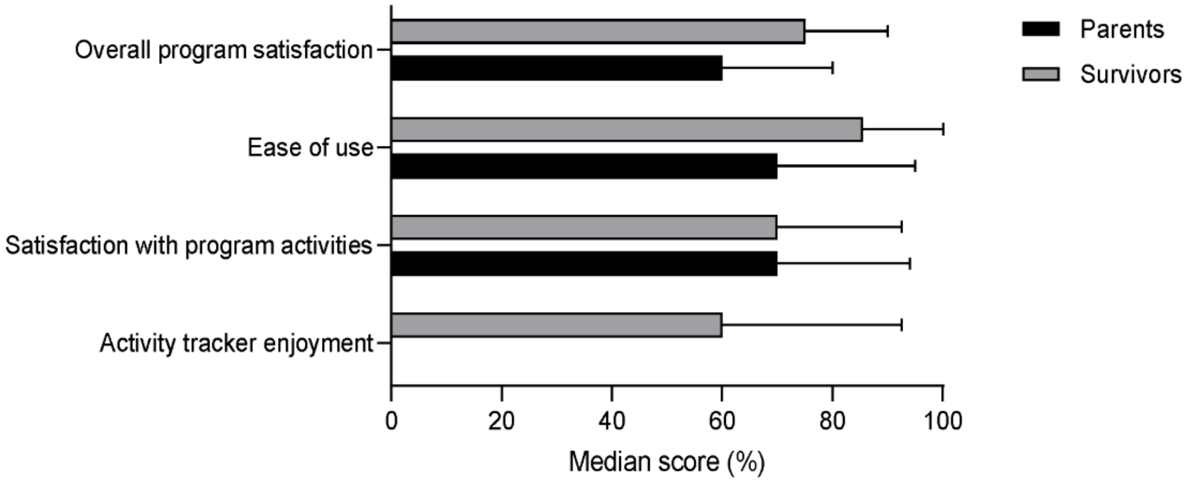
More than half (13/23, 57%) of the participants reported at least one technical difficulty. The most commonly reported technical difficulty was synchronization issues between the Misfit Ray (Fossil Group) activity tracker and the app (13/20, 65%). Of the 4 participants who dropped out after commencing the intervention, 2 (50%) discontinued the study because of these technical difficulties. All remaining technical issues were resolved through consultations (telephone call, SMS text messaging, or email) with the study coordinator (LH). Solutions to the technical difficulties involved replacing the activity trackers, sending new batteries to participants, and resetting the modules.

Acceptability

Survivor-Reported Acceptability

Regarding satisfaction with iBounce, the survivors reported median scores of 86%, 75%, and 70% for ease of use, overall program satisfaction, and satisfaction with program activities, respectively (Figure 2). Qualitatively, the survivors reported that the program activities were fun, convenient, and engaging. Of the 14 survivors who responded to questionnaires, 12 (86%) also reported having learned from the program, and 9 (64%) stated that they would encourage other children to participate in the iBounce program. In total, 22% (3/14) of the survivors reported that they were unsure whether they would recommend participating in the iBounce program to other children, and 14% (2/14) reported that they would not recommend iBounce to other children because it was boring, and the activity tracker was unreliable. Reasons for recommendations included benefits of iBounce as an engaging and educational program for children, with a survivor highlighting that iBounce may be helpful for their friends; for example, “because some of my friends aren’t that healthy and this would direct them into the right track” [Male survivor aged 13 years]. Multimedia Appendix 2 summarizes survivors’ and parents’ responses to open-ended questions.

Figure 2. Median and range values of scores for survivor and parent satisfaction ratings of iBounce at 12 weeks after the intervention (survivors: n=14, parents: n=15).

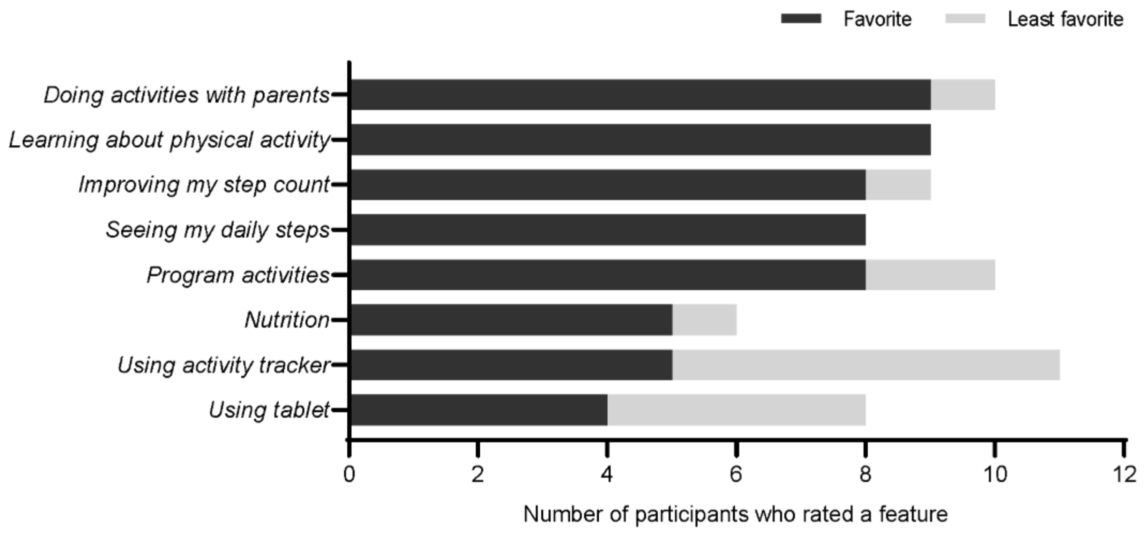


Of the 14 survivors, 9 (64%) rated completing activities with their parents and learning about physical activity as their top-rated program features (Figure 3). The bottom-rated features were using the activity tracker (7/14, 50%) and using the tablet (5/14, 36%).

The median score for activity tracker enjoyment was 60% (IQR 40%-92.5%; Figure 2). In total, 43% (6/14) of the participants enjoyed using the activity tracker, highlighting it as a motivational and educational tool; for example, a survivor reported, “It was so good to be able to see how many steps I could do, then try to improve” [Female survivor aged 11 years]. However, 57% (8/14) of the survivors reported dissatisfaction with the activity tracker because of technical difficulties such as issues with synchronization and connection.

Half of the participants (7/14, 50%) indicated that they would be happy to keep using the activity tracker in the future, whereas 14% (2/14) of the participants were unsure, and more than one-third (5/14, 36%) reported that they would not use the activity tracker in the future because of limitations such as lack of real-time feedback on the tracker and absence of time display or heart rate monitoring, with a survivor reporting, “...I normally use a tracker with a display [so] that I can check my steps and heart beating” [Female survivor aged 8 years]. The open-ended feedback we received regarding improvements to the intervention also reflected suggestions to improve the Misfit Ray activity tracker. Of the 9 participants who provided suggestions to improve iBounce, 6 (67%) provided suggestions related to changes to the activity tracker, 2 (22%) reported *unsure*, and 1 (11%) suggested changes to the program app.

Figure 3. Survivors' acceptability ratings of iBounce program features at 12 weeks after the intervention (n=14). It should be noted that participants were able to choose >1 option.



Parent-Reported Acceptability

The median score for parents' satisfaction with program activities was 70% (IQR 50%-95%; Figure 2). Common themes in the qualitative data included positive endorsements of iBounce as a program that engaged their child in physical activity, raised awareness of health behaviors for both survivors and parents, started a conversation about well-being, and facilitated parent involvement. The median score for satisfaction with the program was 60% (IQR 50%-80%). Parents who were not satisfied with the program (9/14, 64%, scored ≤60) reported technological difficulties such as the Misfit Ray activity tracker's batteries needing to be replaced, which interrupted the program; the program not being targeted to their child's age; and the program being confusing to set up.

In total, 47% (7/15) of the parents reported that participation in the study was beneficial to them (n=1, 14%, reported *very much so*, and n=6, 86%, reported *quite a bit*). One-third (5/15, 33%) reported that participation was *somewhat* beneficial. A few parents reported that participation was *a little bit* (1/15, 7%) and *not at all* (2/15, 13%) beneficial to them. The parents indicated several benefits of iBounce, including the program serving as a reminder or motivation for their child to exercise, encouraging a better attitude toward exercise, and motivating for the parent themselves to promote physical activity for their child.

Many of the parents reported that participation was *not at all* (4/15, 27%) or *a little bit* (6/15, 40%) burdensome, whereas some reported that participation was *somewhat* (3/15, 20%) or *quite a bit* (2/15, 13%) burdensome. Some (4/15, 27%) of the parents described technical difficulties such as the lack of a *back* button on the app and problems synchronizing the activity tracker. In total, 20% (3/15) of the parents reported that having to monitor or remind their child to do the program was burdensome. The majority (10/15, 67%) of parents indicated that they would recommend to other children that they participate in this study, including those who reported the study to be *not at all* (3/15, 20%), *quite a bit* (1/15, 7%), *somewhat* (2/15, 13%), and *a little bit* (4/15, 27%) burdensome. Parents who would recommend iBounce to others endorsed that iBounce highlighted the importance of health behaviors for their child after cancer treatment and that it encouraged them to engage in physical activity.

Physical Activity

Of the 30 participants who opted into the study, 3 (10%) were excluded after opting in, 3 (10%) discontinued the intervention, and 24 (80%) returned the accelerometers at baseline. After data extraction and quality assessment, we excluded 12% (3/24) of the participants because of insufficient available accelerometer data. We therefore included data from 88% (21/24) of the participants at baseline. Of the 19 participants who completed the intervention, 16 (84%) returned their accelerometer for the postintervention assessment. Of these 16 participants, 4 (25%) had incomplete data sets, resulting in the data sets of 12 (75%) participants being available for analysis at the postintervention assessment. Overall, we analyzed 11 complete data sets for both pre- and postintervention assessments because, of these 12 participants, 1 (8%) had insufficient baseline data.

At baseline, the survivors were engaging in an average 41.7 (SD 17.7) minutes per day of MVPA (Table 2). Most (86%, 18/21) of the survivors were not meeting physical activity guidelines over a week. On average, the survivors who met the physical activity guidelines engaged in sufficient MVPA levels on mean 1.2 (SD 1.7) days per week. The survivors did not increase their mean daily MVPA from before to after the intervention (mean 39.2, SD 24.7 minutes per day, change –2.5, SE 7.4, 95% CI –17.6 to 12.6; *P*=.74; Table 2). On average, the survivors spent 5.6 (SD 1.6) hours per day in sedentary behaviors of bouts of at least 60 seconds (excluding sleep time from 10 PM to 7 AM). There was no evidence of change in sedentary behaviors between before and after the intervention (mean 5.6, SD 1.6 hours per day, change +0.02, SE 0.6, 95% CI –1.13 to 1.18; *P*=.97).

We assessed changes in physical activity behaviors among the 11 survivors who had complete accelerometer data at pre- and postintervention assessments. We retained 4 principal components, and our cluster analysis resulted in 5 acceptable cluster groups. Cluster 1 represents the most active group that meets the physical activity guidelines and engages in the most frequent bouts of MVPA, whereas cluster 5 represents the least active group with infrequent and sustained bouts of sedentary behaviors (Textbox 1). Multimedia Appendix 3 shows the duration and frequency of bout lengths in MVPA and sedentary behaviors for each cluster.

Table 2. Change in objectively measured physical activity levels and sedentary behaviors.

	Before the intervention (n=21)	After the intervention (n=12)	SE (95% CI)	*P* value
MVPA[a] (≥3-second bouts), minutes per day, mean (SD)	41.7 (17.7)	39.2 (23.7)	7.4 (–17.6 to 12.6)	.74
Sedentary behaviors[b] (≥60-second bouts), hours per day, mean (SD)	5.6 (1.6)	5.6 (1.6)	0.6 (–1.1 to 1.2)	.97
Number of days meeting guidelines: mean (SD)[c]	1.2 (1.7)	1.3 (2.7)	N/A[d]	N/A
Number of participants meeting guidelines, n (%)[c]				
Did not meet guidelines (<60 minutes per day)	18 (86)	10 (83)	N/A	N/A
Met guidelines (≥60 minutes per day)	3 (14)	2 (17)	N/A	N/A

[a] MVPA: moderate-to-vigorous physical activity.

[b] Sleep time (10 PM to 7 AM) was excluded from our analyses.

[c] Physical activity levels were compared with recommended physical activity guidelines of at least 60 minutes of moderate-to-vigorous physical activity per day for children and adolescents, including weekends.

[d] N/A: not applicable.

Textbox 1. Definition of each cluster group.

Cluster group and definition

Cluster 1: most active

- Meets the daily physical activity recommended guidelines (≥60 minutes per day)
- Engages in the most time spent in moderate-to-vigorous physical activity (MVPA) in ≥3-second bouts that is the most frequent (637 bouts)
- Engages in frequent and sustained levels of sedentary behavior in ≥60-second bouts (>300 minutes, 77 bouts) and ≥300-second bouts (>150 minutes, 11 bouts)

Cluster 2: active

- Engages in frequent and high levels of MVPA (47.2 minutes, 495 bouts)
- Engages in the least amount of sedentary behavior in ≥60-second bouts (<200 minutes, 33 bouts) and ≥300-second bouts (<150 minutes, 6 bouts)

Cluster 3: moderately active

- Engages in the most time spent in longer bouts of MVPA (≥30-second bouts: 6 minutes, 6 bouts)
- Engages in frequent and sustained levels of sedentary behavior in ≥60-second bouts (>350 minutes, 109 bouts) and ≥300-second bouts (>190 minutes, 9 bouts)

Cluster 4: occasionally active

- Engages in occasional and low levels of MVPA in ≥3-second bouts (26 minutes, 298 bouts) and ≥30-second bouts (1 minute, 2 bouts)
- Engages in moderate levels of sedentary behavior (≥60-second bouts: >300 minutes, 111 bouts) but less sustained (≥300-second bouts: 130 minutes, 9 bouts)

Cluster 5: least active

- Engages in low levels of MVPA (≥3-second bouts: 21 minutes, 245 bouts) that is not sustained (≥30-second bouts: 2 minutes, 2 bouts)
- Engages in the most frequent and most time spent in sedentary behavior (≥60-second bouts: >500 minutes, 57 bouts) that is sustained (≥300-second bouts: >420 minutes, 13 bouts)

Table 3 is a visual representation of the movement of participants among the cluster groups before and after the intervention. In total, 27% (3/11) of the participants moved to a more active cluster group after completing the iBounce intervention, highlighting an increase in more frequent and sustained bouts of MVPA, whereas 55% (6/11) stayed in the same cluster; however, of these 6 participants, 2 (33%) were already highly active at baseline. Of the 11 participants, 2 (18%) moved to a less active cluster after completing the iBounce intervention.

Table 3. Daily cluster movement matrix.

	To daily cluster (after the intervention)				
	1	2	3	4	5
From daily cluster (before the intervention)					
1	1[a]	N/A[b]	N/A	N/A	N/A
2	N/A	1[a]	N/A	N/A	N/A
3	1[c]	N/A	1[a]	1[d]	N/A
4	N/A	1[c]	N/A	3[a]	1[d]
5	N/A	N/A	N/A	1[c]	N/A

[a] The diagonal area indicates no improvement in physical activity levels (stayed in the same cluster).

[b] N/A: not applicable.

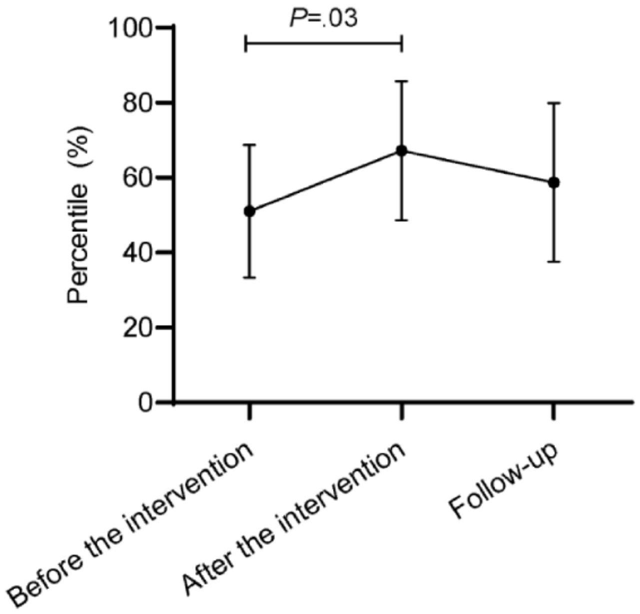
[c] Indicates desirable movements (moving to a more active cluster group after completing iBounce).

[d] Indicates unfavorable movements (moving to a less active cluster group after completing iBounce).

Aerobic Fitness

At baseline, the survivors' mean aerobic fitness performance was at the 44th (SD 32) percentile, indicating average fitness levels. The survivors' aerobic fitness increased from before to after the intervention (mean 61, SD 36 percentile, change +17, 95% CI 1.7-32.1; *P*=.03). There was no difference between the postintervention (week 12) and follow-up assessments at week 24 (mean 54, SD 38 percentile, change –7, 95% CI –23.3 to 9.4; *P*=.39; Figure 4). In addition, there was no change between baseline and follow-up aerobic fitness (change +10, 95% CI –6.9 to 26.8; *P*=.23).

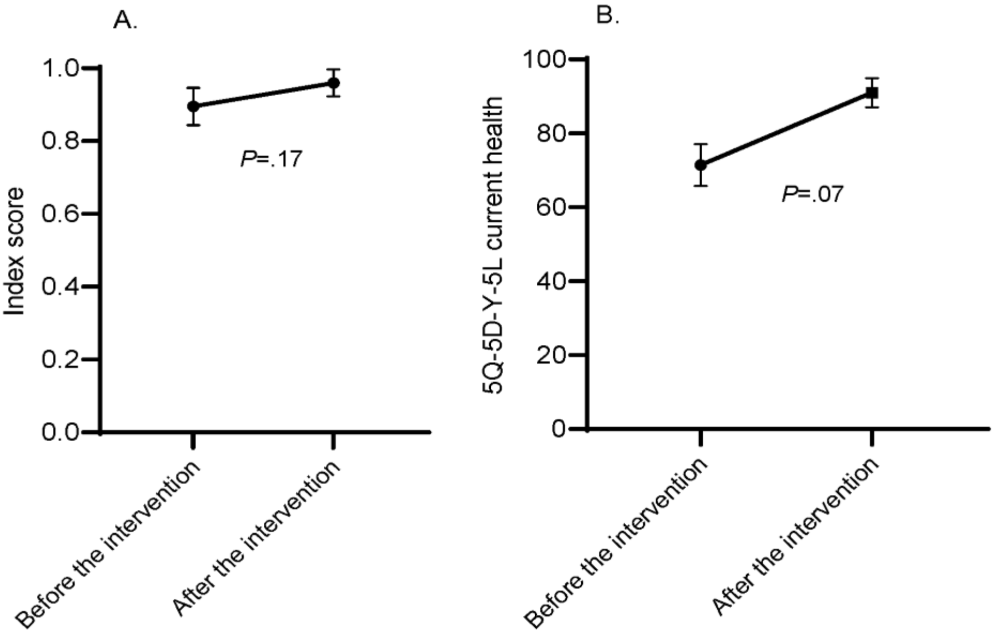
Figure 4. Change in aerobic fitness percentile means from before the intervention and after the intervention to week-24 follow-up.



HRQoL Scores

The survivors commonly indicated problems relating to pain or discomfort (14/26, 54%), anxiety or depression (9/26, 35%), activities of daily living (7/26, 27%), and mobility (7/26, 27%) at baseline (Multimedia Appendix 4). The survivors' average HRQoL score at baseline was 0.89 (SD 0.13; range 0.47-1.00), with 42% (11/26) of the survivors reporting perfect health (score=1.00). There was no significant change in the EQ-5D-Y-5L index score from before to after the intervention (mean 0.89, SD 0.04, change +0.07, SE 0.05, 95% CI –0.03 to 0.16; *P*=.17; Figure 5A). On average, the survivors reported their overall health at baseline as 71.5 out of 100 (SD 28.8; range 0-100). There was insufficient evidence to indicate that the survivors' overall health improved from before to after the intervention (mean 91.0, SD 11.2, change +19.5, SE 10.5, 95% CI –1.89 to 40.96; *P*=.07; Figure 5B).

Figure 5. (A) Change in the EQ-5D Youth 5-Level Questionnaire (EQ-5D-Y-5L) health-related quality-of-life mean index scores and (B) mean current health ratings between preintervention and postintervention assessments. The index scores range from 0 to 1 (0=death, 1=perfect health), and the current health ratings range from 0 to 100 (0=worst health, 100=best health).



Discussion

Principal Findings

Distance-delivered physical activity interventions are promising and feasible programs that can offer support and engagement among survivors and families in improving health behaviors [16]. The iBounce program seems to be safe, feasible, and acceptable, demonstrating moderate opt-in and high retention rates, reflecting that families were interested in physical activity support in survivorship. Our opt-in rate was lower than our feasibility target because of the challenge of study recruitment and potentially the negative impacts of the COVID-19 pandemic. In total, 56.4% (93/165) of the potential participants who were screened did not meet the eligibility criteria, and 58% (42/72) of the eligible participants either declined participation or were unreachable. The challenge of participant recruitment for health behavior interventions among children diagnosed with cancer is common [8,41]. However, our challenges may have been exacerbated because of recruitment from a single site and parents not wanting to commit to research interventions because of the unknown risk of COVID-19 for unvaccinated children diagnosed with cancer and their immunocompromised status [42]. Despite the lower-than-anticipated opt-in rate, the retention rate and program engagement were high, demonstrating that once the survivors expressed interest in the iBounce program, they were highly receptive to it. Activity tracker compliance was also lower than the feasibility target that we set, potentially because of the survivors' preference for a monitor that showed their activity (eg, steps achieved) [43] and the technical difficulties relating to synchronization, which may have affected adherence. Some qualitative comments by the survivors further reflected their frustration with the activity tracker (Multimedia Appendix 2). Future research should explore survivors' priorities with regard to using wearable activity trackers to optimize their acceptability and optimal use. Parent-reported acceptability of the program was also lower than anticipated, potentially because of the technological difficulties that resulted in the program becoming disjointed. One-third of the parents reported iBounce to be *somewhat* (3/15, 20%) or *quite a bit* (2/15, 13%) burdensome, and their qualitative comments were valuable, highlighting the technical difficulties, their dissatisfaction with the Misfit Ray activity tracker, and the suggestion that iBounce may be better suited to younger children. Despite the technical difficulties experienced by participants, it is encouraging that these issues did not seem to adversely affect participant engagement or the delivery of the program content. Future trials of iBounce should include a *troubleshooting* pamphlet with common technical issues and solutions to improve participant retention and reduce burden for the study coordinator.

Most (12/14, 86%) of the survivors were satisfied with the program, particularly the activities that involved their family and friends and content that facilitated health behavior education. Parents also reported high satisfaction with the program activities that encouraged time with their child. Family and peer involvement was a vital element of iBounce, where the survivors were encouraged to exercise, and share their knowledge and skills, with family and friends [19]. We also directly involved parents in the program to assist in the assessment of aerobic fitness at follow-up. There is some evidence to support that lifestyle interventions that include direct parent involvement have demonstrated positive outcomes among childhood cancer survivors [44,45]. A home-based exercise study for children aged <18 years on treatment for acute lymphoblastic leukemia engaged parents through involving them in attending and supervising exercise sessions with their children [46]. The researchers found an improvement in participants' physical activity stage of change after the 6-week intervention [46]. Tanir and Kuguoglu [47] also involved parents in a hospital- and home-based exercise intervention for survivors of acute lymphoblastic leukemia aged 8 to 11 years by requiring at least one parent to attend the exercise sessions with their child for support and motivation. Participants in the study showed significant improvements in physical fitness and muscular strength [47]. Likewise, participants in our study improved their aerobic fitness after 12 weeks. Such findings highlight the potential benefit of involving parents in lifestyle interventions because they may be an avenue of support as well as for promoting behavior change in survivors, particularly at home.

We observed a significant increase in aerobic fitness from before to after the intervention; however, this change was not sustained at the week-24 follow-up. It may be likely that survivors need more support to maintain their behavior changes over time, such as the inclusion of booster sessions to reinforce health behavior messages. Booster sessions have previously been shown to increase long-term impacts [48]. In addition, it is possible that the reliability and accuracy of the results may have been affected because the 6MWT was administered at home, supervised by the parent instead of a qualified exercise professional. Tests of physical functioning and aerobic capacity are commonly used in clinical practice and research for identifying fitness levels and evaluating the efficacy of exercise programs [10,49]. However, the need to travel to a supervised clinic or hospital for assessments is a recognized barrier to exercise participation and a burden, especially for those living in rural and remote regions [50]. Future studies should validate or develop simple, home-based functional assessments for researchers or clinicians to facilitate distance-based exercise testing for childhood cancer survivors. The development of accurate and reliable home-based functional assessments has the potential to enable support and reduce the burden for survivors and the health care system [51].

Despite the encouraging feasibility and acceptability data, our early data did not suggest any significant improvements in the survivors' physical activity levels after participating in the iBounce program. The lack of change in time spent in MVPA among childhood cancer survivors is consistent with previous distance-delivered exercise interventions [23,52,53]. It is possible that iBounce may not be effective in improving physical activity levels. Our small sample size may also have resulted in an insufficient number of participants to demonstrate an effect, although the primary aim of our pilot study was to assess feasibility. However, a strength of our study was our novel investigation of physical activity behaviors using cluster analysis. To complement our assessment of time spent in MVPA before and after the intervention, we used the richness of the accelerometer data and explored the continuity and duration of various physical activity bouts. Physical activity bouts (eg, frequent short bouts or infrequent long bouts) are important to understand how participants achieve their physical activity levels and how they are distributed over the day or week [21,54]. Our cluster analysis showed that 27% (3/11) of the participants moved to a more active cluster, indicating that they increased the frequency and duration of MVPA bouts. Although the total time they spent in MVPA may not have changed after the intervention, the length of bouts increased, which might suggest more structured activity. In total, 18% (2/11) of the participants moved to a less active cluster; however, of these 2 participants, 1 (50%) decreased their sedentary behavior, still indicating a positive outcome. These changes in patterns are useful in understanding the impact of iBounce on survivors' physical activity and sedentary behaviors. Future studies should aim to examine the impact of interventions on various patterns of physical activity, including bouts, frequencies, and intensities.

Improvements in HRQoL after physical activity have previously been reported in childhood cancer survivors [55-57]. Physical activity may improve or maintain aspects of HRQoL, including physical and cognitive function, and reduce cancer-related worry [58]. The HRQoL measures in our study were not statistically different from baseline to 12 weeks after the intervention, potentially because of our small sample size. Compared with normative data in noncancer populations, iBounce participants had mean scores that were similar to those of their noncancer peers, demonstrating high quality of life to begin with [31].

Limitations

The iBounce intervention used an adapted version of the iEngage program, which had already gone through rigorous pilot testing among primary school–aged children [18,19]. The distance-delivered format of our study enabled the survivors to access iBounce and engage in health behaviors, even throughout the COVID-19 pandemic, highlighting the relevance and applicability of iBounce. Although iBounce was available for eligible participants throughout the pandemic, government stay-at-home health orders and social distancing practices limited face-to-face consultations and communication with families, which affected some pre- and postintervention assessments such as the 6MWT. At the week-24 follow-up, parents assessed their child using the 6MWT, a method that has not yet been validated for parents to administer at home. However, the simplicity, low cost, and minimal requirement of equipment for the 6MWT allowed us to educate survivors and families on how to easily assess fitness at home. Another limitation of this study was the ad hoc monitoring of adverse events, which may have led to underreporting of events, particularly lower-grade or nonserious adverse events. Although symptoms such as muscle soreness or fatigue reflect common responses to exercise, these low-grade adverse events are important to report to provide confidence that unsupervised or home-based exercise is safe after cancer treatment [59]. Therefore, future distance-delivered physical activity interventions should regularly monitor for adverse events using a standardized approach throughout the intervention to improve adverse-event reporting and intervention quality. Our sample was heterogeneous in terms of cancer diagnoses and included participants who had average fitness levels at baseline, which may overrepresent survivors who were more active, potentially biasing the results. Furthermore, most (23/27, 85%) of the participants in our study were living in metropolitan areas, and families from regional or rural regions were underrepresented [12]. Potential reasons for the low opt-in rate among rural survivors may be due to the fact that fewer rural families were invited to the study as a result of our single recruitment site, which captures a smaller portion of rural families within New South Wales. Our distance-delivered intervention may likely benefit survivors from regional or rural areas; yet, additional recruitment strategies are needed to engage rural survivors to maximize successful adoption. Our sample also included highly educated parents, and there was no representation from brain tumor survivors. It is not clear why no families of children with a central nervous system (CNS) tumor participated in our study. It may be possible that the program was less appealing to patients with a CNS tumor because of their burden of long-term side effects such as cognitive difficulties, fatigue, and balance difficulties [60]. Future research could explore the needs of patients with a CNS tumor in more depth and consider developing a more tailored intervention for this group. Our intervention focused on English-speaking participants; future trials of iBounce should consider collaborating with non–English-speaking and culturally and linguistically diverse populations because of their increased barriers to accessing care and poorer health outcomes [61].

On the basis of our pilot feasibility and acceptability data, planned changes to iBounce will include ongoing collaboration with childhood cancer survivors to identify their preferred type of wearable activity tracker that will assist them in maintaining or improving their physical activity levels. Further collaborative efforts such as using co-design methods with survivors and parents will be used to update and improve the iBounce design and educational module content to suit a broader range of survivors, including older children and adolescents. To address the technical difficulties experienced by survivors and parents, we plan to streamline the app and remove the need for participants to synchronize the tracker to the program, which was often the cause of the technical issues. We will also provide a troubleshooting resource to reduce burden on participants needing to contact the study coordinator for assistance.

Conclusions

Our digital health education program, iBounce, proved to be feasible and acceptable among childhood cancer survivors. We experienced some recruitment challenges and technical difficulties that resulted in an opt-in rate and module completion rate that was lower than the feasibility targets that we had set. Despite these challenges, after participants did opt in to the program, we found that it was feasible to deliver iBounce and that survivors were highly engaged and enjoyed participating in home-based physical activities with their family. Our preliminary efficacy results are promising, highlighting the potential of iBounce to improve survivors’ fitness levels after completing the program. Our positive feasibility and acceptability data warrant further investigation in a well-powered trial that also addresses the technical issues experienced in this pilot study. The digital aspect of iBounce has the potential to educate, engage, and reach a high proportion of survivors and their families with regard to positive health behaviors at home, no matter where they reside.

Acknowledgments

The authors would like to thank Assistant Professor Kalina Yacef, Professor Corinne Caillaud, Assistant Professor Olivier Galy, and Gaël Clerc for their support in our modification of the iEngage program. The authors also thank Karen Johnston and Donna Drew for their assistance in study recruitment, Mark Donoghoe for his statistical advice, and the participants and their families for their involvement in the study. LH is supported by the Australian Government Research Training Program Scholarship and The Kids’ Cancer Project. CS is supported by a Cancer Institute NSW Early Career Fellowship (2020/ECF1144). CW is supported by the National Health and Medical Research Council of Australia (APP2008300).

Authors' Contributions

LH, CW, RC, KY, and DS were responsible for the study concept, design, and protocol. LH, CW, DS, KY, and RC were responsible for the methodology. Data collection was performed by LH and DM. Data analysis was conducted by LH and CD. DS, CW, KY, and CS supervised the study. LH, CS, CW, DS, and KY prepared the original draft. All authors were responsible for reviewing and editing the manuscript, and all authors approved the final version.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Module topics adapted from iEngage.
[DOCX File , 14 KB - cancer_v8i3e38367_app1.docx]

Multimedia Appendix 2

Survivor and parent responses to open-ended questions about the acceptability of iBounce.

[DOCX File , 21 KB - cancer_v8i3e38367_app2.docx]

Multimedia Appendix 3

Daily clusters.

[DOCX File , 14 KB - cancer_v8i3e38367_app3.docx]

Multimedia Appendix 4

Frequencies and proportions of reported health-related quality of life problems from the dichotomized EQ-5D Youth 5-Level Questionnaire.

[DOCX File , 14 KB - cancer_v8i3e38367_app4.docx]

Multimedia Appendix 5

CONSORT-EHEALTH checklist (V 1.6.1).

[DOCX File , 1823 KB - cancer_v8i3e38367_app5.docx]

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Abbreviations

6MWT: 6-minute walk test
CNS: central nervous system
EQ-5D-Y-5L: EQ-5D Youth 5-Level Questionnaire
HRQoL: health-related quality of life
MVPA: moderate-to-vigorous physical activity

Edited by A Mavragani; submitted 30.03.22; peer-reviewed by M Otth, K Devine; comments to author 14.06.22; revised version received 05.07.22; accepted 13.07.22; published 17.08.22.

Please cite as:
Ha L, Wakefield CE, Mizrahi D, Diaz C, Cohn RJ, Signorelli C, Yacef K, Simar D
A Digital Educational Intervention With Wearable Activity Trackers to Support Health Behaviors Among Childhood Cancer Survivors: Pilot Feasibility and Acceptability Study
JMIR Cancer 2022;8(3):e38367
URL: https://cancer.jmir.org/2022/3/e38367
doi:10.2196/38367
PMID:35976683

Original Paper

Feasibility and Acceptability of an Active Video Game–Based Physical Activity Support Group (Pink Warrior) for Survivors of Breast Cancer: Randomized Controlled Pilot Trial

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Abstract

Background: Survivors of breast cancer with functional limitations have a 40% higher mortality rate than those without. Despite the known benefits of physical activity (PA), <40% of survivors of breast cancer meet the recommendations for PA. The combination of active video games (AVGs) and group-based PA counseling may hold potential for motivating PA adoption and improving physical function. However, this method has not been widely studied in survivors of breast cancer.

Objective: We aimed to determine the feasibility and acceptability of a group AVG-based multicomponent PA intervention and estimate its effect size and variability on PA and physical function in female survivors of breast cancer in a clinic setting.

Methods: Female survivors of breast cancer (N=60) were recruited through the clinic and randomly assigned to the intervention group (12 weekly sessions) or the control group (existing support group). The intervention group received game-based pedometers and participated in weekly group AVG sessions, PA behavioral coaching, and survivorship navigation discussions. A participant manual with weekly reflection worksheets was provided to reinforce the coaching lessons and promote self-led PA. The control group received conventional pedometers and participated in an existing breast cancer support group. Feasibility was assessed by enrollment rate (≥50%), retention rate (≥80%), group attendance rate (75% attending ≥9 sessions [intervention group]), and the number of technological issues and adverse events. Acceptability was measured by participants' attitudes (from strongly disagree=1 to strongly agree=5) toward the use of AVGs and the overall program. The outcomes included PA (accelerometers) and physical function (Short Physical Performance Battery and gait speed). Analysis of covariance was used to determine differences in PA and physical function between the groups. The Cohen *d* and its 95% CI determined the effect size and variability, respectively. All the analyses followed the intention-to-treat principle.

Results: Participants were an average of 57.4 (SD 10.5) years old, 70% (42/60) White, and 58% (35/60) off treatment. The enrollment rate was 55.9% (66/118). Despite substantial long-term hurricane-related disruptions, we achieved an 80% (48/60) retention. The intervention group's attendance rate was 78% (14/18), whereas the control group's attendance rate was 53% (9/17). Of the 26 game-based pedometers, 3 (12%) were damaged or lost. No study-related adverse events occurred. Acceptability items were highly rated. Steps (β=1621.64; *P*=.01; *d*=0.72), Short Physical Performance Battery (β=.47; *P*=.01; *d*=0.25), and gait speed (β=.12; *P*=.004; *d*=0.48) had a significant intervention effect.

Conclusions: The intervention was feasible and acceptable in this population despite the occurrence of a natural disaster. Pilot results indicate that group AVG sessions, PA coaching, and survivorship navigation produced moderate effects on PA and physical functioning. AVGs with PA counseling can potentially be used in existing breast cancer support groups to encourage PA and improve physical function.

Trial Registration: ClinicalTrials.gov NCT02750241; https://clinicaltrials.gov/ct2/show/NCT02750241

(JMIR Cancer 2022;8(3):e36889) doi:10.2196/36889

KEYWORDS

physical activity; survivors of cancer; pilot study; breast cancer; video games; group intervention; physical function; motivation; mobile phone

Introduction

Background

With advances in the diagnosis and treatment of breast cancer, there are currently >3.8 million female survivors of breast cancer from diagnosis to end of life [1] living in the United States [2]. This means that more than 1 in 5 individuals with a history of cancer are female survivors of breast cancer [2]. Emerging evidence has shown that cancer and cancer treatment can exacerbate age-related deficits in physical function [3]. Without intervention, physical function limitations can lead to a cascade of functional decline, resulting in the loss of independence and early mortality [4]. In fact, a cohort study showed that survivors of breast cancer with functional limitations have a 40% higher mortality rate than those without functional limitations [5]. Therefore, intervening to prevent or reduce functional deficits could produce lasting benefits for the quality of life (QOL) of survivors of breast cancer [6].

Physical activity (PA) is a key approach to mitigating functional decline and improving QOL [7]. However, in the American Cancer Society (ACS) Study of Cancer Survivors-II survey, only 37.1% of survivors of breast cancer met the recommendations for PA of 150 minutes of moderate-intensity activity per week [8]. In another cohort study of 631 women, the percentage of survivors of breast cancer who met the PA guidelines decreased from 34% (before diagnosis) to 21.4% (10 years after enrollment) [9]. Furthermore, survivors of breast cancer were found to be similarly inactive or even more inactive than the general population or other populations of patients with chronic conditions [10]. Moreover, there is a growing concern that survivors of breast cancer are experiencing accelerated aging [3,11], which may also decrease their function. Thus, there is a critical need to develop PA interventions to help promote activity and prevent functional decline.

Although many successful behavior-based PA interventions have been effective in helping survivors increase their activity, these interventions are not without limitations [12]. First, a review of 51 behavior-based PA interventions found that as many as 62% were implemented in only 1 setting—individual or group-based—and only 17% used a group design [12]. However, survivors of breast cancer have indicated a need for interventions that offer a mix of individual and group-based settings [13]. Second, these interventions have not been widely integrated into clinical practice or community settings, so there is a need to test more scalable intervention models [10]. Third, the use of behavior change theories such as self-determination theory (SDT), a theory of motivation, coupled with technology-based tools (eg, active video games [AVGs]) to specifically target PA motivation has not been widely studied [14-17].

By meeting basic psychological needs (competence, autonomy, and relatedness), SDT posits that it will help promote autonomous motivation and increase PA [18]. Emerging research has shown that meeting basic psychological needs creates an autonomously supportive environment, which in turn increases the autonomous motivation to engage in PA in survivors of breast cancer [17,19,20]. Autonomous motivation, a motivation that arises from within the individual, includes identified regulation (ie, valuing PA and accepting the behavior as their own), integrated regulation (ie, being active is consistent with their sense of self), and intrinsic motivation (ie, motivation because of activity enjoyment) [18]. These types of motivation are needed for an individual to adopt and maintain PA behavior [20,21].

Among the few studies on group-based PA interventions is a recent meta-analysis that found that survivors who participated in group- and behavior-based PA interventions showed greater improvement in physical function than those who participated in an individual-based PA intervention [22]. Group- and behavior-based PA interventions also produced increases in PA participation and effort [23,24]. Moreover, group- and behavior-based activity interventions provide psychosocial benefits (eg, QOL and social support) that differ from those of individual-based interventions [25]. Our multicomponent PA intervention was designed to address this limitation by delivering the intervention in a group setting combined with a self-led component.

The wide implementation of an evidence-based PA intervention in clinics and communities could effectively address the need for PA during and after cancer treatment in survivors of breast cancer [26]. Given the numerous support groups available for survivors of breast cancer, support groups offer a potential setting for wide integration and dissemination. However, the combination of AVGs in groups, PA behavioral coaching, and breast cancer support has not been widely studied. Thus, there is a need to test this multicomponent design to accelerate the integration of a PA intervention into breast cancer support groups.

Among survivors of breast cancer, commonly cited reasons associated with the decline in activity level are fatigue, physical discomfort, and lack of belief in their ability to be active again (known as self-efficacy) [13,27,28]. Given that these challenges can affect how survivors of breast cancer respond to PA interventions, reframing PA as pleasurable may promote more motivation for the adoption of PA and lead to more effective PA interventions. AVGs may be a potential *gateway* method to motivate PA adoption and improve physical function among survivors of breast cancer [29,30]. Using AVGs to promote PA has several advantages. First, AVGs are designed to promote physical movement and can be used to facilitate low-cost and flexible PA interventions [31,32]. AVGs have the potential to be a cost-effective way to deliver a PA program in the community setting as they do not require someone to learn exercise moves before leading the sessions and they provide a variety of movement contents for the facilitator to select from [33]. Second, AVGs can encourage light to moderate PA and lead to better enjoyment of those activities when used as a tool to promote PA [34,35]. Third, PA duration increases in the intervention context despite discomfort, and the intention to participate in non-AVG PA also increases [34,35]. Finally, many AVGs include evidence-based behavior change techniques, such as those used in behavioral interventions, that are effective in promoting PA [36]. Examples of behavior change techniques used by AVGs include goal setting, feedback on PA progress, encouraging social comparison and interaction, and providing rewards [36]. In addition, the behavior change techniques used by AVGs can be used to target the basic psychological needs for autonomy, competence, and relatedness in SDT [18].

Previous studies that used AVGs in survivors of breast cancer and other survivors of cancer demonstrated that AVG interventions improved physical function (eg, muscle strength, range of motion, and QOL) [37-39]. However, the primary focus of previous studies was on the reduction of functional impairment based on the International Classification of Functioning, Disability, and Health model and QOL [37-40]. Owing to this focus on function, previous interventions did not include PA behavioral coaching, which is critical for promoting the adoption of PA behavior [12]. Furthermore, previous studies have yielded limited data on how AVGs affect the amount of PA [37-39]. Taking together the evidence in the literature, we have designed a unique method of delivering a multicomponent PA intervention to promote PA and physical function in survivors of breast cancer.

Objectives

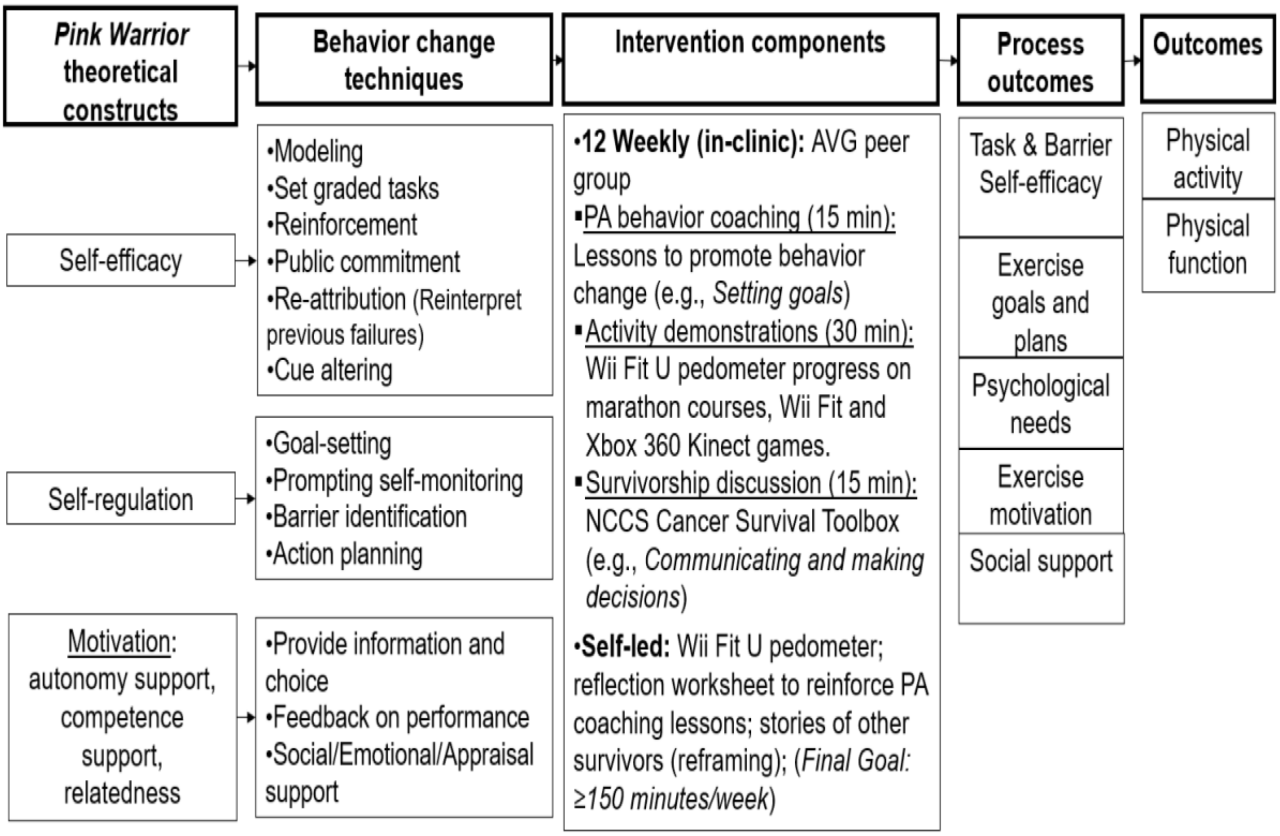
The primary aims of this pilot study were to (1) determine the feasibility and acceptability of a clinic-based multicomponent PA intervention (*Pink Warrior*) with a combination of AVG group play, group PA behavioral coaching, and breast cancer support (ie, survivorship navigation) and (2) determine the effect size and variability of the intervention on PA and physical function in female survivors of breast cancer. To our knowledge, the combination of AVG group play, PA behavioral coaching, and breast cancer support has yet to be tested in female survivors of breast cancer.

Theoretical Framework

We adapted the *Pink Warrior* PA behavioral coaching materials based on the Active Living After Cancer (ALAC) program [41]. We also integrated the National Coalition for Cancer Survivorship (NCCS) Cancer Survival Toolbox and the Personal Health Manager kit of the ACS into the breast cancer support component [42]. Similar to the World Health Organization 2020 Guidelines on Physical Activity and Sedentary Behavior, the ALAC program focuses on adding PA to daily living through a group-based approach that teaches behavior change strategies and skill building. ALAC was tested in a randomized controlled trial [41] and expanded to clinical and community settings in another study [43]. Both studies found an improvement in the physical functioning of survivors of breast cancer after the intervention. Participants reported less pain and less daily activity limitation. Functional assessment indicated an increase in distance for the 6-minute walk test and in the amount of sit-to-stand activity completed in 30 seconds [41,43]. *Pink Warrior* adapted the ALAC program to include AVG technology to introduce various forms of PA and written materials that would allow minimally trained breast cancer support group facilitators (eg, social workers and graduate students) to implement the *Pink Warrior* intervention. Given previous research, we hypothesized that the multicomponent intervention would be feasible and acceptable for female survivors of breast cancer.

Although the focus of this study is not the theoretical framework, methods, and components we used to develop the intervention, we have included the following summary to facilitate future replication of our *Pink Warrior* intervention [44]. Figure 1 shows the *Pink Warrior* intervention logic model, which summarizes the selected theoretical constructs, selected behavior change techniques, intervention components, process outcomes, and final outcomes of interest. The *Pink Warrior* intervention was based on the constructs of the social cognitive theory [27] and SDT [18]. Under social cognitive theory, we focused on the self-efficacy and self-regulation constructs. Self-efficacy and self-regulation are associated with the initiation of and increase in PA [45]. However, researchers have found that increasing autonomous motivation under SDT is important to promote PA over time [20]. On the basis of SDT, meeting the basic psychological needs for autonomy, competence, and relatedness will encourage autonomous motivation and lead to an increase in PA [46]. Thus, the *Pink Warrior* intervention was designed to increase participants' autonomous motivation to engage in PA by targeting the self-efficacy, self-regulation, autonomy, competence, and relatedness constructs. The behavior change techniques we selected to target the theoretical constructs central to the *Pink Warrior* intervention included modeling, reinforcement, cue altering, goal setting, self-monitoring, action planning, barrier identification, and providing feedback on performance (Multimedia Appendix 1 [17,47]). Behavior change techniques are observable and replicable active ingredients used to target theoretical constructs and elicit behavior change [12,46]. We used the behavior change technique taxonomy developed by Michie et al [48] to align the behavior change techniques with the selected theoretical constructs. We chose these specific behavior change techniques because a systematic review demonstrated their effectiveness in targeting the theoretical constructs and increasing PA [44,49].

Figure 1. Pink Warrior logic model. AVG: active video game; NCCS: National Coalition for Cancer Survivorship; PA: physical activity.

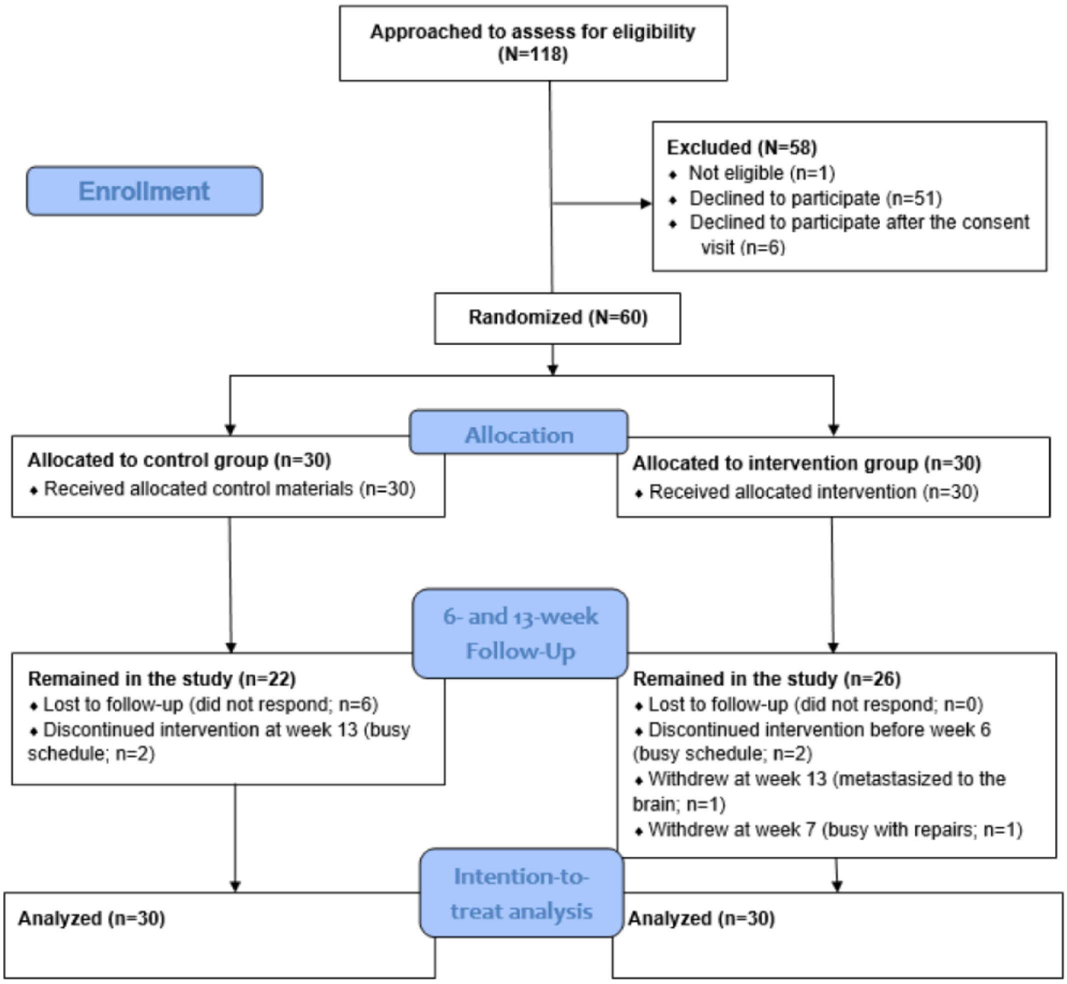


Methods

Participant Enrollment

Our pilot study reporting was prepared in accordance with the CONSORT (Consolidated Standards of Reporting Trials) 2010 statement for randomized pilot and feasibility trials [50]. The CONSORT diagram of this study is shown in Figure 2. We conducted a phase 1b parallel pilot randomized controlled trial in which we used a 1:1 group allocation [51]. Participants (N=60) were recruited in 3 cohorts of 20 between July 2016 and July 2018 by mailing to registries through university announcements, flyers passed out within local cancer support groups, in-clinic flyers, and in-clinic recruitment. Cohort 1 was recruited over 6 months in 2016, and cohort 2 was recruited over 9 months in 2017 because of substantial long-term disruption to the lives of individuals in the recruitment area caused by widespread flooding from Hurricane Harvey. Cohort 3 was recruited over 6 months in 2018. The major inclusion criteria were age ≥18 years at diagnosis; a breast cancer diagnosis; ability to read, write, and understand English; approval from oncologists to participate; and ability to see a television screen from 2 to 4 feet. The major exclusion criteria included self-report of engaging in ≥150 minutes of planned moderate PA per week during the previous week, being currently involved in another PA intervention, or health issues that precluded safe participation. We purposely used less restrictive inclusion criteria to emulate the inclusiveness of a breast cancer support group. A standardized screening script was used by research coordinators and graduate students to determine study eligibility.

Figure 2. CONSORT (Consolidated Standards of Reporting Trials) pilot and feasibility flow diagram.



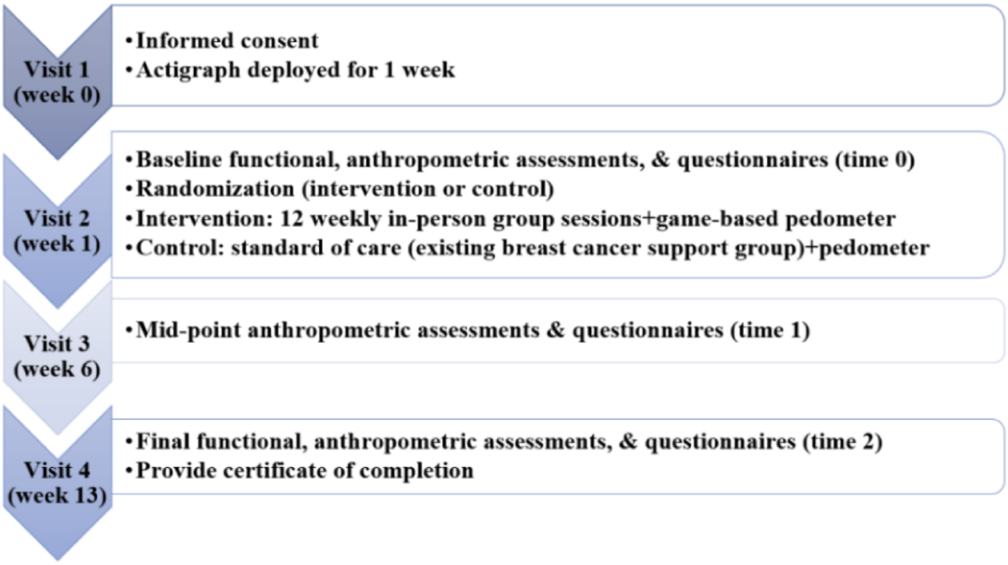
Participant Randomization

Participants were randomly assigned to the PA intervention that combined AVG group play, PA behavioral coaching, and breast cancer support (intervention group) or to participate in the existing breast cancer support group at the study clinic with a pedometer (control group). We used the randomization procedure previously reported by Lyons et al [52]. Briefly, a project staff member (SJW) who was not involved in the assessment used a random number generator [53] to preassign numbers 1 to 20 (cohort 1), 21 to 40 (cohort 2), and 41 to 60 (cohort 3) to either the intervention or control group. The same staff member then sealed each piece of paper with the group allocation in a standard opaque envelope with carbon paper and foil. SJW then randomly shuffled a stack of 20 sealed envelopes per cohort and numbered them sequentially according to the study identification number. The carbon paper was used to provide an audit trail. The interventionist would sign and date each envelope that she opened and save the inner paper with the group allocation and carbon-copied signature and date in the participant file. The foil was used to prevent the interventionist from seeing the group assignment inside the envelope.

Procedure

All participants attended 4 scheduled informed consent and assessment visits. The study flow is summarized in Figure 3. The total study duration for each participant was 13 weeks, but the PA intervention duration was 12 weeks. Visit 1 was the informed consent visit. After informed consent was obtained, a research-grade activity monitor (*ActiGraph*) was provided for participants to wear for a week, and a packet of baseline questionnaires was provided for participants to complete before visit 2. Approximately 1 week later, participants returned for visit 2, where we conducted the full baseline functional assessment (time 0) and randomization and provided orientation for the study group into which the participants were randomized. Visit 3 was the midpoint assessment (time 1), which consisted of the completion of the questionnaires and PA assessment. The full final assessment occurred at visit 4 (time 2). Participants were not blinded to their group assignment. We were not able to conduct a blinded assessment owing to limited staffing resources. We obtained permission from the participants at the time of recruitment to send reminders via phone, SMS text message, or email to schedule appointments and the day before an appointment as a reminder.

Figure 3. Study flow diagram.



Ethics Approval

The Institutional Review Board at the University of Texas Medical Branch approved all procedures (protocol number: 16-0040), and our study was registered at ClinicalTrials.gov before data collection (NCT02750241).

Intervention Group

The participants assigned to the intervention group took part in 12 weekly in-person, multicomponent PA intervention sessions. Participants were given a participant manual that contained weekly PA behavioral skill-building topics, self-led reflection worksheets, and breast cancer support discussion topics. Each of the in-person weekly group sessions consisted of three components: (1) a *PA behavioral coaching* (ie, *cognitive behavioral skill building*) component to promote the increase and maintenance of PA behavior, (2) an *AVG-basedactivity demonstration and practice* component to provide guided practice and increase mastery of activity skills using AVGs, and (3) a *breast cancer support discussion* component to provide support and resources for survivors of breast cancer. The weekly structured group session lasted approximately 60 minutes. A trained facilitator (graduate students pursuing a master's degree or a research coordinator) would summarize the weekly PA discussion topic aimed at providing behavior change skills during the PA behavioral coaching component, help set up the AVGs, and facilitate the breast cancer survivorship discussions.

Within the *PA behavioral coaching component*, the adapted *Pink Warrior* intervention content focused on helping survivors of breast cancer overcome barriers to becoming more active and increasing self-regulation skills. The behavior change strategies included receiving feedback on PA, gaining knowledge regarding the benefits of PA, evaluating value toward activity, self-monitoring, goal setting, and action planning. These behavior change strategies addressed activity barriers such as lack of self-efficacy related to PA, lack of time because of competing demands, and lack of motivation because of general reasons or fatigue. The participants were asked to complete the reflection worksheet and accomplish the activity goals during the week following the PA behavioral coaching session. The reflection worksheets corresponding to the weekly coaching lessons were given to the participants to reinforce and encourage behavior changes toward self-led PA outside the group sessions.

AVGs that involved motion-controlled movement were used for the *AVG-basedactivity demonstration and practice component* of the *Pink Warrior* intervention. The AVGs were delivered through either the Wii Fit U (Nintendo EAD) game console or the Xbox 360 Kinect (Microsoft) game console in the group sessions. Participants only played the games in the weekly group session and were not given a Wii Fit U or Xbox console to use at home. Table 1 provides a summary of the types of games chosen by the study team in collaboration with the occupational therapist and the lymphedema therapy specialist at the study clinic. The fitness-based activities involved functional-based exercises such as balance exercises as well as body weight exercises and cardiovascular endurance exercises. As seen in Table 1, the fitness-based activities were chosen to introduce different activities that mimicked those that the participants could find to take part in on the web or in person.

Table 1. Examples of the games.

	Mind-body activities	Fitness-based activities
Wii Fit U	Walking game and yoga	Just Dance, Zumba, and dance games (Wii Fit U minigames and Your Shape Fitness Evolved 2012)
Xbox 360 Kinect	Your Shape Fitness Evolved 2012 (Zen energy, yoga, African rhythms, and Bollywood dance)	Your Shape Fitness Evolved 2012 (kickboxing; boot camp; and upper-, mid-, and lower-body training), Zumba, and Just Dance

As an example of social play, participants were able to track individual and group PA achievements in a gamified way during the weekly PA coaching session by wearing the Wii Fit U fitness tracker. Under the Wii Fit U game system, each participant was able to create an anonymous Mii character and select a marathon course (eg, the London marathon) that they would like to complete. Weekly, the accumulated steps recorded by the Wii Fit U fitness tracker were converted into the distance traveled (miles), and the participants were able to see themselves advance on the marathon course once the trackers were paired with the Wii Fit U game console. At the completion line, each participant's avatar could then choose a new outfit with the destination's design (eg, the London tower for the London marathon). Having the ability to see each other's weekly accomplishments allowed for further enhanced motivation through social comparison and relatedness [31]. Participants were encouraged to meet their weekly step goals (eg, increase by 10% weekly) by seeking out AVG-based PAs that they found enjoyable in the community (eg, in-person or web-based tai chi classes or web-based videos) or by walking. Participants were given links to web-based videos of people playing the games to be used during the week. Paper-based PA logs were also provided for participants to record their activities on a daily, weekly, and monthly basis.

For the *breast cancer support component*, resources from the NCCS Cancer Survival Toolbox and ACS Personal Health Manager kit were used to elicit survivorship discussions. This component was designed to provide resources and support to survivors of breast cancer. Notably, it is the standard of care at the study clinic to provide the ACS Personal Health Manager kit to all new patients with breast cancer. However, the clinical team did not provide a detailed discussion on the content of the Personal Health Manager kit. Therefore, we integrated the NCCS Toolbox and ACS Personal Health Manager kit into the breast cancer support discussions to provide survivors of breast cancer with the tools to find credible resources.

Control Group

Participants assigned to the control group at visit 2 (Figure 3) received the standard of care provided by the study clinic plus a step count monitoring intervention. The standard of care at the clinic included a monthly breast cancer support group that used its own materials. As part of the standard of care at the clinic, patients were also given the ACS Personal Health Manager kit, which included educational handouts related to PA during treatment and range of motion exercises developed by an occupational therapist who was also the lymphedema therapy specialist at the clinic. Furthermore, participants assigned to the control group were introduced to the facilitator of the existing breast cancer support group at the study clinic after the initial assessment. Control group participants were encouraged to take part in the clinic-based breast cancer support group every month until visit 4. The control group participants did not receive the *Pink Warrior* intervention or NCCS information while they were active in the study. However, the intervention materials were offered to the control group participants at study visit 4.

The step count monitoring intervention provided to the control group participants included a regular pedometer (*Omron HJ-321*) to be worn for the duration of the study period (between visits 2 and 4; Figure 3) [54]. During visit 2, we also helped control group participants set an activity goal and provided paper-based PA logs for them to record their activities on a daily, weekly, and monthly basis. We chose this type of control group intervention because of evidence related to the health benefits of PA among patients with and survivors of cancer [55]. In addition, similar interventions have also produced a short- and long-term increase in steps [56].

Outcomes

Feasibility

Feasibility was assessed using the enrollment rate, retention rate, intervention group attendance rate, number of technological issues and adverse events reported by the research participants, and type of games played during the intervention group sessions. On the basis of typical outcomes of feasibility studies [57], we defined feasibility as the successful enrollment of at least 50% of the eligible participants approached or screened by the research coordinator and graduate students. The retention rate was feasible if at least 80% of participants completed the final assessment (Figure 3) based on previous PA or exercise studies conducted on survivors of breast cancer [57]. The group attendance or adherence rate was determined from the weekly or monthly attendance log maintained by the group facilitators. Group attendance was considered to be feasible if >75% of participants attended at least nine sessions in the intervention group. The number of technical and adverse events reported by the participants was determined using the participant database maintained by the study team. Information concerning the feasibility of the types of games played was obtained using a facilitator log.

Acceptability

The acceptability of the group AVG-based PA intervention components was measured using items adapted from Vandelanotte et al [58,59] and Lyons et al [52]. Acceptability was measured by participants' agreement (from strongly disagree=1 to strongly agree=5) regarding the use of AVGs and the overall program. Participant acceptability and satisfaction data were collected at time 1 and time 2. Participant satisfaction was determined based on a questionnaire with 5-point scale responses. Participants were asked to report their satisfaction with the support time and length, intervention materials and staff, activity demonstrations, and discussion topics. They were also asked to provide written feedback at time 2.

PA Changes

The PA metrics examined in our intervention included average daily steps, average minutes of light PA, and average minutes of moderate to vigorous PA (MVPA). PA metrics were objectively measured using ActiGraph, a validated research-grade 3-axis accelerometer. The wear time was 7 days at each assessment point. As continuous measurement was not feasible, a week-long sample was taken at baseline, week 6 (–1 week to +1 week), and week 12 (–1 week to +1 week). We followed the accelerometer data processing protocol published by Keadle et al [60] for this pilot study, in which PA estimates were considered for analysis if the monitor was worn for at least 10 hours per day on at least one day. The step counters—Wii Fit U fitness tracker and Omron HJ-321—were used to promote self-monitoring behavior only.

Physical Function

The Short Physical Performance Battery (SPPB) was used to objectively measure physical function. The battery consists of 6 components: repeated chair sit-to-stand activity, balance test, semitandem stand, tandem stand, side-by-side stand, and 3-meter walk [61]. The handgrip strength test was objectively measured using the Jamar Digital Hand Dynamometer. Grip strength was assessed to measure changes in physical strength [26].

Self-reported Measures

Other self-reported measures included demographics such as age, gender, race and ethnicity, education, type of cancer diagnosis, and the type of treatment the participant was receiving. Self-reported measures were collected using paper-based questionnaires. The feasibility indicators were based on an enrollment and assessment database maintained by the study research coordinator. All other assessments took place face-to-face.

Participants did not receive any monetary incentives. Rather, a water bottle, a tote bag, and a T-shirt were provided to both the intervention and control group participants as a *thank you* or token of appreciation for participating in the study.

Statistical Analysis

Data were analyzed using the SAS software (version 9.4; SAS Institute). Differences at baseline were investigated using Student *t* tests (2-tailed) and chi-square tests. Within-group comparisons between week 14 and baseline were performed using paired *t* tests. Differences between groups were estimated using analysis of covariance controlling for baseline values of the dependent variable and any baseline-intervention interaction (model: week 14 = [week 14 – week 0] + group + [week 14 – week 0] × group). The groups were coded as 0 (control) and 1 (intervention). Responses were missing at random and, thus, missing data were imputed using regression models [62]. The models consisted of the intervention status variable, the opposite time point, and 6 variables without missing observations. These 6 were selected from the 12 highest-ranked associations based on the prediction sum of squares statistic for each variable to be imputed. Multimedia Appendix 2 shows the imputation regression models for each variable imputed. For each outcome, the Cohen *d* [63,64] and its 95% CI determined effect size and variability, respectively. All statistical analyses used a significance level of .05. The primary purpose of this study was to evaluate the feasibility of the intervention components and study procedures to inform a larger intervention trial. Therefore, this study was not powered to detect a statistically significant difference in the PA and physical function outcomes. The statistical tests were conducted to provide estimated effect sizes and inform power and sample size estimates for the development of a follow-up intervention trial.

Results

Characteristics

As shown in Table 2, participants (N=60) on average were aged 57.4 (SD 10.5) years with a BMI of 30.6. Most participants (35/60, 58%) were off active cancer treatment at baseline, and the average time since diagnosis was 24.1 (SD 35.8) months. Of the 60 participants, 22 (37%) reported symptoms related to chemotherapy-induced peripheral neuropathy, and 33 (55%) had below-average grip strength for their age and gender at baseline [65]. No study-related adverse events were reported. We did not see any significant differences between the intervention and nonintervention groups related to the demographic characteristic variables.

Table 2. Participant characteristics at time 0 (N=60).

Characteristic	Total	Intervention (n=30)	Control (n=30)	*P* value[a]
Race and ethnicity, n (%)				.31
0—Non-Hispanic White	42 (70)	21 (70)	21 (70)	
1—African American	10 (17)	3 (10)	7 (23)	
2—Hispanic	4 (7)	3 (10)	1 (3)	
3—Other	4 (7)	3 (10)	1 (3)	
Stage, n (%)				.79
0	7 (12)	2 (7)	5 (17)	
I	28 (47)	14 (47)	14 (47)	
II	14 (23)	8 (27)	6 (20)	
III	9 (15)	5 (17)	4 (13)	
IV	2 (3)	1 (3)	1 (3)	
Treatment type, n (%)				.80
Surgery only	11 (18)	5 (17)	6 (20)	
Surgery and chemotherapy	9 (15)	5 (17)	4 (13)	
Surgery, chemotherapy, and radiation	24 (40)	11 (37)	13 (43)	
Chemotherapy only	2 (3)	2 (7)	—[b]	
Chemotherapy and radiation only	2 (3)	1 (3)	1 (3)	
Surgery and radiation	12 (20)	6 (20)	6 (20)	
Current treatment status, n (%)				.43
Off treatment	35 (58)	16 (53)	19 (63)	
On treatment	25 (42)	14 (47)	11 (37)	
Self-reported symptoms related to chemotherapy-induced peripheral neuropathy, n (%)				.59
Yes	22 (37)	12 (40)	10 (33)	
No	38 (63)	18 (60)	20 (67)	
Grip strength below age and gender norm, n (%)				.80
Yes	33 (55)	17 (57)	16 (53)	
No	27 (45)	13 (43)	14 (47)	
Age (years), mean (SD; range 29-80 years)	57.38 (10.48)	56.10 (10.65)	58.67 (10.33)	.35
Time since diagnosis (months), mean (SD)	24.10 (35.83)	25.53 (39.14)	22.67 (25.62)	.74
BMI (kg/m^2), mean (SD)	30.62 7.46)	29.44 (6.24)	31.79 (8.46)	.22

[a] *P* values calculated using the chi-square test for equal proportions for categorical variables and the 2-sample *t* test for continuous variables.

[b] No participants from the control group were in this category.

Feasibility and Acceptability

The enrollment rate was 55.9% (66/118 eligible participants provided consent). In the intervention group, 13% (4/30) of the participants dropped out compared with 27% (8/30) of the participants in the control group (Figure 2). The most common reason for dropping out of the study was hurricane-related issues (eg, busy with house repairs). Despite substantial and long-term hurricane-related challenges, we achieved 80% (48/60) retention. Without accounting for missing sessions because of hurricane closures, participants in the intervention group attended a mean of 8.92 (SD 1.72) of the 12 sessions. We removed intervention participants (8/26, 31%) who were affected by the hurricane (eg, unable to attend because homes were flooded for weeks or severely damaged) from the adherence calculation to account for missing sessions because of hurricane closures, which produced a mean of 9.5 (SD 1.34) sessions. The intervention attendance rate was 78% (14/18 of included participants who completed at least nine sessions). In the control group, without accounting for missing sessions because of hurricane closures, participants attended a mean of 1.36 (SD 1.33) of 3 sessions. We removed control participants (5/22, 23%) who were affected by hurricane closures, which produced a mean of 1.56 (SD 1.37) sessions.

Of the 26 Wii Fit U game-based pedometers, 3 (12%) were damaged (eg, water damage) or lost. We were able to set up the game consoles in a small conference room (Figure 4). The location accommodated up to 4 participants and a facilitator at a time. On average, we formed 3 groups per cohort of 10 intervention participants because of room restrictions. Facilitator logs indicated that participants frequently selected mind-body activities (eg, tai chi and low-intensity dance games) during the first half of the intervention period (sessions 1-5) and progressed toward frequent selections of fitness-based activities (eg, Zumba and cardio boxing) during the second half of the intervention period (sessions 6-12). A total of 100% (60/60) of the intervention participants rated their acceptance of the *Pink Warrior* intervention at ≥4 on a scale of 1 to 5 (Table 3). Examples of postintervention feedback are included in Multimedia Appendix 3.

Figure 4. Room setup.

Table 3. Acceptability of the Pink Warrior intervention (time 2; N=26).

Item	Value, mean (SD)
Liked the Pink Warrior program	5.0 (0.2)
Appropriate activities	4.8 (0.4)
Program helped set reasonable goals	4.8 (0.5)
Contents were relevant	4.8 (0.4)
Program was worth my time and effort	5.0 (0.2)
Liked the contents presented (manual)	4.8 (0.5)
Liked the group setting	4.7 (0.6)
Liked the AVG[a] portion	4.8 (0.5)
Liked the cancer survivorship topics	4.8 (0.4)
Like the program length	4.4 (0.9)
I would continue to participate	4.6 (0.7)

[a] AVG: active video game.

PA and Function

The PA and objective physical function measurement results for the intervention and control groups are shown in Table 4. Intention-to-treat analyses in which missing data were imputed showed moderate effect sizes between the groups for PA outcomes such as the number of steps (*d*=0.72, 95% CI 0.20-1.24) and MVPA (*d*=0.72, 95% CI 0.19-1.24). For physical functioning outcomes, we found small between-group effect sizes, such as gait speed (*d*=0.48, 95% CI −0.03 to 0.99) and total SPPB score (*d*=0.25, 95% CI −0.26 to 0.75).

Analysis of covariance models controlling for baseline values of the dependent variable and any baseline-intervention interaction are shown in Table 5 and report the estimated β coefficients and corresponding *P* values from the Student *t* test. The results from our pilot intervention suggested that gait speed, total SPPB score, average daily steps, and MVPA had a significant intervention effect controlled for baseline and baseline-intervention interaction. Grip strength and light PA had nonsignificant intervention effects.

Table 4. Physiological effects of the intervention—mean of differences between baseline and final assessment for the intervention and control groups.

Variable	Intervention		Control		Effect size (between-group differences), Cohen *d* (95% CI)
	Mean of difference (SD)[a]	*P* value[b]	Mean of difference (SD)	*P* value	
Average grip strength	−0.094 (3.047)	.87	0.568 (1.826)	.10	0.26 (−0.25 to 0.77)
Gait speed	0.109 (0.194)	.004	0.030 (0.131)	.23	0.48 (−0.03 to 0.99)
Total SPPB[c] score	0.653 (0.857)	<.001	0.421 (1.012)	.03	0.25 (−0.26 to 0.75)
Steps	1556.200 (2614.8)	.003	−22.700 (1639.300)	.94	0.72 (0.20 to 1.24)
Light PA[d]	13.322 (80.05)	.37	−10.687 (63.625)	.37	0.33 (−0.18 to 0.84)
MVPA[e]	11.988 (18.994)	.002	0.999 (10.3444)	.60	0.72 (0.19 to 1.24)

[a] Final assessment (time 2) – baseline assessment (time 0).

[b] *P* values indicate significant difference between final assessment and baseline.

[c] SPPB: Short Physical Performance Battery.

[d] PA: physical activity.

[e] MVPA: moderate to vigorous PA.

Table 5. Analysis of covariance results.

Variable	Week 0		Group or intervention status	
	β (95% CI; adjusted)[a]	*P* value	β (95% CI; adjusted)[a]	*P* value
Average grip strength	.806 (0.733 to 0.878)	<.001	−0.138 (−0.676 to 0.400)	.80
Gait speed	.838 (0.696 to 0.980)	<.001	.118 (0.079 to 0.157)	.004
Total SPPB[b] score	.515 (0.428 to 0.601)	<.001	.470 (0.299 to 0.642)	.008
Steps	.915 (0.688 to 1.142)	.002	1621.637 (1063.480 to 2179.794)	.005
Light PA[c]	.899 (0.723 to 1.075)	<.001	21.014 (2.130 to 39.897)	.27
MVPA[d]	.414 (0.166 to 0.661)	.10	11.235 (7.672 to 14.799)	.003

[a] Adjusted for baseline treatment interaction.

[b] SPPB: Short Physical Performance Battery.

[c] PA: physical activity.

[d] MVPA: moderate to vigorous PA.

Discussion

Principal Findings

The aims of this study were to (1) describe the feasibility and acceptability of a clinic-based multicomponent PA intervention (*Pink Warrior*) with a combination of AVG group play, group PA behavioral coaching, and breast cancer support (ie, survivorship navigation) and (2) determine the effect size and variability of the intervention on PA and physical function in female survivors of breast cancer. Our results demonstrated that the group AVG-based PA intervention (*Pink Warrior*) was feasible and acceptable in a sample of middle-aged survivors of breast cancer who were on and off treatment. Evidence of feasibility was indicated by 55.9% (66/118) enrollment of eligible participants, 80% (48/60) retention at the end of the study, a 78% (14/18) adherence rate among intervention group participants, minimal technology issues, and no study-related adverse events. Evidence of acceptability was indicated by the mean acceptability scores exceeding 4 out of 5. The *Pink Warrior* intervention produced moderate effect sizes for PA metrics (ie, 0.72 for steps and 0.72 for minutes of MVPA) and a small effect size for objective physical function outcomes (ie, 0.48 for gait speed and 0.25 for SPPB score). We also found significant intervention effects on gait speed, total SPPB score, average daily steps, and MVPA. The effect sizes and significant intervention effects suggest that a larger-scale implementation of the intervention has the potential to produce a small to moderate effect and also reach minimal clinically important differences in PA and physical function metrics.

As previous AVG-based interventions in survivors of breast cancer did not specifically evaluate the feasibility and acceptability of the interventions, we compared our findings with other PA interventions conducted in survivors of breast cancer. Overall, our feasibility findings fall within the range of accepted values for PA interventions conducted in survivors of breast cancer [57] and also within the range of accepted values for AVG-based interventions conducted in individuals with cancer [66]. Our enrollment rate of 55.9% (66/118) was higher than the overall median enrollment rate of 45% across various PA interventions in survivors of breast cancer [57]. In addition, our overall 80% (48/60) retention was within the range of other AVG-based interventions in survivors of cancer (50%-100%) [66]. Similar to the findings of the systematic review conducted by Singh et al [57], we found a greater dropout rate in the control group than in the intervention group. Even though our adherence rate was lower than the overall median adherence rate (81%) reported by Singh et al [57], it is within the acceptable range for PA interventions in survivors of cancer on and off treatment (62%-96.6%) [66,67]. Most of our adherence issues resulted from the fact that 47% (14/30) of *Pink Warrior* intervention group participants were on treatment. Many of the missed sessions were because the participants were experiencing side effects from chemotherapy and were not able to travel to the in-person group AVG session. Most attrition issues during our study resulted from the post–Hurricane Harvey recovery burden on some participants. Mainland Galveston County, where the clinic-based sessions took place and where many participants lived, was among the hardest-hit areas during this extreme flooding event, resulting in substantial long-term disruptions.

In addition to its feasibility, the results of our AVG-based intervention indicated acceptability. The mean acceptability score of >4 is consistent with other exergame-based PA interventions [66]. Specifically, our intervention participants rated the content, group setting, and AVG portion of the intervention close to 5 out of 5. According to the facilitator log, intervention participants selected a variety of games from both the Wii Fit U and Xbox 360 Kinect game consoles. The high acceptability may be related to having PA variety, which enabled participants to try different activities that ranged from mind-body to fitness-based activities. Beyond the questionnaire feedback, acceptability was further demonstrated by how often participants joined either the weekly intervention group sessions or the usual clinic-based breast cancer support group. The intervention group participants attended 78% (14/18) of the scheduled AVG-based group sessions, whereas the control group participants attended 53% (9/17) of the scheduled clinic-based breast cancer support group sessions. Our results indicate that AVG-based activities along with PA coaching can potentially be added to the existing clinic-based support group to enhance engagement and participation among survivors of breast cancer who are on and off treatment.

Our PA outcomes indicate that the AVG-based intervention benefited the participants. The increase in average number of steps per day among the intervention participants was similar to that published by Sajid et al [68]. The increase of 1556.2 average daily steps among our intervention participants falls between the increases in average daily steps for the Wii intervention group in the study by Sajid et al [68] (+1223.8 steps per day) and their home-based walking and resistance intervention group (+19,414.4 steps per day) at the end of their 6-week intervention program. Similarly, the control group participants in both our study and the study by Sajid et al [68] experienced a decline in average daily steps (−22.7 and −383.4 steps per day, respectively) [68]. As there is limited published information on the influence of AVGs on PA levels, we further compared our findings with PA interventions that used wearables and smartphone apps [69]. Compared with the findings of Gal et al [69], our effect size for average daily steps was higher (d=0.72 vs d=0.51), as was our effect size for average minutes of MVPA (d=0.72 vs d=0.43). Beyond achieving a moderate effect size for average daily steps and average minutes of MVPA, the increase of >1000 steps per day estimated in 13 weeks also met the threshold for a minimal clinically important difference. A recent systematic review by Hall et al [70] found that an increase of 1000 steps per day among adults (mean age range 49.7-78.9 years) was associated with a decreased risk of all-cause mortality and cardiovascular disease–related morbidity or mortality. Hence, this finding is promising as it points to the effectiveness of a multicomponent PA intervention using AVGs for survivors of breast cancer during and after treatment.

The changes in the physical function outcomes among our PA intervention group are also promising. The intervention participants showed an increase in SPPB score (+0.653 in SPPB score) at the end of the intervention, whereas the Wii intervention group in the study by Sajid et al [68] did not show an increase in SPPB score. The difference between our intervention results and the finding of Sajid et al [68] suggests that the PA coaching that was integrated into our AVG-based PA intervention promoted engagement in activities that helped increase the total SPPB score. We were unable to locate other exergame interventions in survivors of cancer that specifically reported a change in gait speed [66]. However, the effect size found for gait speed as a result of our intervention, although small (0.11 m/s), showed a clinically important change. Evidence from the literature indicates that an increase of 0.11 m/s in gait speed is associated with a lower risk of morbidity and mortality [71]. The slight but not significant reduction in grip strength in our intervention group was a surprising finding. This finding may be related to several factors. First, we had more survivors of breast cancer who were on treatment in the intervention group than in the control group. A reduction in strength during cancer treatment has been established [72]. Second, the activities chosen mainly targeted lower-body functioning. Given that Sajid et al [68] showed an increase in grip strength with the use of resistance bands, resistance training could potentially be integrated into AVG-based PA interventions.

Strengths and Limitations

Our phase 1b pilot randomized controlled trial had several strengths. First, it involved an innovative intervention design that paired group-based AVGs with PA behavioral coaching to promote PA behavior among survivors of breast cancer. We systematically designed the intervention by aligning the intervention components with behavior change methods and theoretical constructs. Previous studies that used AVGs in survivors of breast cancer and other survivors of cancer primarily focused on the reduction of functional impairment; thus, their focus was not on promoting the adoption of PA behavior [37-39]. Second, our use of objective measures of PA and physical function overcame some of the limitations (eg, overreporting and underreporting) that are associated with self-reported measures [73-75].

However, our study also had several limitations that are associated with the study design. First, this was a pilot study with a small sample size. Therefore, we were not fully powered to detect statistically significant differences in the participants' outcomes or the long-term maintenance of PA behavior and physical function. Thus, our focus was on evaluating the effect size of the main outcome measures, which will provide the effect estimates needed to design a larger trial. Despite the small sample size, our AVG-based PA intervention produced moderate effect sizes and clinically important changes, which indicate that a larger-sample trial is worthwhile. Second, the pilot intervention was designed to test the feasibility and acceptability of the full intervention. The focus was on developing the most efficacious multicomponent program rather than on evaluating the impact of specific intervention components. Therefore, we were not able to determine the feasibility, acceptability, or effects of the individual portions of the intervention. Given that we found moderate effect sizes and clinically important changes in PA and physical functioning outcomes, a factorial-designed efficacy trial will be considered for a larger trial to determine the mechanisms of action of the intervention's individual portions. Third, there was a difference in the number of group sessions offered to the control and intervention participants. This is because participants assigned to the control group received the standard of care provided by the study clinic plus a step count monitoring intervention. The highly advertised monthly breast cancer support group was a part of the study clinic's standard of care. The differences in the number of sessions could potentially affect the differences in outcomes. Even so, the control group participants were provided with a step count monitoring intervention in addition to the standard of care to allow for activity tracking. A systematic review and meta-analysis found that similar interventions have also produced short- and long-term increases in steps. Therefore, the moderate effect sizes and clinically important changes found in our study would still be considered valid. Fourth, our *Pink Warrior* intervention involves more extensive facilitator training than the current support group format. Therefore, time for facilitator training may be an issue for future implementations. However, as the study has demonstrated feasibility, a subsequent study will be conducted to evaluate how to efficiently deliver facilitator training. Finally, this study was limited to the greater southeastern Texas community. Therefore, our pilot results may not be nationally generalizable. However, we will use our results to inform the design of a larger and more generalizable study.

Conclusions

In summary, our results suggest that a clinic-based multicomponent PA intervention that combines AVG group play, group PA behavioral coaching, and breast cancer support (eg, survivorship navigation) is feasible and acceptable for middle-aged survivors of breast cancer on and off treatment. Given our results, the use of AVGs combined with manualized PA behavioral coaching can potentially be a scalable and promising strategy that can be integrated into existing breast cancer support groups to promote PA in survivors of breast cancer. Future studies are needed to understand how to efficiently integrate AVGs and PA behavioral coaching into existing breast cancer support groups. Through such integration, we will then be able to increase reach and deliver an evidence-based PA intervention to promote PA and enhance physical function. In addition, we need to better understand how and why AVGs help increase PA and physical function by comparing a group that includes AVGs with PA coaching and survivorship navigation with a group that only has PA coaching and survivorship navigation.

Acknowledgments

This study was internally funded by the President's Cabinet Award at University of Texas Medical Branch (UTMB). Additional salary support was provided by the Cancer Prevention Research Institute of Texas (RP140020 and RP170668); the National Institute on Disability, Independent Living, and Rehabilitation Research (90AR5009); a Mentored Research Scholar Grant in Applied and Clinical Research (MRSG-14-165-01-CPPB) from the American Cancer Society; the American Heart Association (13BGIA17110021 and 16PRE27090012); the National Institute of Child Health and Human Development (National Center for Medical Rehabilitation Research), the National Institute for Neurological Disorders and Stroke, and the National Institute of Biomedical Imaging and Bioengineering (P2CHD065702); the Claude D. Pepper Older Americans Independence Center (P30AG024832); the National Institute on Aging (1R01AG064092); the Center for Energy Balance in Cancer Prevention and Survivorship, Duncan Family Institute for Cancer Prevention and Risk Assessment; and the MD Anderson Cancer Center Support Grant (CA016672). Editorial support was provided by Bryan Tutt, Scientific Editor, Research Medical Library. The authors would also like to thank the following individuals for their assistance with participant recruitment, data collection, data analysis, and manuscript editing: Jason Bentley, PhD, MS (UTMB); V Suzanne Klimberg, MD, PhD (UTMB); Julie Park, MD (UTMB);

Sandra S Hatch, MD (MD Anderson and UTMB); Rohit Venkatesan, MD (MD Anderson and UTMB); Issam Alawin, MD (Utica Park Clinic); Eloisa Martinez, BS (UTMB); Alaina Teague, MS, RD (UTMB); and Madison Walker, BS (UTMB).

Conflicts of Interest

None declared.

Multimedia Appendix 1

Summary of theoretical constructs, behavior change methods, and intervention components.

[PDF File (Adobe PDF File), 100 KB - cancer_v8i3e36889_app1.pdf]

Multimedia Appendix 2

Models for imputation of missing data.

[PDF File (Adobe PDF File), 108 KB - cancer_v8i3e36889_app2.pdf]

Multimedia Appendix 3

Examples of postintervention feedback.

[PDF File (Adobe PDF File), 91 KB - cancer_v8i3e36889_app3.pdf]

Multimedia Appendix 4

CONSORT-eHEALTH checklist (V 1.6.1).

[PDF File (Adobe PDF File), 4292 KB - cancer_v8i3e36889_app4.pdf]

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Abbreviations

ACS: American Cancer Society
ALAC: Active Living After Cancer
AVG: active video game
CONSORT: Consolidated Standards of Reporting Trials

MVPA: moderate to vigorous physical activity
NCCS: National Coalition for Cancer Survivorship
PA: physical activity
QOL: quality of life
SDT: self-determination theory
SPPB: Short Physical Performance Battery
UTMB: University of Texas Medical Branch

Edited by A Mavragani; submitted 29.01.22; peer-reviewed by B Bock, K Taylor; comments to author 25.02.22; revised version received 01.07.22; accepted 04.07.22; published 22.08.22.

Please cite as:
Swartz MC, Lewis ZH, Deer RR, Stahl AL, Swartz MD, Christopherson U, Basen-Engquist K, Wells SJ, Silva HC, Lyons EJ
Feasibility and Acceptability of an Active Video Game–Based Physical Activity Support Group (Pink Warrior) for Survivors of Breast Cancer: Randomized Controlled Pilot Trial
JMIR Cancer 2022;8(3):e36889
URL: *https://cancer.jmir.org/2022/3/e36889*
doi:*10.2196/36889*
PMID:*35994321*

Original Paper

Improving Clinical and Family Communication for Adult Child Caregivers of a Parent With a Blood Cancer: Single-Arm Pre-Post Pilot Intervention

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Abstract

Background: Adult child caregivers of parents with cancer may face challenges when communicating with the patient and other family members, communicating during clinical interactions, and navigating web-based information seeking.

Objective: We developed and pilot-tested the *Healthy Communication Practice* program for adult child caregivers of parents with a blood cancer, which aims to help participants learn and implement communication skills central to caregiving. We assessed the feasibility and acceptability of the training.

Methods: Eligible participants completed a preprogram survey. We assessed the feasibility of participants completing the intervention in the allotted time. Participants had 2 weeks to complete the 2-part, 90-minute online program and completed a postprogram survey that included program evaluation items and the Acceptability of Intervention Measure (AIM) using a 1-5 rating scale (5=strongly agree).

Results: Of 50 caregivers who initially expressed interest, 34 consented, and 30 completed the program and both surveys (88% completion rate). Caregivers had a mean age of 45.07 (SD 11.96) years and provided care for parents who had a mean age of 73.31 (SD 9.38) years. Caregivers were primarily daughters (n=22, 73%). Overall, scores on the AIM scale were high (mean 4.48, SD 0.67). Specifically, caregivers felt the content met their communication needs (mean 4.58, SD 0.62) and their own needs as a caregiver of a parent with a blood cancer (mean 4.39, SD 0.72).

Conclusions: We demonstrated the feasibility and acceptability of the *Healthy Communication Practice* program, which aims to enhance family and clinical communication skills among caregivers of a parent with a blood cancer. Future studies will examine the efficacy of the program and its impact on both caregiver and patient communication and health outcomes.

(JMIR Cancer 2022;8(3):e38722) doi:10.2196/38722

KEYWORDS

caregiver; clinician-patient communication; healthy communication practice; eHealth literacy; family communication; feasibility; acceptability; oncology; blood cancer; cancer patent; web-based information seeking; health information; clinical communication; smartphone; mobile phone

Introduction

Family caregivers of individuals diagnosed with cancer face many challenges as they integrate the emotional, logistical, and financial pressures of cancer caregiving into their often busy lives [1,2]. Over the past 2 decades, researchers have developed psychosocial interventions to address some of the challenges that cancer caregivers face [3]. However, all caregivers are not the same. One key differentiating characteristic of caregivers is their relationship to the individual with cancer. Family caregiver-patient dyads generally represent 3 caregiver types: an individual caring for their spouse, child, or parent. The third type of caregiver, adults caring for an aging patient, receives the least attention in research [4], despite the expectation that they will increase in number due to population shifts and the forthcoming "silver tsunami" [5]. In addition, research suggests that adult child caregivers of parents, particularly daughters, can experience higher levels of strain [6], stress [7], guilt [8], and burden [9] compared to those caring for a spouse.

Furthermore, there has been little research on caregiving for patients with a hematologic or blood cancer. There are unique challenges associated with blood cancer caregiving among both acute and chronic blood cancer disease subtypes, and families facing a blood cancer diagnosis can be at a higher risk for psychological distress compared to those coping with other types of cancers [10,11]. The median age at diagnosis for the most common types of blood cancer (leukemia and non-Hodgkin lymphoma) is 67 [12,13]. Given that aging adults are more likely to be coping with a blood cancer, it is not uncommon for midlife adult children to become the primary caregiver of a parent diagnosed with a blood cancer [1]. Midlife caregivers report significant stress and burden related to family functioning, which can be heightened when juggling care for multiple generations. Many midlife caregivers must manage multiple roles in addition to caring for their parent, including demands within their own families, homes, and professional lives [1].

Communication is a central component of caregiving. In our previous work [14-16], we identified communication challenges that adult children face when caring for a parent with a blood cancer that are uniquely complex, given their role and the relational shift that occurs when they take care of a parent who used to care for them [16]. Furthermore, our previous work demonstrates that these adult child caregivers commonly report caregiving communication skills deficits in navigating cancer information in web-based and clinical settings and in facilitating open and supportive communication within the family [14,16,17].

Therefore, we developed a web-based intervention, the *Healthy Communication Practice* program, to help adult children caring for a parent with a blood cancer develop and implement communication strategies that can improve their caregiving experience (Multimedia Appendix 1). The program was designed to take approximately 90 minutes to complete and be accessible across multiple platforms including computers, tablets, and smartphones. The specific aims of this study are as follows:

- To examine the feasibility of the Healthy Communication Practice program among adult children caring for a parent with a blood cancer.
- To examine the acceptability of the Healthy Communication Practice program among adult children caring for a parent with a blood cancer.

Methods

Study Design

We conducted a single-arm, pre-post pilot study of a web-based communication intervention at the University of Florida.

Ethics Approval

The University of Florida Institutional Review Board approved the study (202101030). All participants provided consent before the preintervention survey.

Intervention

The *Healthy Communication Practice* is a self-paced, web-based program developed for adult children who care for a parent, parent-in-law, or stepparent currently living with a blood cancer (eg, leukemia, lymphoma, myeloma). Grounded in communication and education theories [18-25] and based on our extensive preliminary work (in-depth interviews and surveys) with cancer caregivers [14-17], this program teaches caregivers essential communication skills in eHealth literacy, clinical encounters, and family relationships. We teach concepts and skills to help caregivers navigate web-based cancer information, communicate with their parent's doctors, find meaning in their caregiver role, and use open and supportive communication to strengthen relationships and facilitate communication within their family. To achieve these aims, the program is divided into 2 parts: (1) navigating cancer information in web-based and clinical settings; and (2) facilitating open and supportive communication in the family. Participants could stop the program when needed and return later without losing their progress.

We developed the program in collaboration with experts in web-based education and instructional design (JA and DD). We used a variety of instructional techniques including experts introducing concepts and skills; authentic caregiver narratives; video demonstrations of clinical and family encounters; and interactive activities designed to keep participants engaged such as writing, reflection prompts, and quizzes. An advisory board was formed consisting of 3 oncologists and 2 caregivers, and a clinical oncology social worker provided feedback on the program before the pilot test. The process of working with the advisory board allowed us to ensure we had presented realistic caregiving scenarios and correct medical advice.

Recruitment and Procedures

We recruited participants through The Leukemia & Lymphoma Society [26], the International Waldenstrom’s Macroglobulinemia Foundation, and ResearchMatch. To be eligible to participate, individuals had to reside in the United States, be 18 years of age or older, and be providing care for a parent, parent-in-law, or stepparent with a blood cancer at the time of recruitment. Their parent had to be currently living, diagnosed at least 3 months prior to inclusion (in order for them to have experience caregiving), and either in treatment or had treatment completed within the last year. Participants who met the criteria for the study and provided consent were given questionnaires at 3 different points in time: (1) a preprogram survey before the start of the program, (2) a postprogram survey within 1-7 days of program completion, and (3) a postprogram survey 3 months after the completion of the program. This paper reports only on data from the pre- and postprogram surveys. All screening and questionnaire data were collected online using REDCap. All potential participants received study information via email. As such, we inferred that they had access to a device and internet to complete the study. Data collection on the pre- and postsurveys took place between June 2021 and January 2022.

Participants who screened into the study were immediately directed to the preprogram survey, which contained demographic and other questions (Table 1) including the consent form. The first author then sent participants an individualized link to the *Healthy Communication Practice* program. The unique link allowed us to know when a participant started the intervention, monitor their progress, and know when they finished the intervention. In addition, the unique link allowed the participants to log back in whenever they wanted, with their progress having been saved. Participants were given 2 weeks to complete the program, and up to 2 reminders were sent as needed. Upon completing the program, we sent participants an immediate postprogram survey followed by a US $75 e-gift card.

Table 1. Demographics of caregivers and their parents.

Characteristics	Values (N=30)
Caregiver age (years), mean (SD)	45.07 (11.96)
Caregiver age (years), min-max	24-67
Parent age (years), mean (SD)	73.31 (9.38)
Parent age (years), min-max	57-89
Relationship type (caregiver to parent), n (%)	
Daughter, daughter-in-law, or stepdaughter	22 (73)
Son, son-in-law, or stepson	8 (27)
Relationship type (parent to caregiver), n (%)	
Mother, mother-in-law, or stepmother	16 (53)
Father, father-in-law, stepfather	11 (37)
Unreported	3 (10)
Children, n (%)	
Caregivers with children	12 (40)
Caregivers with children under 18 years of age	6 (20)
Siblings, n (%)	
Caregivers with siblings	22 (73)
Caregivers with 1 sibling	7 (23)
Caregivers with 2 siblings	8 (27)
Caregivers with 3 siblings	6 (20)
Caregivers with 4 siblings	1 (3)
Race[a], n (%)	
White	24 (80)
Black or African American	4 (13)
Asian	5 (17)
Native Hawaiian or Pacific Islander	1 (3)
American Indian	0 (0)
Ethnicity, n (%)	
Hispanic	5 (17)
Non-Hispanic	25 (83)
Education, n (%)	
High school graduate or General Education Diploma	3 (10)
Some college degree	1 (3)
2-year degree	2 (7)
4-year degree	11 (37)
Master’s degree	10 (33)
Doctoral degree	2 (7)
Professional degree	1 (3)
Employment status, n (%)	
Employed full time	17 (57)
Employed part time	4 (13)
Self-employed	3 (10)
Not employed	3 (10)

Characteristics	Values (N=30)
Retired	3 (10)
Relationship status, n (%)	
Single or never married	9 (30)

[a] Caregivers were allowed to select more than 1 option.

Measures

Prior to conducting the study and based on previous research [27,28], we determined that the intervention would be deemed feasible if 70% of consented participants completed the intervention within the allotted 2-week time period and the postsurvey within the allotted 1-week time period. We recognize that there are various ways of defining feasibility [29-31], but for the purposes of this study, we chose to use completion as was done in a previous caregiver intervention [27]. Our decision was based on *Healthy Communication Practice* being a newly developed intervention and our primary concern being whether people would complete it in the given time, rather than how we would recruit them. We assessed acceptability of the program using the Acceptability of Intervention Measure (AIM) [32]. This is a 4-item measure scored on a 5-point Likert scale (1=strongly disagree, 5=strongly agree). Items asked whether the *Healthy Communication Practice* program met participants' approval and met participants' needs, whether the participants liked the program, and whether they welcomed the program. As the AIM is still relatively new and there were no cutoff scores for it, we decided prior to the study that the intervention would be deemed acceptable if participants completing 80% or more of the intervention had mean scores of 4 or higher on the AIM items. In addition, we asked participants to rate the extent to which they felt the program was clear and met their needs as an adult child caregiver of a parent with a blood cancer, and whether the caregiver stories in the program were authentic and relatable. These items were measured on a 5-point Likert scale, with 5 as the highest score (ie, meets all needs, highly authentic, highly relatable*)*. As a further measure of acceptability, we assessed usability by asking about the type of device and type of browser they used. Participants were also asked if they encountered any problems when navigating the web-based program, and if so, they were asked to briefly describe them in an open-ended question.

Statistical Analysis

We used SPSS (version 28; IBM Corp) to calculate descriptive statistics (frequencies, means, and SDs) for the demographics, the feasibility data, and the acceptability data consisting of the AIM scale, usability questions, and course evaluation items.

Results

A total of 34 caregivers consented to the study and completed the preprogram survey. Of these, 30 (88%) completed the intervention and the postprogram survey. All 30 participants completed the study within the 2-week time period and 28/30 (93%) completed the postprogram survey within the 1-week time period, meeting our a priori standard of feasibility.

Demographics of the 30 participants are shown in Table 1. The average age of caregivers was 45.6 (SD 11.4; range 24-67) years, and the average age of their parents was 73.5 (SD 9.1; range 57-89) years. Most caregivers (22/30, 73%) were the daughter, stepdaughter, or daughter-in-law of the person for whom they provided care. Participants were asked to select all the races that applied to them. A total of 80% (n=24) of participants reported their race as White, 13% (n=4) as Black or African American, 17% (n=5) as Asian, and 3% (n=1) as Native Hawaiian or Pacific Islander. The majority (25/30, 83%) reported their ethnicity as non-Hispanic, with 17% (n=5) reporting as Hispanic. About half (57%) of participants were employed full time, while the remaining caregivers were either employed part time, retired, self-employed, or not employed. Myeloma (n=11, 37%) and leukemia (n=9, 30%) were the most common types of blood cancer reported.

Prior to the study, and as noted above, we set our acceptability threshold as an average score of 4 on the AIM items. As shown in Table 2, participants found the *Healthy Communication Practice* intervention to be acceptable using the AIM scale (mean 4.48, SD 0.67). Most participants indicated that it was clear how to progress through the program (mean 4.71, SD 0.53) and did not report encountering any problems using the web-based program (n=26, 84%). Most (n=18, 60%) solely used a computer (laptop or desktop) to complete the program, followed by a smartphone (n=4, 13%). The remainder used only a tablet or a combination of devices (eg, smartphone and computer).

Table 2. Acceptability of intervention measure.

Items	Rating, mean (SD)
The *Healthy Communication Practice* program meets my approval	4.53 (0.63)
The *Healthy Communication Practice* program is appealing to me	4.40 (0.86)
I like the *Healthy Communication Practice* program	4.45 (0.68)
I welcome the *Healthy Communication Practice* program	4.58 (0.62)
Overall rating	4.48 (0.67)

As shown in Table 3, participants felt the content met the communication needs of caregivers (mean 4.58, SD 0.62) and found that the program met their needs as a caregiver of a parent with a blood cancer (mean 4.40, SD 0.72). In their open-ended feedback responses, they described the program as "an eye-opener," "very helpful," and "an excellent learning experience." A participant noted, "appreciate you taking the time to do this. No one really understands what caregivers go through until they are thrust into the position. It is challenging and can break you in ways you never expected. So, thank you for shining a light and helping with coping mechanisms."

Table 3. Program evaluation.

Items	Rating, mean (SD)
How well does the content of the program meet the communication needs of a caregiver of a parent with a blood cancer?	4.58 (0.62)
How well do you feel the course met your needs as a caregiver of a parent with a blood cancer?	4.39 (0.72)
Please rate the authenticity of the caregiver stories	4.19 (0.75)
Please rate how well you could relate to the caregiver stories	4.32 (0.98)

Participants also specified how the program met their needs by teaching them skills for communicating with clinicians including navigating triadic communication (eg, "to ask permission from my mom before I jump in and start asking questions or speak for her or about her with her physicians. I never realized how important that can be"). They also described learning family communication skills in being open and supportive (eg, "showing up and listening, validating... how to lead the family, as lead caretaker... It's super helpful showing me how to show up better, for everyone, and even myself"). Furthermore, participants reported in their open-ended feedback that it was "easy to identify with" the caregiver stories. They also evaluated the caregiver stories featured throughout the program as authentic (mean 4.19, SD 0.75) and indicated they could relate to the caregiver stories (mean 4.32, SD 0.98).

In addition, participants reported one area for improvement. Although they found the stories relatable, some indicated that it would be helpful to see narratives of more challenging family dynamics (eg, challenges with in-laws, "dysfunctional" relationships, noncooperative parents). They also mentioned it would be helpful to complete the program earlier in their caregiving experience.

Discussion

Principal Findings

We developed a web-based, interactive video-based communication training intervention, *Healthy Communication Practice*, for adult children caring for a parent with a blood cancer. This intervention was developed and tailored to this distinct caregiver type and disease context to ensure their unique communication skills needs were met (G Fennell, PhD, unpublished data, 2007). Piloting the intervention among adult child caregivers of a parent currently or recently in treatment (completed within the last year), we found the intervention to be feasible, as the majority of consented caregivers completed the study (ie, all participants completed the intervention within 2 weeks, and the majority completed the posttraining survey within 1 week). Furthermore, the intervention was evaluated as acceptable by the participants. They reported the program was easy to navigate and met their needs, and that the narratives were authentic and relatable.

The training was engineered to work on a computer, tablet, or smartphone. Although the training was designed to work across technological platforms, most participants reported using a computer to complete the program. Only 4 participants used a smartphone to complete the entire program. The nature of the communication skills training within the program may have felt more comfortable for participants to complete it on a computer given the videos, audio narratives, and interactive activities. Future research should investigate why participants may have chosen to use a computer, and how the program may be better adapted as an app for mobile phone use. Overall, the choice device did not seem to deter participants from completing the program as almost all participants completed it.

Comparison With Prior Work

When midlife caregivers juggle more roles like caring for a diagnosed parent and caring for children, they likely experience more burden and have a heightened need for supportive interventions like the *Healthy Communication Practice*. In our study, the number of participants reporting full-time employment (n=17, 57%) reflects national estimates for all caregivers (61%) [33]. The majority of caregivers in our study (n=18, 60%) reported having no children. Of those who did have children, only 6 caregivers (20%) had children under the age of 18 years, even though the majority of caregivers were in the earlier phase of midlife (ie, their average age was 46 years), a phase of adulthood in which we would expect caregivers to be responsible for caring for both younger and older generations. However, adult children who have competing roles and responsibilities like parenthood are less likely to become their parent's caregiver [34,35], particularly when extensive care is needed [36] (ie, care is delegated to childless adult children). An estimated 26% of family cancer caregivers nationally have a child or grandchild under the age of 18 years living with them [37]. Given our sample characteristics, it may have been easier for caregivers who are juggling fewer roles or coping with less caregiving burden to complete this communication skills intervention. Further research should explore ways to reach those with a heightened caregiving load and the best technologies for delivery to further enhance caregivers' ease of completion.

The *Healthy Communication Practice* program is innovative primarily because of its focus on communication in the context of cancer caregiving. A recent systematic review on cancer caregiving interventions [28] found 33 papers on cancer caregiving interventions, none with a primary focus on communication. As caregiving is enacted primarily through communication, it is critical to address this with cancer caregivers. Other interventions focus primarily on concepts and tasks such as mindfulness [38,39]; stress management [40]; patient symptom management [40]; and topics such as goal setting, planning, accessing family support services, and building problem-solving skills [41]. Our previous research has shown that adult child caregivers' families who communicate more openly report less caregiver burden, better clinical interaction skills, and better perceived quality of the clinical interaction [17]. Interventions that help family caregivers hone their communication skills are a critical component to supporting caregivers as they navigate the difficulties of caring for a loved one with a blood cancer.

Limitations

Limitations of our study include a small sample size. In addition, our study design lacked a control group. A further weakness of our sample is selection bias. Due to our recruitment through large national patient advocacy organizations, we likely recruited those who were already motivated to pursue caregiver resources. In addition, as mentioned above, we recruited more participants without children than with children, which may not fully represent midlife adult child caregivers.

Conclusions

The innovative *Healthy Communication Practice* program is feasible and acceptable in a population of caregivers of a parent with a blood cancer. Future opportunities exist to establish the efficacy of the program and adapt it to other disease caregiving contexts (eg, dementia) and familial contexts (eg, spouses).

In order to establish the efficacy of the program, future research should include a randomized controlled trial of the intervention, testing its impact on both caregiver and patient short- and long-term health outcomes (eg, psychological, relational, and physical well-being; caregiving burden) as well as communication outcomes (eg, increased willingness to communicate with clinicians and family members, more open communication in the family, clinical communication skills engagement). Additionally, future research on this type of intervention should also explore downstream effects of improving caregivers' communication skills on patient outcomes.

The *Healthy Communication Practice* program could be adapted to more caregiver groups, and thus tailored to recognize and address their distinct needs and experiences in different caregiver relationships (eg, spouses), various age groups (eg, young adults), and other cancer types (eg, breast cancer). If preliminary research in these contexts demonstrates similar core areas in terms of communication skills development needs (eg, navigating web-based and clinical communication; open and supportive family communication), the core concepts of *Healthy Communication Practice* could remain and be tailored with new narratives and video scenarios that reflect the dynamics of the targeted relationships, age group, and disease context. This might also include less functional or more tense relational dynamics to promote narrative transportation. Future research could also explore the efficacy of including a booster 3-6 months following the training to provide caregivers with a reminder of the skill set they learned and offer continued encouragement to enact these communication strategies in their day-to-day lives.

Acknowledgments

We thank our advisory board Skyler Johnson MD; Cheryl Martin; Matthew Matasar, MD; Martina Murphy, MD; Lynn Steele, LSW, OSW-C; and Kevin Wright, PhD for their feedback. We thank the International Waldenstrom's Macroglobulinemia Foundation for the recruitment assistance.

This paper is dedicated to the memory of Dr Geraldine Fennell, whose work articulated the importance of effectively developing and delivering tailored support and information to caregivers, especially to subgroups of caregivers with distinct needs.

This study was funded by the Carolan Research Institute and The Lymphoma & Leukemia Society. Research reported in this publication was supported by the University of Florida Clinical and Translational Science Institute, which is supported in part by the National Center for Advancing Translational Sciences at the National Institutes of Health (NIH) under award number UL1TR001427. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

Authors' Contributions

CLB and CLF designed the study, contributed to the study implementation and intervention development, and wrote and edited the manuscript. ENW conducted data analysis, contributed to the study implementation, and contributed to manuscript writing and editing. AJA, SRP, KD, JA, and DD contributed to the intervention development and manuscript editing. GCS and CNH also contributed to the study implementation and manuscript editing. ENW and MSH contributed to the study design, reviewed the intervention, and contributed to editing the manuscript. MSH also contributed to the implantation of the study. TBA conducted data analysis, and wrote and edited the manuscript. All authors approved the manuscript for publication.

Conflicts of Interest

AJA receives support from Blue Note Therapeutics. Other authors declare no conflicts of interest.

Multimedia Appendix 1
Healthy Communication Practice program screenshots.
[PDF File (Adobe PDF File), 3322 KB - cancer_v8i3e38722_app1.pdf]

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Abbreviations

AIM: Acceptability of Intervention Measure
NIH: National Institutes of Health

Edited by A Mavragani; submitted 27.04.22; peer-reviewed by A Carr; comments to author 18.05.22; revised version received 20.05.22; accepted 24.05.22; published 05.07.22.

Please cite as:
Bylund CL, Wollney EN, Campbell-Salome G, Applebaum AJ, Paige SR, DeGruccio K, Weiss E, Sae-Hau M, Arnold J, Durante D, Amin TB, Hampton CN, Fisher CL
Improving Clinical and Family Communication for Adult Child Caregivers of a Parent With a Blood Cancer: Single-Arm Pre-Post Pilot Intervention
JMIR Cancer 2022;8(3):e38722
URL: https://cancer.jmir.org/2022/3/e38722
doi:10.2196/38722
PMID:35788019

Original Paper

Perceived Unmet Needs in Patients Living With Advanced Bladder Cancer and Their Caregivers: Infodemiology Study Using Data From Social Media in the United States

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Abstract

Background: Locally advanced or metastatic bladder cancer (BC), which is generally termed advanced BC (aBC), has a very poor prognosis, and in addition to its physical symptoms, it is associated with emotional and social challenges. However, few studies have assessed the unmet needs and burden of aBC from patient and caregiver perspectives. Infodemiology, that is, epidemiology based on internet health-related content, can help obtain more insights on patients' and caregivers' experiences with aBC.

Objective: The study aimed to identify the main discussion themes and the unmet needs of patients with aBC and their caregivers through a mixed methods analysis of social media posts.

Methods: Social media posts were collected between January 2015 and April 2021 from US geolocalized sites using specific keywords for aBC. Automatic natural language processing (regular expressions and machine learning) methods were used to filter out irrelevant content and identify verbatim posts from patients and caregivers. The verbatim posts were analyzed to identify main discussion themes using biterm topic modeling. Difficulties or unmet needs were further explored using qualitative research methods by 2 independent annotators until saturation of concepts.

Results: A total of 688 posts from 262 patients and 1214 posts from 679 caregivers discussing aBC were identified. Analysis of 340 randomly selected patient posts and 423 randomly selected caregiver posts uncovered 33 unique unmet need categories among patients and 36 among caregivers. The main unmet patient needs were related to challenges regarding adverse events (AEs; 28/95, 29%) and the psychological impact of aBC (20/95, 21%). Other patient unmet needs identified were prognosis or diagnosis errors (9/95, 9%) and the need for better management of aBC symptoms (9/95, 9%). The main unmet caregiver needs were related to the psychological impacts of aBC (46/177, 26.0%), the need for support groups and to share experiences between peers (28/177, 15.8%), and the fear and management of patient AEs (22/177, 12.4%).

Conclusions: The combination of manual and automatic methods allowed the extraction and analysis of several hundreds of social media posts from patients with aBC and their caregivers. The results highlighted the emotional burden of cancer for both patients and caregivers. Additional studies on patients with aBC and their caregivers are required to quantitatively explore the impact of this disease on quality of life.

(JMIR Cancer 2022;8(3):e37518) doi:10.2196/37518

KEYWORDS

real-world evidence; unmet needs; quality of life; social media; bladder cancer; caregivers

Introduction

In 2021, approximately 84,000 people were expected to be diagnosed with bladder cancer (BC), making it the sixth most common cancer in the United States [1]. Locally advanced and metastatic stages are the aggressive stages of BC (generally termed advanced BC [aBC]) and have a poor prognosis, with the 5-year survival rate for stage IV BC estimated to be 6.4% [2]. More than 90% of BC cases involve individuals aged over 55 years, and 75% involve men [3,4].

People with BC often experience physical symptoms, including bleeding, pain, dysuria, and urinary obstruction, and they also report emotional and social challenges [5]. Patients have reported several unmet needs related to their quality of care that may vary according to disease stage and level of patient fragility, but nevertheless, there is significantly diminished physical, mental, and social quality of life (QOL) after diagnosis. A study by De Nunzio et al found that patients complained about a lack of therapeutic options for the stage of their disease [6]. Moreover, some current treatments may significantly affect QOL, specifically cystectomy, which may negatively impact mental QOL [7].

Caregivers are often responsible for managing the care of patients with BC; however, their perspective is underrepresented in the current literature. Although few studies have assessed QOL from the caregiver perspective, some recent evidence shows that caregiver QOL declines with disease stage [8]; however, more information is needed regarding their unmet needs.

Previous research on patients with BC relied on traditional research methods, such as systematic reviews [9] and questionnaires [10]. However, evidence-based practice in public health has shown some time-related challenges due to the delays that occur between data collection, publication, and the implementation of the findings. Furthermore, public health must operate on a wide scale, addressing the needs of substantial populations. This implies critical operational issues, variability, and complexity, as well as resource requirements and sustainability considerations, leading to several drawbacks, including high cost and time constraints [11]. These challenges could lead to a need for new approaches to help circumvent some obstacles of traditional methods.

Recently, social media has become increasingly compelling for obtaining valuable data concerning patients for infodemiological studies. In the early 2000s, Gunther Eysenbach first described infodemiology as a science research tool that searches the internet for health-related content posted by internet users [12]. One of the benefits of infodemiology is that it collects and analyzes high volumes of data in a time-efficient manner, in contrast to traditional methods, such as registries, questionnaires, and surveys. Thus, using technological advances instead may offer additional insights and shorten the time-consuming processes of analysis [13].

In recent years, patients with cancer have generally been increasing their use of social media networks to obtain information and support for health-related purposes [14]. Indeed, social media and online forums connect patients and caregivers to a broader patient and caregiver community with similar experiences. Within these communities, patients and caregivers seek and share support, information, advice [15], and self-care [16]. While patients with BC use the internet less often than patients with other cancers, their caregivers are active internet users [17]. Nevertheless, social media has become a novel and efficient resource for obtaining retrospective data to explore patient and caregiver perspectives about their cancer throughout the journey [15]. Previous research based on social media provided insights into patients' and caregivers' experiences with cancer [18] and patients' unmet needs in regard to information and emotional support [19].

This retrospective mixed methods study aimed to identify the main discussion themes and the unmet needs that patients with aBC and their caregivers describe in their social media posts.

Methods

Study Design and Population

This noninterventional, retrospective, real-world, mixed methods study included data retrieved from social media posts written by patients with aBC and their caregivers. Publicly available US geolocated messages in English that were posted between January 1, 2015, and March 4, 2021, were considered. Publicly available data from social media sites (eg, Twitter) and forums (eg, patient association forums) were included. Posts on Facebook and Instagram were excluded, as most posts on these sites are private.

Data Extraction

Data (verbatim social media posts) were identified and extracted, and irrelevant material was eliminated.

All public posts available on the web containing one of the relevant keywords were identified using the Brandwatch extractor [20]. This tool is based on queries that include selected keywords evocative of the subject of interest. Using the query, the Brandwatch extractor searches through available public data sources and identifies keywords within posts matching the ones in the query. Then, the posts, including the identified keywords, are downloaded along with their associated metadata, such as author or publication date, constituting a data set.

In this study, we constructed an extraction query (available in Multimedia Appendix 1) with keywords related to BC. The resulting data set then underwent further cleaning to exclusively obtain testimonies of patients and caregivers related to aBC. First, posts from irrelevant sources, such as potential advertising sites or forums related to pets and animals, were removed using regular expression rules. Next, a machine learning algorithm, the Extreme Gradient Boosting classifier [21], identified patient and caregiver experiences. This algorithm was previously trained on a social media data set constructed with diverse pathologies and sources of data. Predictions were formulated according to 3 variables (lexical field, syntax, and semantic style). Recorded performances in the context of training were evaluated at 78% sensitivity (ie, the proportion of identified true positives) and 69% positive predictive value (ie, the proportion of true positives among detected positives). In this study, posts pertaining to neither patients nor caregivers were filtered out. Then, a manual review was performed to ensure that the remaining posts were related to patient or caregiver experiences, thus excluding false positives. We identified posts about aBC using keywords evocating advanced levels of disease (eg, metastatic, stage IV, and advanced; see Multimedia Appendix 1 for all keywords) within the 5 words next to “bladder cancer” or “urothelial carcinoma.” The remaining data set constituted verbatim posts of patients and caregivers related to aBC. Since usernames are associated with messages, all messages from usernames containing aBC were kept in the data set even if there was no specific mention of aBC. The resulting posts were separated into one data set for patients and another for caregivers.

Ethical Considerations

The data used in this study were obtained from sources where posts were publicly available. No private groups or web pages were accessed to gather data. When communicating or expressing themselves on the platforms included in our study, users had already consented to their data being used for other purposes.

Data Analysis

Demographics

Patient or caregiver age and sex were determined by manual review, where possible (ie, when explicitly mentioned, as presented below).

> *[…] my dad died in August aged 68 from stage 4 bladder cancer*

Otherwise, age and sex data were coded as “undetermined.”

Analysis of Experiences

To identify the main themes of discussion, an unsupervised automated algorithm was used to cluster posts according to their main topic. All the data were used for this analysis. To further identify difficulties and unmet needs, the annotators performed a manual qualitative analysis using a method of saturation on a random sample of the data that is described in detail below.

Main Themes of Discussion

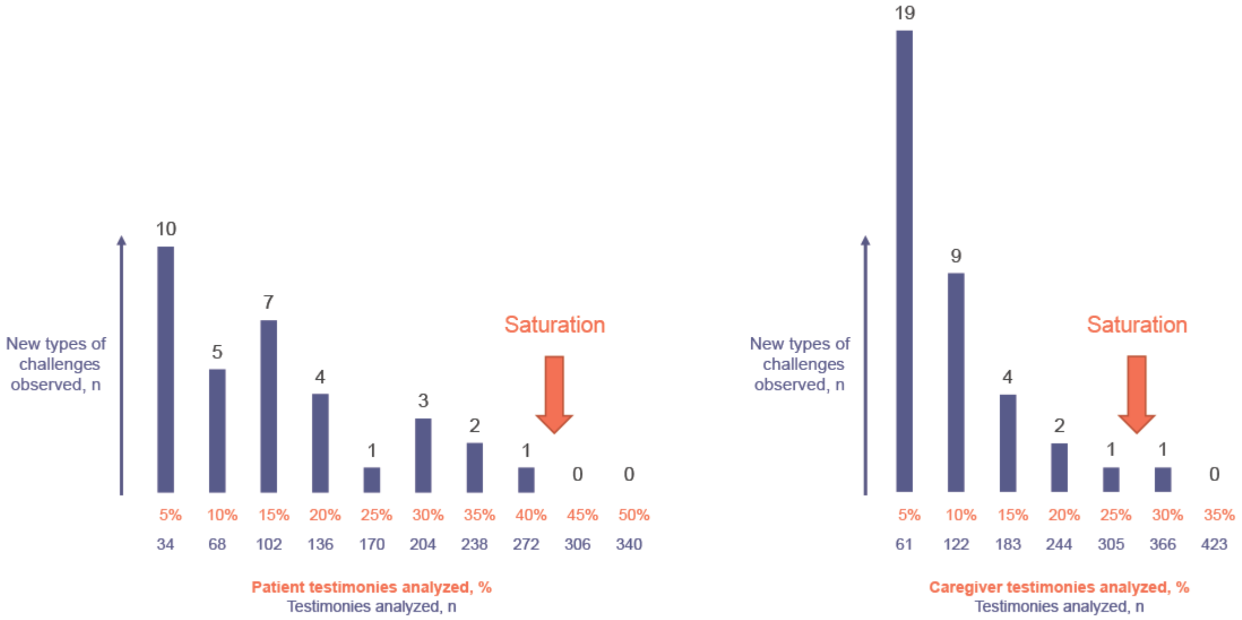
To identify the main discussion themes and explore all available data about aBC, verbatim patient and caregiver posts were analyzed using a natural language processing and text mining approach called biterm topic modeling (BTM) [22,23]. BTM is a clustering method that groups similar texts according to the topics they contain. We opted to use this method in this study because of its demonstrated better performances on small-size documents [20,22]. The modeling considers posts as distributions of topics, which are themselves probability distributions over all words in the corpus. The presence of topics in posts is then used as clustering criteria. Simultaneously, for each topic, words are ordered according to their probability in this topic. The top co-occurring words can be used to label the topic through human interpretation. BTM then helps in understanding the topics of discussions of patients with aBC and their caregivers by providing a categorization of posts according to common discussed topics, described by co-occurring terms.

Expressed Difficulties and Unmet Needs

To identify patients’ and caregivers’ unmet needs and categorize them, 2 independent evaluators (SR and PL) used qualitative analysis. Given the diversity of unmet needs, data saturation was used to obtain a representative sample of expressed difficulties/unmet needs. From all available posts, repeated random samples, empirically set at 5% of the total size each, were qualitatively analyzed each time until saturation was achieved. Saturation was considered achieved when 2 consecutive samples no longer yielded more than 1 new identified unmet need category (Figure 1). Two additional batches of 5% each were analyzed after saturation was first reached for further validation of our findings. As guidelines for determining saturation related to social media content are lacking, we used this novel previously described saturation approach in the qualitative analysis phase [24-26]. Difficulties were coded into distinct unmet need categories to ensure standardized data labeling and coded into whether the difficulty was related to an unmet need for the patient, caregiver, or both. For example, the following message was related to a caregiver’s unmet need:

> *I got some dreadful news today. My 42-year-old daughter has stage 3 bladder cancer. It has me terrified.*

Figure 1. Saturation methodology for patients' and caregivers' posts.



Results

Description of the Population and Posts

The extraction yielded a total of 144,029 posts related to BC written by 68,079 users. Overall, after the cleaning step, 1214 posts from 679 caregivers and 688 posts from 262 patients were included in the study, with a median of 1.79 posts per caregiver and 2.63 posts per patient (Figure 2). The posts were retrieved from 72 caregiver discussion sources and 32 patient sources. Among them were social networks (eg, Twitter), general discussion websites (eg, Reddit), and health-related (eg, inspire website) and disease-specific (eg, bladdercancersupport website) forums. The majority of patient (139/262, 53.1%) and caregiver posts (333/679, 49.0%) came from Twitter (Table 1). Multimedia Appendix 2 contains the complete list of sources of both data sets.

Sex was mentioned for 42.4% (111/262) of patients and 15.8% (107/679) of caregivers. Age was available for 16.0% (42/262) of patients and only 3.3% (22/679) of caregivers. Among patients, 21.8% (57/262) were male; in contrast, among caregivers, only 2.8% (19/679) were male (Table 1).

Figure 2. Extraction process.

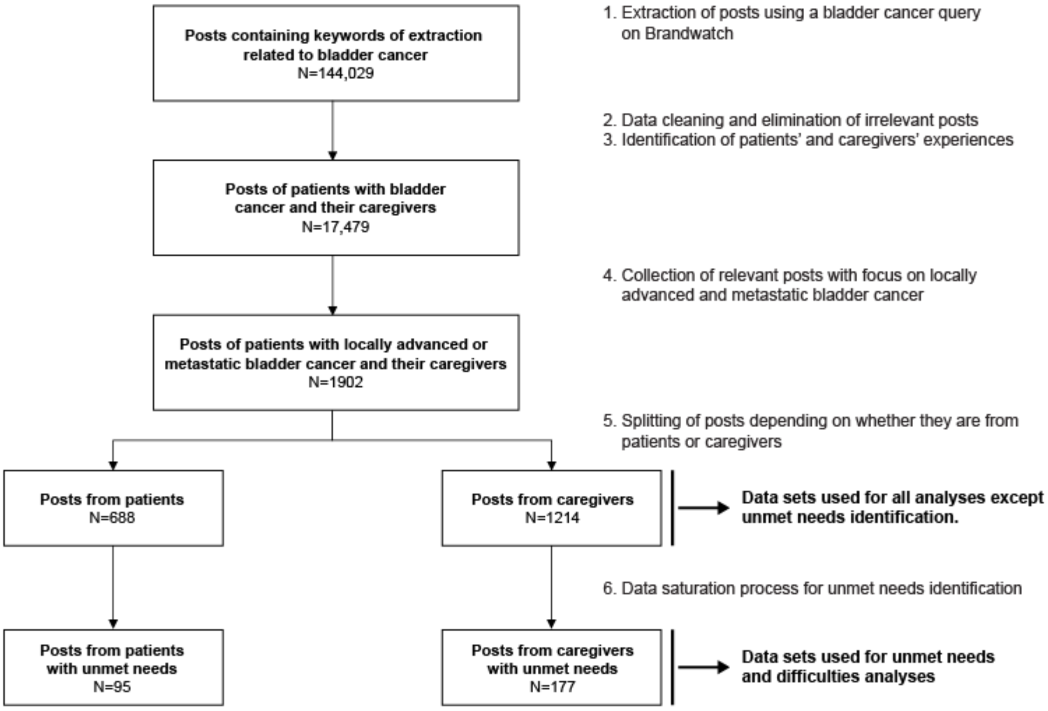


Table 1. Patient and caregiver characteristics.

Characteristics	Patients[a] (N=262)	Caregivers[b] (N=679)
Social media users, n (%)		
Twitter	139 (53.1)	333 (49.0)
Reddit	16 (6.1)	95 (14.0)
Inspire	31 (11.8)	27 (4.0)
Bladdercancersupport	26 (9.9)	34 (5.0)
Others	50 (19.1)	190 (28.0)
Users' sex, n (%)		
Female	54 (20.6)	88 (13.0)
Male	57 (21.8)	19 (2.8)
Undetermined	151 (57.6)	572 (84.2)
Users' age, n (%)		
<40 years	9 (3.4)	14 (2.1)
40-59 years	14 (5.3)	2 (0.3)
≥60 years	19 (7.3)	6 (0.9)
Undetermined	220 (84.0)	657 (96.8)

[a] There were 688 posts and 32 sources.

[b] There were 1214 posts and 72 sources.

Themes of Discussion

Using BTM separately on the whole patient and caregiver data set, posts were clustered according to their topics of discussion. Each topic was labeled and illustrated with a representative title.

The most frequent discussion themes in patient posts (Table 2) were specific to the diagnosis and different treatment possibilities, including traditional or alternative treatments, in 35.8% (246/688) of posts. Patients also exchanged messages of hope or support and shared experiences (113/688, 16.4%), while the health care pathway was addressed in 15.1% (104/688) of patient posts and included comments about patient management, screening or diagnosis methods, health care teams, etc. Symptoms and clinical signs of aBC were the dominant discussion topic in 8.4% (58/688) of patient posts. Issues related to QOL were expressed in 4.9% (34/688) of posts.

Caregivers provided messages about support and hope most frequently, accounting for 22.5% (273/1214) of posts, highlighting the sense of community that social networks might offer (Table 3). The second most frequently mentioned theme revolved around the complications of aBC (19.0% [231/1214] of posts). The third most frequent theme focused on diagnostic methods and medical procedures (18.2% [221/1214] of posts). Messages requesting scientific information about treatments were identified in 9.3% (113/1214) of posts, and themes concerning the end-of-life stage occurred in 7.6% (92/1214) of posts. Financial aspects, particularly social coverage or insurance, appeared least frequently (5.3% [64/1214] of posts).

Messages where the topic of discussion was too specific for it to constitute a main theme were pooled into the category of "other topics" (18.1% [220/1214] of caregiver messages and 19.3% [133/688] of patient messages). Some of these "other topics" included the relationship between the patient and his/her grandchildren, dementia or Alzheimer disease in relation to aBC, and the impact of COVID-19 and its repercussions.

Table 2. Main discussion themes in patient posts.

Themes	Patient posts (N=688), n (%)	Representative quotations
Diagnosis and different treatment possibilities, including traditional or alternative treatments	246 (35.8%)	"In 2014, I was diagnosed with metastatic bladder cancer [...]"
Exchange of messages of hope or support and sharing of patient experiences	113 (16.4%)	"My name is X. I currently have stage 4 bladder cancer and am also a retired physician. If you have any questions after your cystoscopy tomorrow let me know."
Discussions around the health care pathway	104 (15.1%)	"Discussed chemo after the surgery with MSG oncologist Dr. X (a world Rock Star Dr). Decided to have chemo locally (I am from Delaware) instead of driving back and forth to New York City every week. My Delaware oncologist and Dr. X didn't see eye to eye on treatment."
Symptoms and clinical signs of advanced bladder cancer	58 (8.4%)	"First was bladder cancer, tumor removed from bladder and was doing fine for a year then a lump in my arm popped up, within 6 weeks I was told to go on hospice due to Stage 4 metastatic bladder cancer that spread to my back, sacrum, hip, had it replaced, shoulder, mouth, lungs. I was free for about 2 months then it's back in my lung. Growing very slow compared to the extremely aggressive I had before."
Focus on patient quality of life	34 (4.9%)	"[…] Occasionally, I leak from my stoma, but only when my pouch is too full. This mostly occurs at night when I don't wake up on my own to cath. (I'm past the point of setting my alarm.) I sleep with a rubber bed protector under my bottom sheet that I bought at Target in the baby section. This only happens about once every 2 weeks. I wish you well with your decision. It's a tough one, but hopefully, as you research more the diversion that fits your needs will become apparent. Good luck!!"

Table 3. Main discussion themes in caregiver posts.

Themes	Caregiver posts (N=1214), n (%)	Representative quotations
Sharing experiences and messages of hope and support	273 (22.5%)	"My father was recently diagnosed with stage 4 small cell bladder cancer. At first it was considered unknown primary. Can anyone please shed some light on this topic? Perhaps survivor stories. Praying and trying to stay positive."
Complications around advanced bladder cancer	231 (19.0%)	"Hi, about 6 months ago my 88-year-old father was diagnosed with a high grade invasive bladder cancer. Unfortunately his general health also took a turn for the worse. Over the last 6 months he has been in and out of hospital with recurring chest infections. [...]."
Focus on diagnosis and medical procedures	221 (18.2%)	"My husband was diagnosed with stage 4 bladder cancer in February. In April they removed the bladder, prostate, and part of urethra, and created a neobladder from intestinal tissue. It worked well for about a month, then developed scar tissue and stopped working for the most part. So, since May, he has had nephrostomy tubes directly out the back from the kidneys into drainage bags."
Scientific information on drug treatments	113 (9.3%)	"[…]Can someone tell me the most common side effects that may occur in a 72-year-old male patient given MVAC? The 5-year survival rate is 15%, but has that improved any with all of the recent clinical trials? I just want to get some advice on what to expect as I will not be with my father for a full year as I finish my studies."
Accompanying the patient in the terminal phase and until death	92 (7.6%)	"The only regret I have was not spending everyday with my father, but at the time I didn't know a lot about cancer and thought he'd beat it."
Discussions around social coverage, insurance, and financial aspects around patient care	64 (5.3%)	"[...] I asked how much his morphine prescription was costing. It was as much as our rent at that point, and it only increased as time went on. That was just for the painkiller, not for anything else. [...]"

Unmet Needs

Unmet needs were identified through manual coding of a random sample from each of the patients' and caregivers' data sets in order to identify the most frequently expressed unmet needs.

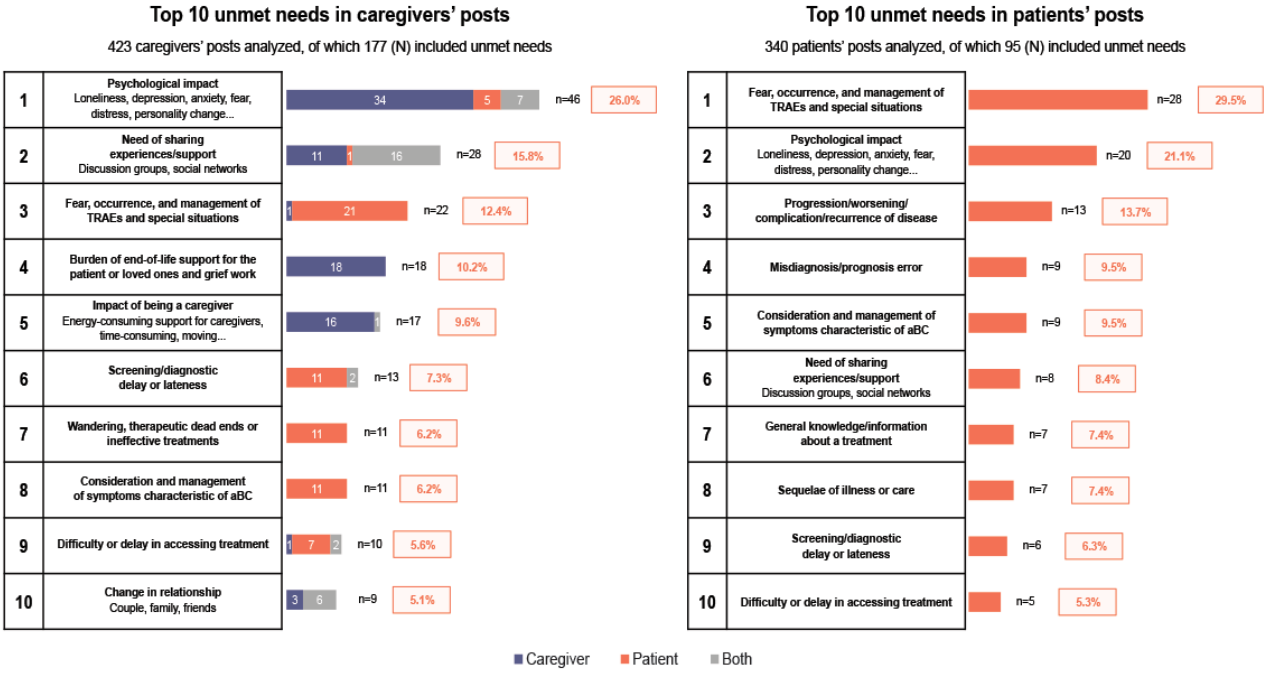
Patients

Among the 340 patient posts analyzed, 95 mentioned at least one difficulty among the 33 unique categories of unmet needs identified.

Challenges concerning treatment-related adverse events (AEs) and special situations related to treatments were found in 29% (28/95) of patient posts (Figure 3). These AEs and special situations were associated with aBC treatments, including surgical procedures, as illustrated in the following message:

> *I had a urostomy done about 4 weeks ago, for aggressive/muscle invasive bladder cancer. My only real problem at the moment concerns night bag system kinks/leaks. During the day, I use either a one piece pouch or a one piece pouch with a leg bag (all Hollister). These options have been working great, with very few surprises/leaks. However, 3 times in the last 1.5 weeks, I have had a leak/kink/failure in my night bag system […]*

Figure 3. Distribution of unmet needs expressed in either patient or caregiver posts. aBC: advanced bladder cancer; TRAE: treatment-related adverse event.



Other patients discussed AEs and special situations by providing information when describing their care journey and their treatments. They share these details to provide other patients with useful knowledge and to seek advice for themselves, as reported in the following post:

> *I had 2 bags of Cisplatin once a week for 19 weeks. I did get neuropathy in my hands, which I still mildly have. I had cervical, ovarian, and bladder cancer. Stage 3.*

A psychological impact, with feelings of loneliness, depression/discouragement, anxiety/stress, fear, or personality change, was reported in 21% (20/95) of patient posts. Difficulties with planning ahead for the future and a fear of the unknown were described in the following message:

> *I'm newly diagnosed with advanced bladder cancer. I'm scared about this and what's to come. Most likely, it will be chemo and removal of the bladder. Any support and input from people in the same situation will be most appreciated.*

An increase in psychological distress was observed throughout the patient's journey, starting from the diagnosis and extending to the posttreatment stage, as illustrated in the following post:

> *I had cervical, ovarian, and bladder cancer the 1st time. Intestinal cancer the 2nd and now 3rd time. […] So like I said, I'm a bad example. But I did have MAJOR anxiety right after I was cured the 1st time.*

Other major unmet needs and challenges identified in the messages included progression, worsening, complication, or recurrence of the disease (13/95, 14%); misdiagnosis or prognostic errors (9/95, 9%); and management of symptoms characteristic of aBC, such as blood in the urine (9/95, 9%). It is noteworthy to state that no difficulties or unmet needs related to caregivers were identified during the analysis of patient posts.

Caregivers

Among the 1214 caregiver posts analyzed, unmet needs were identified in 423 posts, 177 of which included at least one difficulty.

Psychological impact was the major difficulty caregivers described (46/177, 26.0%) (Figure 3). Similar to patients, the psychological impact was expressed throughout the patients' health care journey, from diagnosis through treatment and management to death, as described in the following posts:

> *Hi there, my husband was diagnosed with stage 3 bladder cancer. […] He talked to the on call doctor. The on call Dr. said to go to the ER if there was no urine output. He seems to be urinating ok but the worry is making it worse emotionally.*
>
> *I lost my dad to stage 4 bladder cancer in 2012. I was pregnant, and just trying to be the one to hold it altogether but I wasn't doing a very good job. The only thing I can say is we go through this because we have to. It's hard. It still hurts. I don't get as sad as often as I did, but when I do, its heart wrenching.*

> *Being a caretaker is exhausting and will take every ounce of energy you have emotionally and physically.*
>
> *Horrifying. Just horrifying. I lost my husband last March from bladder cancer. Insidious disease.*

Caregivers also expressed the need to share experiences and to support other caregivers (28/177, 15.8%). Some caregivers sought support groups for not only the patient but also themselves, as illustrated in the following message:

> *Is there a cancer support group on Twitter? My father has stage 4 bladder cancer and has metastasized and would love to get more info from other patients and survivors.*

Caregivers also solicited advice from people with similar experiences, requesting information, guidance, and recommendations, as follows:

> *My father was diagnosed with invasive bladder cancer in February 2016. […] We are now running into several problems which have resulted in readmission into the hospital on several occasions. I would like to hear if others have encountered similar issues. […] I realize this may be a constant battle but I need any tips possible. He drinks constantly but with the new "bladder" and stoma I feel he loses more water. Tips/advice? […] Please share your journey, hardships, and advice. I really want to help him get through this and provide the best possible life and outcome for him.*

Alternatively, some posts expressed the need for spiritual support with requests for prayers, for example:

> *So my dad has bladder cancer. Mom is taking it pretty hard. Please keep my family in your prayers if you think about it. Thank you. #cancersucks*

Challenges concerning AEs and specific treatment-related situations were found in 12.4% (22/177) of caregiver posts. Posts about AEs specifically concerned the patient and mentioned one or more AEs, the potential management, and the fear either patients or caregivers feel regarding the impact of the AEs, as expressed in the following message:

> *My 84-year-old father was diagnosed in May 2016 with a high grade urothelial bladder cancer. […] The chemo was very harsh on my dad and set him back...dropping his blood count & platelets numerous times requiring blood transfusions & platelets.*

Caregivers also expressed challenges associated with the burden of end-of-life support and the grief of losing a loved one (18/177, 10.2%), being a caregiver (17/177, 9.6%), having a late diagnosis or delayed screening (13/177, 7.3%), and aBC symptom management (11/177, 6.2%), for example:

> *[…] No, it doesn't get any easier. The fear, the waiting and sitting around the house is like being on death row. Cancer not only is killing the patient, it's killing the family too.*

Discussion

Principal Findings

To our knowledge, this is the first study to analyze data retrieved from social media posts written by patients with aBC and their caregivers to gain insights into the perspectives of both the patient and caregiver about the difficulties encountered when living with aBC. We found that a majority of caregiver concerns focused on the psychological impact of aBC, whereas patients mainly focused on managing AEs. Our findings also support recent literature suggesting that patients particularly need psychological support and information about aBC and its treatment [17,27,28]. These insights are particularly valuable as they are based on analysis of open-ended verbatim posts, which are typically not captured using traditional survey methods.

Interestingly, we found that almost twice as many caregivers as patients had posted online about aBC (1214 vs 688). Although few patients or caregivers who posted specified their age and sex, most caregivers who did were women aged between 30 and 40 years, whereas most patients who did were men aged between 50 and 60 years. These patients who were active on social media were among the younger population living with aBC. Older patients tended to post much less, possibly because of lower electronic literacy [29]. These findings are consistent with those of a recent review suggesting that caregivers actively use the internet to access information on behalf of patients [30]. Furthermore, this lower representation of people with aBC accessing information online may just be due to the fact that aBC is more prevalent in older men [3,4].

Treatment, psychological impact, and disease and symptom management were the unmet needs that patients discussed most often, which is in accordance with the few published studies highlighting the challenges faced by patients. These challenges include making long- and short-term treatment decisions [5]; the need for equipment support (eg, support using stomal appliances, catheters, and incontinence) [5]; the need for informational, intimacy, and psychological support [31-33]; and improving mental health [34]. These latter challenges are particularly important, because supporting psychological needs and improving mental health can positively impact treatment outcomes and survival-related outcomes [34].

Furthermore, our findings confirmed the negative impact that aBC has on caregiver QOL. This is consistent with results from other studies on the short-term [35,36] and long-term [37] burden on the caregivers of people with other cancer types. The main unmet need caregivers expressed in this study was a lack of support, which drove them to seek support and advice on social media. Caregivers also highlighted that the time and energy required for end-of-life logistics and support were particularly challenging. We found that social media provided caregivers with a forum where they could convey their concerns and express both their challenges in caring for someone with aBC and the challenges faced by the patient. The unmet needs and challenges highlighted in this study emphasize the importance of considering the caregiver's role and needs, and not just the patient's role and needs.

This information may be used in the development of personalized and holistic approaches, centering around the needs of patients and their caregivers. The data presented may help health care professionals to further grasp the impact of the disease on their patients, which in turn will enhance the management of their health care journey. Feedback on social media may be used for health monitoring, developing initiatives for patients with BC, and developing targeted awareness campaigns.

Study Strengths and Limitations

The strengths of this study include a mixed method approach combining natural language processing with qualitative analysis. The study analyzed data from a 6-year period and included a large sample size. Furthermore, open-ended verbatim posts were analyzed, providing more data than traditional survey methods.

However, the observational nature based on social media data has some limitations. The posts extracted were limited to publicly available messages, thus excluding Facebook and Instagram. Moreover, relevant posts may have inadvertently been excluded during the filtering process. Data from social media posts may have been limited by the selected information and perspectives that patients and caregivers chose to post, depending on their technological literacy, BC experience, and understanding of key medical aspects. This means that some key contextual information, such as disease stage or specific treatment information, may not have been captured. Additionally, our study was subject to selection bias, as patient and caregiver posts may not be representative of all patients with BC or aBC and their caregivers. Indeed, the level of social media engagement differs according to age, sex, socioprofessional level, education, and technological literacy.

The natural processing analysis may have been limited by the threshold values chosen to reduce background noise, which were set empirically in this study, similar to our previous work [36,38,39]. Lastly, the saturation method used to identify unmet needs was only applied to random data extracts as opposed to analyzing the full data set. Thus, it is possible that saturation was not met in the full data set, and some perspectives or unmet needs may have been missed. Despite these limitations, this study offers valuable findings on the unmet needs of patients living with aBC and their caregivers, based on their direct inputs.

Future Work and Impact on Care

This study identified leverage points to improve the patient experience. Both patients and caregivers described the psychological impact that aBC has on them and the need for clear BC information and practical advice. Patients also reported the need for clearer communication between themselves and practitioners [33]. Patient-physician online interaction about BC is less developed than that for other cancers. Breast cancer has the largest online community, and online discussions have existed for many years [18]. The social media output for prostate cancer is increasing, particularly on Twitter [27]. Furthermore, a recent study rated the quality of BC content available on YouTube as moderate to poor, meaning that patients are at risk of being exposed to misinformation and potential harm [28]. This highlights the need for clear, accessible, and accurate information about BC and its treatment and management. Emotional support to counteract the psychological impact of BC is also essential. The use of social media is a method that could be adopted to help meet these needs.

As previously shown in the literature, difficulties for people with BC differ according to age, sex, and treatment [40]. However, Grov and Valeberg highlighted a similar impact on caregiver mental health and decreased QOL regardless of disease stage [41]. Future research is required to explore whether this is reflected on social media.

The results of this study may help raise awareness about patient and caregiver unmet needs with health care professionals. This could help ensure that patients receive holistic patient-centered treatment that does not focus solely on the aBC but considers the patient as a whole. Furthermore, it could help to improve available information, communication, and support for both patients and caregivers.

Our innovative data analysis method combined the BTM method, a well-accepted natural language processing technique for analyzing social media posts [39,42,43], with qualitative analysis of a random data sample coupled with saturation. These 2 complementary methods could be used to explore unmet needs or perspectives expressed on social media about other diseases.

Conclusions

Social media and online forums are innovative and efficient resources for obtaining data on patient and caregiver perspectives about aBC, which may be difficult to assess through traditional research methods. These online forums complement real-world evidence for unmet needs in specific populations.

People living with aBC mostly expressed unmet needs concerning treatment, psychological impact, or disease and symptom management, whereas caregivers expressed the emotional burden of caring, especially during end-of-life stages, as well as the need for support. These data may help raise awareness about these unmet needs, which may otherwise have remained unknown if patients and caregivers had not posted these perceptions on social media, among health care professionals and clinicians.

Acknowledgments

Medical writing support was provided by Nathalie Baudry of the microenterprise NB-Pharmaconsult and Joelle Malaab of Kap Code, Paris, France, and was funded by the healthcare business of Merck KGaA, Darmstadt, Germany (CrossRef Funder ID: 10.13039/100009945) and Pfizer. Editing assistance was provided by Amanda Whereat, Speak the Speech Consulting, and was funded by the healthcare business of Merck KGaA, Darmstadt, Germany (CrossRef Funder ID: 10.13039/100009945) and Pfizer. Preliminary results of this study were presented at Virtual ISPOR Europe 2021.

Conflicts of Interest

MB is employed by EMD Serono. BA, A Marrel, and VB are employed by Icon, which has contracts with the healthcare business of Merck KGaA, Darmstadt, Germany. SR, PL, PF, A Mebarki, and SS are employed by Kap Code, which was contracted by Icon to conduct this study.

Multimedia Appendix 1
Query and keywords used.
[DOCX File , 41 KB - cancer_v8i3e37518_app1.docx]

Multimedia Appendix 2
Sources of patient and caregiver posts.
[DOCX File , 50 KB - cancer_v8i3e37518_app2.docx]

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Abbreviations

aBC: advanced bladder cancer
AE: adverse event
BC: bladder cancer
BTM: biterm topic modeling
QOL: quality of life

Edited by A Mavragani; submitted 07.04.22; peer-reviewed by W Tang, A Castro; comments to author 14.07.22; revised version received 17.08.22; accepted 23.08.22; published 20.09.22.

Please cite as:
Renner S, Loussikian P, Foulquié P, Arnould B, Marrel A, Barbier V, Mebarki A, Schück S, Bharmal M
Perceived Unmet Needs in Patients Living With Advanced Bladder Cancer and Their Caregivers: Infodemiology Study Using Data From Social Media in the United States
JMIR Cancer 2022;8(3):e37518
URL: https://cancer.jmir.org/2022/3/e37518
doi:10.2196/37518
PMID:36125861

Original Paper

Adoption of Telemedicine in a Rural US Cancer Center Amid the COVID-19 Pandemic: Qualitative Study

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Abstract

Background: The COVID-19 pandemic necessitated a rapid shift to telemedicine to minimize patient and provider exposure risks. While telemedicine has been used in a variety of primary and specialty care settings for many years, it has been slow to be adopted in oncology care. Health care provider and administrator perspectives on factors affecting telemedicine use in oncology settings are not well understood, and the conditions associated with the COVID-19 pandemic offered the opportunity to study the adoption of telemedicine and the resulting provider and staff perspectives on its use.

Objective: The aim of this paper is to study the factors that influenced telemedicine uptake and sustained use in outpatient oncology clinics at a US cancer center to inform future telemedicine practices.

Methods: We used purposive sampling to recruit a mix of oncology specialty providers, practice managers, as well as nursing and administrative staff representing 5 outpatient oncology clinics affiliated with the Dartmouth Cancer Center, a large regional cancer center in the northeast of United States, to participate in semistructured interviews conducted over 6 weeks in spring 2021. The interview guide was informed by the 5 domains of the Consolidated Framework for Implementation Research, which include inner and outer setting factors, characteristics of the intervention (ie, telemedicine modality), individual-level factors (eg, provider and patient characteristics), and implementation processes. In total, 11 providers, 3 leaders, and 6 staff participated following verbal consent, and thematic saturation was reached across the full sample. We used a mixed deductive and inductive qualitative analysis approach to study the main influences on telemedicine uptake, implementation, and sustainability during the first year of the COVID-19 pandemic across the 5 settings.

Results: The predominant influencers of telemedicine adoption in this study were individual provider experiences and assumptions about patient preference and accessibility. Providers' early telemedicine experiences, especially if negative, influenced preferences for telephone over video and affected sustained use. Telemedicine was most favorably viewed for lower-acuity cancer care, visits less dependent on physical exam, and for patient and caregiver education. A lack of clinical champions, leadership guidance, and vision hindered the implementation of standardized practices and were cited as essential for telemedicine sustainability. Respondents expressed anxiety about sustaining telemedicine use if reimbursements for telephonic visits diminished or ceased. Opportunities to enhance future efforts include a need to provide additional guidance supporting telemedicine use cases and evidence of effectiveness in oncology care and to address provider concerns with communication quality.

Conclusions: In a setting of decentralized care processes, early challenges in telemedicine implementation had an outsized impact on the nature and amount of sustained use. Proactively designed telemedicine care processes with attention to patient needs will be essential to support a sustained role for telemedicine in cancer care.

(JMIR Cancer 2022;8(3):e33768) doi:10.2196/33768

KEYWORDS

telemedicine; telehealth; remote consultation; clinical oncology; implementation science; qualitative research; telemedicine methods; telemedicine organization and administration; telemedicine trends; clinical oncology methods; clinical oncology organization and administration; oncology; digital health; virtual care; COVID-19

Introduction

The COVID-19 pandemic led to an unprecedented need to deliver care for cancer and other conditions remotely [1-4]. Telemedicine has long been touted as a promising but underused mode of delivering cancer care, especially in rural areas where access is often constrained by the need to travel significant distances [5-12]. While technologies to support telemedicine have been around for decades [13-15], it was only when the public health emergency occurred locally—necessitating the curtailing of all nonessential in-person contact in March 2020 [16-21]—that our region in the rural New England region of the United States experienced a rapid uptake. At the start of the pandemic, telemedicine support at the Dartmouth Cancer Center (DCC) was provided by a small department used to handling a fraction of the visits experienced during the pandemic (outpatient televisit rates increased some 10,000%). The basic visit process entailed a multistep setup requiring the patient to download, install, and configure a computer software or smartphone app, or to be available for a phone call for a telephone visit once payment policy shifted to permit telephone visits [16-20,22]. After the first 3 months of the pandemic, the video visit process simplified to one where video visits could occur via a much simpler application accessible via the patient portal either on a computer or smartphone. Resources supporting the transition to televisits were largely limited to web-based training materials for learning to use the telemedicine platform, without the capacity for providing technical support or individualized workflow adaptations at the department or clinic level.

Quantitative analysis of telemedicine use (including the use of either telephone or video to provide real-time care similar to an in-person office visit) within the DCC over a 1-year time frame from pandemic onset revealed relatively low use compared to other specialties [23], and further analysis showed significant variability in use by clinic site corresponding to a larger magnitude of difference in telemedicine use rates compared with patient, geographic, or medical factors [24].

In a broader context, published studies of use trends of telehealth for cancer care suggest disparities in telehealth use, with patients in urban settings favoring telehealth more than rural [25], as well as other groups including older adults and patients of color [26]. Recent qualitative studies of telehealth for cancer care during the COVID-19 pandemic suggest that there is a subset of care situations within survivorship that is acceptable to providers and patients alike [27], and that telehealth has broadly been acceptable to many patients and providers even as concerns about a lack of physical exam are raised [28].

To better understand the underlying factors to the observed local variation in use amid the rapid transition in care delivery, we conducted a rapid-cycle qualitative study of semistructured interviews with a diverse mix of oncology providers and clinic staff in the spring of 2020.

Methods

Study Setting

The DCC, an affiliate of Dartmouth Health, serves the bistate region of New Hampshire and Vermont as well as parts of New York, Massachusetts, and Maine with headquarters at Dartmouth-Hitchcock Medical Center (DHMC) in Lebanon, New Hampshire. DCC operates 5 oncology clinics serving 18,000 to 20,000 patients per year across the catchment area. The proportion of patients who are dual eligible for both Medicaid (state-sponsored insurance for eligible low-income patients) and Medicare (nationally sponsored insurance for eligible older adults aged 65 or older or with specific disabilities) ranges from 19.1% to 25% across the oncology clinic sites (Table 1).

Approximately 71% of patients seen in 2020 resided in rural settings [29]. The COVID-19 pandemic impacted care starting in mid-March 2020, with Dartmouth-Hitchcock Medical Center responding to a state-mandated lockdown by postponing or transitioning all nonessential care to telemedicine on March 18, 2020. Restrictions continued until April 30, 2020, at which point efforts sought to normalize care volumes through screening processes and visitor restrictions while continuing to incorporate telemedicine where appropriate.

Table 1. Patient demographic characteristics as a percentage of total population served by DCC[a] across oncology clinics in 2019.

Characteristics	Clinics				
	A (n=2341), n (%)	B (n=9923), n (%)	C (n=2631), n (%)	D (n=1882), n (%)	E (n=1502), n (%)
Race					
White	2271 (97.0)	97.3 (9655)	2394 (91.0)	1673 (88.9)	1458 (97.1)
Black	12 (0.5)	60 (0.6)	84 (3.2)	47 (2.5)	6 (0.4)
Hispanic	14 (0.6)	99 (1.0)	84 (3.2)	85 (4.5)	11 (0.7)
Sex					
Female	1367 (58.4)	5487 (55.3)	1584 (60.2)	1150 (61.1)	765 (50.9)
Male	974 (41.6)	4436 (44.7)	1047 (39.8)	732 (38.9)	737 (49.1)
Medicaid[b]	447 (19.1)	1935 (19.5)	658 (25.0)	356 (18.9)	360 (24.0)
Age					
>65	1470 (62.8)	5517 (55.6)	1181 (44.9)	804 (42.7)	993 (66.1)
>85	206 (8.8)	506 (5.1)	134 (5.1)	83 (4.4)	93 (6.2)

[a] DCC: Dartmouth Cancer Center.

[b] Includes those *dual eligible* for Medicaid and Medicare.

Sampling and Recruitment

Across the 5 clinic locations, we recruited a purposive sample of oncology clinical providers, leaders, regional practice managers overseeing telemedicine implementation, and nonphysician staff (eg, schedulers and nurse managers) to participate in semistructured interviews. Of the 67 medical doctors and nurse practitioners employed at DCC who used some amount of telemedicine between January 2020 and October 2020, we sampled 30 clinical providers representing low-to-high telemedicine use, a mix of oncology specialties, the 5 clinic locations, and varied proportion of rural patients served. Leaders, practice managers, and clinical providers were recruited through direct email invitations from study leaders. Following interviews with regional managers, we used snowball sampling to identify a mix of other nonphysician staff members representing all 5 clinics with direct experience supporting telemedicine during the pandemic.

Data Collection and Analysis

We used the Consolidated Framework for Implementation Research (CFIR) to inform data collection and analysis. The CFIR includes over 30 evidence-based constructs grouped within the 5 domains of intervention characteristics, outer setting, inner setting, characteristics of individuals targeted by the intervention, and the process of implementation. The CFIR was developed to examine complex interventions across different settings, including hospitals as well as primary care and telehealth settings [30-34]. We created 2 semistructured interview guides for providers and staff, which explored constructs from all 5 CFIR domains with particular emphasis on identifying barriers and facilitators to telemedicine uptake and sustainability associated with inner or outer contextual factors; telemedicine technology and functionality; provider experiences, knowledge, and attitudes toward telemedicine technology given typical clinical workflows; perceptions of patient and caregiver attitudes and capabilities in using the technology; and overall implementation processes and adaptability. Following the creation of the guides and use in a few initial interviews, we made final modifications to the question wording and probes to improve interview clarity, flow, and consistency among the interviewers.

Two researchers (DV and RB) conducted semistructured interviews with cancer care providers, and 1 researcher (JAT) conducted all staff interviews. None of the interviewers had explicit clinical experience or roles within the institution, and all of them were unknown to interview participants. All 3 researchers listened to a sample of the early interviews and then met to debrief, adjust the interview guide as noted above, and reach consensus on interview methods before completing future interviews. The interviews lasted approximately 45 minutes and were recorded with participant permission for later transcription.

We used the web-based transcription service, “Rev.com,” to create word-for-word transcripts of the interviews that were then uploaded into the qualitative analysis platform Dedoose (Socio Cultural Research Consultants, LLC). Two researchers (DV and RB) coded and analyzed the transcripts using mixed inductive and deductive methods [35,36]. The 2 researchers coded a sample of transcripts separately and then met to debrief and reach consensus. The researchers used a mix of in-person debriefing sessions, emails, and internal Dedoose memos to reach consensus and discuss any personal or professional biases that arose throughout the analysis process. If the coding team was unable to reach consensus, additional members of the study team were consulted (JAT, MM, and AT). Thematic saturation was reached across the full sample as evidenced by no new themes and subthemes coming forth in exploring the main CFIR constructs of interest [37].

Ethical Considerations

The study received Dartmouth Health institutional review board approval (STUDY 02000578). The participants were provided with an information sheet and opportunity to ask questions prior to participation. The participants were verbally consented, and permission was obtained for the audio recording of interviews. Names, titles, and practice settings were deidentified and will not be included in any published data.

Results

Overview

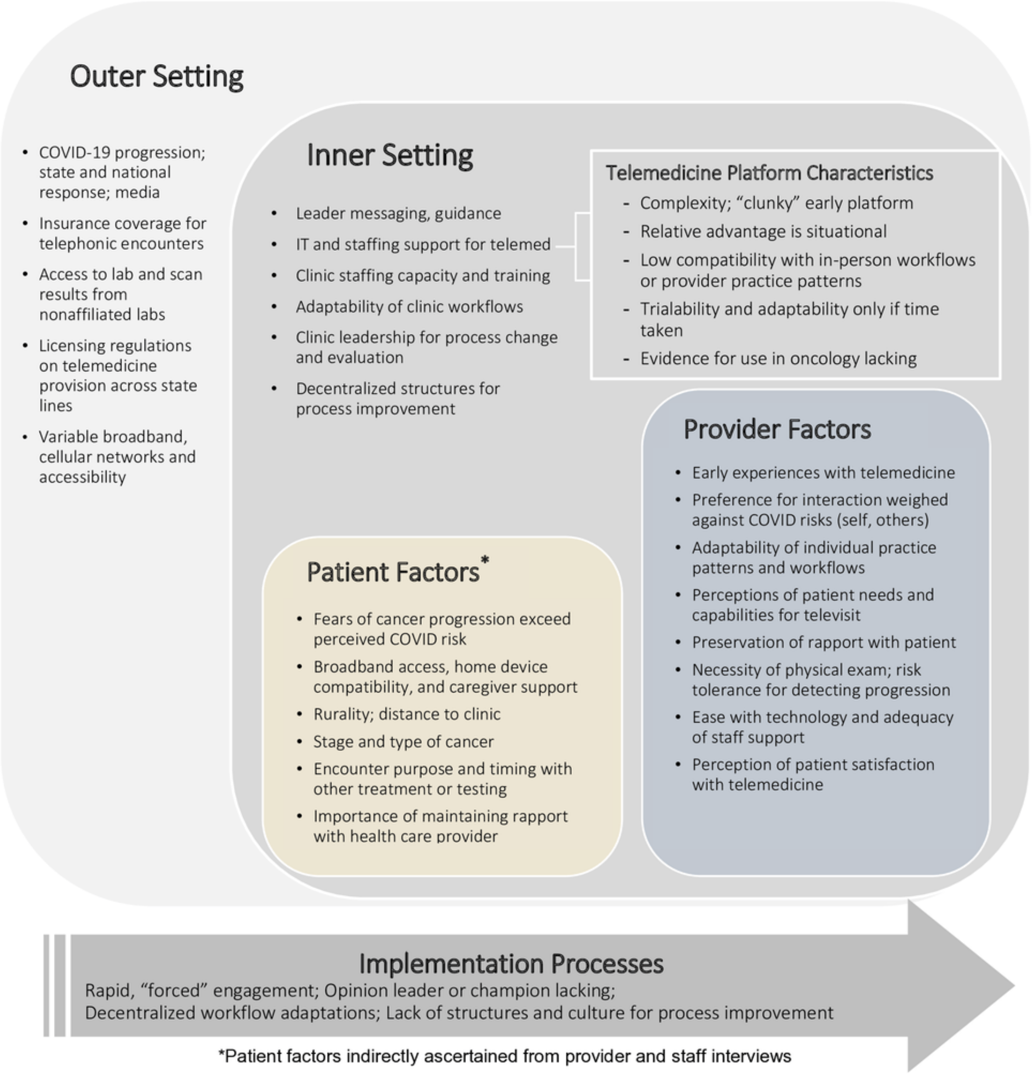
We conducted 11/20 (55%) provider, 3/20 (15%) leader, and 6/20 (30%) staff interviews (Table 2). All providers reported adopting some form of telemedicine for a significant proportion of visits in the early months of the pandemic (March-June 2020), predominantly via phone (vs video), consistent with our prior quantitative analysis [24]. Telemedicine use (video and phone combined) by the providers in this sample also mirrored that of the entire DCC oncology service, which peaked at an average weekly telehealth visit rate of 26% of visits in the initial lockdown phase, settling out to an average of 10%-12% after lockdown [23].

The qualitative findings shed light on these use patterns. Figure 1 presents the factors having the greatest influence on uptake and sustained use of telemedicine that emerged in the staff and provider narratives by the CFIR domain. Figure 2 presents a summary of the factors across all CFIR domains, which emerged as either facilitating telemedicine use or acting as barriers dissuading or constraining telemedicine use. The results are summarized below; select quotations can be found in Table 3.

Table 2. Interview participant demographics.

Category	Value, n (%)
Position level	
Provider (medical doctors and nurse practitioners)	11 (55)
Leaders or practice managers	3 (15)
Staff (schedulers and registered nurse managers)	6 (30)
Provider telemedicine use	
Low (0%-9%)	3 (28)
Medium (10%-17%)	4 (36)
High (18%-30%)	4 (36)
Years in role	
Less than 1	5 (25)
1-4	5 (25)
5-10	3 (15)
11-15	2 (10)
>15	4 (20)
Not specified	1 (5)

Figure 1. Main themes organized by the Consolidated Framework for Implementation Research construct; telemed: telemedicine.



Outer Setting

- COVID-19 progression; state and national response; media
- Insurance coverage for telephonic encounters
- Access to lab and scan results from nonaffiliated labs
- Licensing regulations on telemedicine provision across state lines
- Variable broadband, cellular networks and accessibility

Inner Setting

- Leader messaging, guidance
- IT and staffing support for telemed
- Clinic staffing capacity and training
- Adaptability of clinic workflows
- Clinic leadership for process change and evaluation
- Decentralized structures for process improvement

Telemedicine Platform Characteristics

- Complexity; "clunky" early platform
- Relative advantage is situational
- Low compatibility with in-person workflows or provider practice patterns
- Trialability and adaptability only if time taken
- Evidence for use in oncology lacking

Provider Factors

- Early experiences with telemedicine
- Preference for interaction weighed against COVID risks (self, others)
- Adaptability of individual practice patterns and workflows
- Perceptions of patient needs and capabilities for televisit
- Preservation of rapport with patient
- Necessity of physical exam; risk tolerance for detecting progression
- Ease with technology and adequacy of staff support
- Perception of patient satisfaction with telemedicine

Patient Factors*

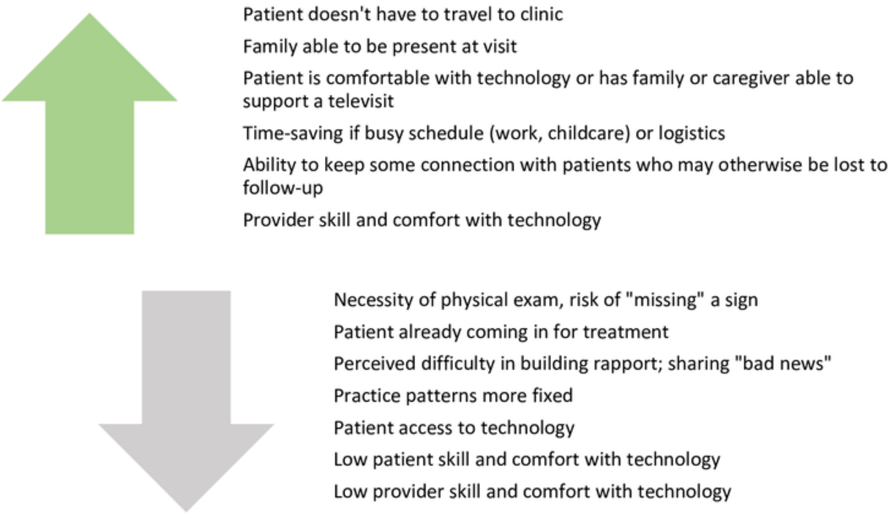
- Fears of cancer progression exceed perceived COVID risk
- Broadband access, home device compatibility, and caregiver support
- Rurality; distance to clinic
- Stage and type of cancer
- Encounter purpose and timing with other treatment or testing
- Importance of maintaining rapport with health care provider

Implementation Processes

Rapid, "forced" engagement; Opinion leader or champion lacking;
Decentralized workflow adaptations; Lack of structures and culture for process improvement

*Patient factors indirectly ascertained from provider and staff interviews

Figure 2. Facilitators and barriers to telemedicine uptake.



Patient doesn't have to travel to clinic

Family able to be present at visit

Patient is comfortable with technology or has family or caregiver able to support a televisit

Time-saving if busy schedule (work, childcare) or logistics

Ability to keep some connection with patients who may otherwise be lost to follow-up

Provider skill and comfort with technology

Necessity of physical exam, risk of "missing" a sign

Patient already coming in for treatment

Perceived difficulty in building rapport; sharing "bad news"

Practice patterns more fixed

Patient access to technology

Low patient skill and comfort with technology

Low provider skill and comfort with technology

Table 3. Selected quotations organized by the Consolidated Framework for Implementation Research (CFIR) domain.

CFIR domain	Exemplar quotes
Outer setting	• "The biggest barrier [was ordering and receiving] labs [from other facilities] and putting them into the patient's chart for the doctor to review before the visit… There have been a couple instances where we have had to delay telemedicine visits for our patients because the doctor doesn't have the results yet" (staff). • "Well, institutionally, if it's not paid for, they won't use it…They haven't embraced it before COVID. I think COVID just pushed it into the mainstream. So that's a huge barrier in theory. And I hope [insurances] will recognize the benefit" (provider).
Inner setting	• "The other piece that we're still trying to create a better workflow for is the rooming process…[Providers] don't have the clinical support to be able to have somebody touch base with the patient prior to them joining the video, or the telephone call if that's the case. That piece is something that we're still trying to make more efficient, is having that virtual rooming where the MA is able to start the visit, collect that information, get it entered into the encounter for the provider" (staff). • "The main workflow in the clinic is we get our schedule, and we looked at the schedule, and I go through the patients and look at the diagnosis. And then I decide which patient is appropriate for telehealth, and which patient is not. And it is the secretaries who called the patient" (provider).
Intervention characteristics	• "I think the lack of a real physical examination is a real rapport problem. There's something quite unique about the physician doing a physical exam that communicates a lot of unspoken things to the patient… [It is] hard to describe" (provider). • "[My mix of phone vs video is three fourths phone and one fourth video]. The videos can be a little tedious and for the video, the patient has an appointment for which they're sitting in front of their computer. So, if I'm running 30-minutes late, they're stuck in front of their computer. Where the phone…they could more or less live their life and go about their day and I'll call them on their cell phone. And so, from my perspective [it] is much more convenient" (provider). • "I do think over the telephone I miss the non-verbal cues. If I'm in the exam room or virtually I'm with the patient and a family member and I say something and they get this look on their face and I can say so, you look like you're maybe not comfortable with that or your wife just shook her head in the opposite direction of you. There's more non-verbal cues that then tell me to sort of pursue that a little further, especially things like depression. Sometimes I can tell that more. They may not say they're depressed, but I can tell they're not really maintaining eye contact well or they're kind of a flat affect. You don't get that over the telephone" (provider).
Characteristics of individuals	• "For our patients, who are either frail, rural, or both, when there's travel issues, or even they don't have a lot of gas money, like being able to say, "Listen, it's okay. We'll do a tele-visit," is awesome" (provider). • "We have an older, sicker population who may be less computer savvy, may have less access to high-speed Internet, and have a reluctance to incorporate the technology into their lives" (provider).
Implementation processes	• "[Providers are using telemedicine] for long-term follow-ups, for discussion visits, for chemo teachings, for results discussion visits, for patients who live far away and don't want to come in. And for patient side, I see it as for the exact same reason, for patients who say, "I live two hours away. Can this be a phone visit?" And we say, "No problem. Happy to help" (staff). • "[The providers] see a lot of patients on treatment, so they see them, when they're getting their treatment in the infusion suite… I don't know how many of them have done [telemedicine] in between. I'm just starting to see because we share a lot of patients where they'll do an in between checkup visit by video. I'm seeing a little more of that where they're not actually getting their chemo, but I think the majority of their patients are actually getting treatment the same day they see the provider" (provider leader).

Outer Setting Factors

The pandemic and the associated public health response by national, state, and institutional leaders were both a trigger for implementing telemedicine and a source for widespread disruption in usual clinical practice workflows. All interview participants described a considerable amount of initial confusion in the transition to telemedicine due to questions about reimbursement allowances (eg, whether Medicaid, Medicare, or commercial insurances covered telephone as well as video visits, and whether payment rates would be the same as in-person care) and provider licensing regulations, compounded by mixed media messages and unknowns related to the spread and exposure of the virus. Another challenge to the early transition reported mainly by staff participants was associated with the shift by many patients to using local, nonaffiliated clinics for lab testing, which were not linked to the electronic health record. Providers and staff alike reported this necessitated additional staff time to obtain and integrate results into the record for providers to have during a telemedicine visit; if it was not obtained, it caused scheduling disruptions. Another external setting factor that emerged was the major policy change allowing reimbursement of telephonic visits at rates on par with in-person or video-based visits. This policy change was a key factor to overcoming technology frustrations experienced in early video visits and was cited by most respondents, providers, and staff alike, as it is important for the sustained use of telemedicine in oncology.

Inner Setting Factors

According to the participants, practice and provider workflows for using telemedicine were nonexistent at all oncology clinics at the start of the pandemic. Existing clinic workflows for in-person visits were reported to be largely incompatible with the new flows needed for the telehealth transition, and staff and providers alike wished for greater guidance from DCC leaders to help with initial implementation. As noted above, there was considerable confusion and questions about which visits could and could not be carried out via telemedicine in the early days, and the respondents overall reported a lack of clear direction or support from an internal champion to address questions. Moreover, the providers reported that the overall pace of care did not allow for dedicated time to effectively engage with training materials on their own, and there was no institution-wide push to ensure all providers complete telemedicine training.

Clinic leaders, schedulers, and providers reported taking matters into their own hands to develop ad hoc strategies to make the shift to telemedicine early on. Workflows and staff responsibilities were modified to support telemedicine visits. On some teams, staff were tasked with calling patients in advance to prepare them for the telemedicine visit, practice with the technology, and gather medication and medical history information; however, clinics rarely had the staffing resources to carry this out consistently. As the pandemic evolved, clinic teams continued to refine internal workflows, patient messaging, and coordination with new lab vendors to support telemedicine use, all with a high degree of variation across clinics and largely based on local preferences of providers and perceived patient needs.

Intervention (Telemedicine) Characteristics

Provider dissatisfaction with the telemedicine user interface, particularly with video visits in the early days of the pandemic, emerged as a critical variable in determining ultimate use of the technology for patient care and preferences for phone over video. The providers described the telemedicine platform in use at the onset of the pandemic as “clunky” and requiring multiple steps to log in. Many reported quickly transitioning to phone visits because of the technical challenges both they and their patients encountered with the video interface, citing frustration and wasted time trying to establish and maintain a successful video connection. Even after a year, a few providers in our sample had still not conducted a video visit after hearing about colleagues’ experiences. Following an institutional switch to a different telemedicine platform in the summer of 2020, the participants reported improved connectivity and visit satisfaction, although not enough to convince those more hesitant with the technology to reattempt video visits.

Telemedicine was perceived as holding relative advantage over in-person visits for some clinical situations described below. Moreover, the technology offered providers time savings and greater flexibility in scheduling visits around research, meetings, and serving multiple clinic sites, while it was also reported as reducing travel demands for rural patients and those with busy work, home, and school schedules. Despite these advantages, respondents wanted more evidence of the efficacy of telemedicine, particularly in the context of cancer care where many feared missing disease progression when conducting clinical exams virtually.

Trialability and adaptability with the telemedicine technology happened to varying degrees among clinic teams as reported in the interviews. Novel uses for telemedicine in oncology care emerged during the implementation, most notably in the form of what was locally referred to as “chemo teaches” (meetings to prepare patients and caregivers on what to expect while undergoing chemotherapy) and other patient or family education. Telemedicine allowed family members who were geographically remote or working to participate in education sessions and visits. The easing of state licensure restrictions (also an external setting factor) enabled several providers to provide telemedicine consultation to patients outside of their usual geographic area, supporting continuity for patients who needed to travel as well as enabling new consultations and second opinions.

Characteristics of Individuals

Provider-Level Characteristics and Preferences

Of all the factors influencing telemedicine uptake and implementation, provider preference had the greatest effect on both the ratio of telemedicine to in-person visits and the modality of those telemedicine visits (phone vs video). A combination of early negative experiences with video, comfort with technology (or lack thereof), convenience, and perceptions of patient preferences contributed to a majority of providers in our sample, almost exclusively opting for telephonic visits if in-person visits were not possible.

Preferences were also influenced by attitudes around risk of COVID-19 exposure (self, staff, and patients) balanced against the degree to which providers valued direct patient interactions to connect with patients and assess clinical conditions. Provider willingness to experiment with the technology and adapt individual practice workflows was more of a predictor of telemedicine use than clinical specialty or years in practice (ie, provider age).

Most providers in our sample felt it was harder to achieve their preferred level of rapport with their patients in televisits (phone or video), though some found video visits afforded new ways to connect with patients by observing them in home settings and family encounters. For difficult conversations or when health literacy was in question, in-person and video visits were universally preferred. In the narratives, providers often couched their own preferences around supporting their patients’ preferences (real or perceived). The providers reported using patient preferences to determine visit type yet acknowledged that patient willingness to use telemedicine (either telephonic or video) could be modified by messaging about the different options during appointment scheduling.

Perceptions of Patient-Level Characteristics and Preferences

A patient’s geographic distance to the medical center had a mixed effect on telemedicine use. According to staff and providers, for some rural patients, telemedicine offered a solution against frequent, lengthy trips into the clinic for more routine visits (especially in poor weather conditions or when transportation assistance was needed). For other patients, the providers cited reports of poor internet connectivity or cell service, which hindered telemedicine use. The participants gave examples that suggested they would assess a patient’s skill or comfort with technology in determining whether to offer a telemedicine visit. Older, rural patients were reported to be more likely to choose phone or in-person visits rather than using telemedicine technology because of a lack of familiarity with technology. Family or caregiver support (eg, in assisted living settings) was observed by staff and providers to buffer against technology challenges. Younger patients were cited as being more willing to engage with technology but were constrained by other factors, including busy work and family schedules that led providers to offer telephonic visits more often than video visits.

Staff and providers agreed regarding the clinical situations better suited for telemedicine. These included patients with less aggressive or more stable cancers such as hematological cancers; cancers for which a physical exam was less important because scans or lab results largely dictated treatment decisions; patients in remission; or clinical situations where visits could reasonably alternate between in-person and telemedicine (eg, if the patient needed monthly monitoring). These considerations are summarized in Table 4.

Table 4. Situations in cancer care better and worse suited to telemedicine use, as reported from staff and provider interviews.

Category	Better for telemedicine	Worse for telemedicine
Cancer type	• Less aggressive • Generally stable over time (eg, hematological cancers) • Monitoring or treatment largely based on labs or imaging scans	• Rapidly progressing or unstable • Need to assess tolerance to new therapy • Physical exam important to assess (eg, breast, GI[a] or GU[b], and head or neck cancer)
Visit type	• Routine interval monitoring between treatments • Patient or family education (eg, chemo teaches) • Survivorship follow-up visits	• Patient already on site for treatment visit or scan • ”Decision point“ for changes (eg, hospice transition or continuation of therapy)

[a] GI: gastrointestinal.

[b] GU: genitourinary.

For more rapidly progressing cancers such as breast, gastrointestinal or genitourinary, as well as head and neck cancers, the providers had a strong preference for seeing their patients in person, as they were concerned they may miss important disease progression that could influence treatment decisions. In these cases, they reported a heavy reliance on the physical exam and other aspects of an in-person visit to assess a patient’s response to and tolerance of treatment, especially around important decision points in care.

Overall, providers and staff reported that while telemedicine can be incorporated into oncology care, the nature of oncology and the fact that patients with oncology-related needs are already coming in for treatment do not lend themselves to a high level of telemedicine adoption. Patient and provider perceptions of confidentiality and privacy concerns in using technology did not emerge as a main theme in this study.

Implementation Processes

Interview participants voiced a desire for a clear vision for telemedicine use in oncology, substantiated by evidence, supported by recognized champions, and standardized through official policies such as continued reimbursement for telephonic visits in specific clinical situations.

Logistical and workflow improvement recommendations included staff support to virtual “room” patients at the start of a telemedicine visit, establishing dedicated space for televisits, where equipment was already set up, establishing preappointment protocols and scheduling processes to ensure patients were adequately prepared, and clarifying roles and training to ensure clinics had the capacity to support both in-person and televisits in a smooth fashion. Challenges and burdens of staff time in obtaining lab results from outside vendors indicate a need for formal partnerships, data sharing agreements, and integrated electronic systems to share results more efficiently.

The participants identified a need to continue to improve accessibility and ease in using the telemedicine technology for patients and providers alike. Translation services were a challenge for some to incorporate within telemedicine visits. The providers voiced a need for more training and peer-to-peer learning opportunities to gain greater ease in adjusting their visit flow, maximizing the information obtained from patients in a digital setting, and ensuring understanding on the part of patients and caregivers.

Discussion

Principal Findings

Telemedicine use in oncology, as characterized by the participants in this sample, reflected a complex interaction of multiple factors beyond pandemic-specific circumstances. A relative void of institutional steering and support allowed provider opinions about the relative benefit (eg, patient convenience or improved access) and risks (eg, concerns about compromising clinical care quality, impaired rapport building, and reduced communication quality) to drive variable use of telemedicine. A larger context of no clear oncologic *standard of care* pertaining to the efficacy and safety of telemedicine to fall back on further enabled a wide range of opinions and practices. These dynamics were skewed by technology challenges early in adoption, which led to preferential engagement with telephone over video for visit modality.

While there were clear positive impressions of telemedicine among staff and providers to support its ongoing use, at the time of this study, there were no significant continuing efforts or conversations among care teams or at a center- or department-wide level around long-term adaptation for sustained use. The presence of a local champion (an individual on work units who formally or informally promotes a process or intervention to their colleagues) is generally regarded as important to successful and sustained adoption of telemedicine [38,39] and is a core part of the "diffusion of innovation" model as put forth by Rogers and expanded upon by Greenhalgh et al [40]; such an individual was not apparent within the oncology department in our interviews. Study team members involved in telehealth deployment across this period noted that telemedicine champions seemed to already exist and emerge organically in other services at the organization; it is unclear precisely why this did not occur for oncology at our center, and a proactive effort to identify or designate a champion would be useful for future innovation efforts. Organizational learning and process improvement specific to telemedicine was slow to emerge, and expanded messaging and infrastructure in these areas could facilitate sustained, ongoing process improvement. Such approaches could provide an opportunity to revisit and shift some of the patterns set early in pandemic-forced adoption toward patient-oriented and shared goals (eg, minimizing frequency of patient transport when clinically feasible) and away from anecdotal impressions of care team members (eg, assumptions that certain patients or demographics are best served via face-to-face or telemedicine without directly eliciting preferences, or telemedicine use depending on provider comfort with technology rather than clinical context).

Comparison With Prior Work

Organizational barriers may explain in part the differences in telemedicine use in our study versus the work by Patt et al [15], who reported less significant barriers in uptake and a >95% reported rate of video telemedicine use in a survey-based study; our study furthers theirs in that it used in-depth semistructured interviews rather than a survey tool to gather data for analysis.

Our findings align with larger theoretical frameworks around the implementation of novel processes and innovations, including the CFIR model as well as diffusion of innovation. These models all support the complex interplay of a myriad of factors influencing the success of any innovation and underscore the advantages of being able to plan and prepare for systemwide transitions such as this; such a preparation was not possible with the sudden shift in patient care necessitated by the COVID-19 pandemic. We noted the most influential factors pertaining to our rural, multisite cancer center above, including elements specific to the innovation itself (technologic challenges and the impacts of using telemedicine for the patient encounter), communication channels (a relative lack of leadership or operational support both in implementation and ongoing improvement work), and adopters (individual attitudes and motivations to adopt change).

Limitations

While DCC serves a broad population base, most of the patients are located within Northern New England, and it is quite likely that other institutions with their own distinct populations and institutional cultures will have different challenges and opportunities. It is also possible that implementation in other circumstances without the rapid adoption due to a pandemic may have different dynamics and key factors for implementation. Our sample was sufficient to reach thematic saturation on major themes, but it leaves room for a more detailed exploration of some of the subthemes that emerged, including variation in provider messaging to patients around the visit options (in-person, telephonic, and video), provider and staff comfort with technology, and specific operational practices to minimize schedule disruption associated with telemedicine visits.

While staff and providers offered important insights to the attitudes, challenges, needs, and feedback of their patients, we did not directly interview patients for this study. It is notable that studies such as that carried out by Smith et al [28] included patients and caregivers in their interviews and found similar themes to our work regarding the acceptability and efficiency of telehealth generally for cancer care, alongside concerns regarding the lack of physical exam. Further investigation and analysis of patient perceptions of telemedicine use in cancer care—especially as we transition to a postpandemic environment where more patients are familiar with telemedicine and novelty—should further extend understanding of the risks and benefits of telemedicine use in oncology settings to equitably serve the needs of diverse populations.

Conclusion

In a setting of decentralized care processes, early challenges in telemedicine implementation had an outsized impact on the nature and amount of sustained use. Proactively designed telemedicine care processes with attention to patient needs will be essential to supporting a sustained role for telemedicine in cancer care.

Acknowledgments

The team wishes to thank Jennifer Snide for her support in the quantitative analysis that helped inform this study. We would also like to thank Stephen D Leach for championing the study's recruitment efforts.

This work was supported by the National Cancer Institute at the National Institutes of Health (P30CA023108-S5). The National Cancer Institute had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; and decision to submit the manuscript for publication. The research team had full autonomy in all aspects of the study.

Authors' Contributions

MM, RB, JAAT, KMC, ML, TDT, WZ, and ANAT conceptualized the study; RB, DV, JAAT, TDT, and WZ participated in data curation and formal analysis; ANAT was responsible for funding acquisition; RB, DV, JAAT, and KMC carried out the study investigation. MM, RB, DV, JAAT, KMC, ML, and ANAT contributed to study methodology; RB, DV, JAAT, KMC, and ML carried out project administration; RB, DV, JAAT, KMC, ML, TDT, WZ, and ANAT where responsible for providing resources; RB and DV provided software support; ANAT carried out study supervision; MM, RB, DV, JAAT, KMC, and ML validated the study; MM and RB carried out study visualization; MM, RB, DV, and JAAT where responsible for writing—original draft; and MM, RB, DV, JAAT, KMC, ML, TDT, WZ, and ANAT carried out the writing—review and editing.

Conflicts of Interest

None declared.

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Abbreviations

CFIR: Consolidated Framework for Implementation Research
DCC: Dartmouth Cancer Center

Edited by A Mavragani; submitted 29.09.21; peer-reviewed by I Wilson, E De Clerq; comments to author 14.05.22; revised version received 28.06.22; accepted 21.07.22; published 16.08.22.

Please cite as:
Mackwood M, Butcher R, Vaclavik D, Alford-Teaster JA, Curtis KM, Lowry M, Tosteson TD, Zhao W, Tosteson ANA
Adoption of Telemedicine in a Rural US Cancer Center Amid the COVID-19 Pandemic: Qualitative Study
JMIR Cancer 2022;8(3):e33768
URL: https://cancer.jmir.org/2022/3/e33768
doi:10.2196/33768
PMID:35895904

Publisher:
JMIR Publications
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