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Original Paper

# Patients' and Health Care Providers' Opinions on a Supportive Health App During Breast Cancer Treatment: A Qualitative Evaluation

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## Abstract

**Background:** Health apps are increasingly being used in clinical care and may hold significant theoretical potential. However, they are often implemented in clinical care before any research has been done to confirm actual benefits for patients, physicians, and researchers.

**Objective:** This study aimed to explore experiences of patients and health care providers with the use of a supportive breast cancer app during the first 6 months following diagnosis, in terms of benefits for clinical practice and research purposes.

**Methods:** Between June 2013 and April 2014, breast cancer patients of all ages were invited shortly after diagnosis to use a supportive breast cancer app, and were followed for 6 months. Patients were asked to use the app at their own convenience. In-depth interviews were conducted regularly with patients and their medical team (ie, physicians and nurses) to evaluate their experiences.

**Results:** A total of 15 patients aged 30-63 years participated. The medical team consisted of 7 physicians and 3 specialized breast cancer nurses. Out of the 15 patients, 12 (80%) used the app to obtain information on breast cancer and treatment. A total of 11 out of 12 patients (92%) evaluated this information as useful. All 15 patients used the app to record consultations with practitioners, and 14 (93%) found this useful. Symptom registration was used by 8 out of 15 patients (53%), and was found useful by 4 out of these 8 patients (50%). Overall, 14 out of 15 patients (93%) would recommend the app to other patients. The app, in particular the recording function, was rated as useful by 9 out of 10 medical professionals (90%), and they reported that it did not increase consultation time. These 9 professionals would recommend the app to their patients.

**Conclusions:** This evaluation of a supportive health app shows positive experiences among patients and their medical teams. Based on experiences in this study, patients may need to be actively encouraged to regularly register symptoms within health apps to generate sufficient patient-reported app data for use in clinical practice and scientific research.

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## KEYWORDS

breast cancer; health apps; quality of life; patient-reported outcomes; PROs

## Introduction

Health apps are increasingly being used by physicians and patients in routine clinical care [1]. Lancet Oncology predicted that by 2018, approximately 1.7 billion mobile phone and tablet users will have downloaded at least one health app [2]. These apps have the potential to be of benefit to patients, physicians, nurses, and researchers. The US Food and Drug Administration (FDA) has noted that health apps can help patients “in the management of their health and wellness, promote healthy living and gain access to useful information whenever and wherever they need it” [2]. Apple recently introduced ResearchKit, with the aim to combine patient data from various health apps and make them accessible to medical researchers [3]. This may further promote the use of health apps for research purposes.

In the field of breast cancer research, patient-reported outcomes (PROs) are becoming increasingly important to better understand and quantify symptoms, psychosocial well-being, and side effects of treatment from a patient’s perspective [4,5]. Mobile health apps may prove to be useful in the collection of PROs, as many patients already use their mobile phones to collect and share personal information. However, it is still unknown to what extent health apps can be used to collect reliable PROs.

The use of supportive health apps may hold significant theoretical potential, but little research has been done about actual benefits prior to implementation in clinical care [1,6-8]. This information should be available before physicians and nurses advise their patients to use an app during their treatment.

This study aimed to explore first experiences with the use of a supportive breast cancer app during diagnosis and treatment, with the aim to better understand potential benefits in clinical practice. In addition, we aimed to evaluate to what extent self-reported app data could be used for research purposes. The aim was to evaluate the app on three levels: patient experience and satisfaction, physicians’ and nurses’ opinions, and scientific potential.

## Methods

Between June 2013 and August 2013, and between March 2014 and April 2014, breast cancer patients consecutively visiting the Department of Surgery of the University Medical Center

Utrecht in the Netherlands were invited to use a supportive breast cancer app. All patients were invited to participate, with the exception of patients who were unable to read and understand the Dutch language, patients under the age of 18 years, and patients who were considered too emotional to receive study information at the time of recruitment.

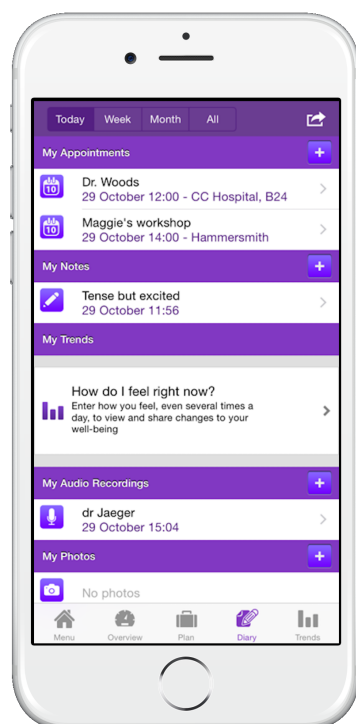
Shortly after diagnosis, the study was first introduced by a nurse practitioner and patients received written study information to read at home. If the patient was interested in participating, a meeting with the researcher was scheduled 1-3 days later for the informed consent procedure.

Patients were recruited within the first week after breast cancer diagnosis, which allowed them to start using the app prior to deciding on a final treatment plan. Each patient was followed for 6 months to evaluate her experiences with the app shortly after diagnosis, but also during treatment and after treatment was initiated. Patients were asked to use their own mobile devices. However, if they were interested in participating but did not have a mobile phone or tablet, the researcher offered an iPad, which they could borrow during study participation.

Out of the few available Dutch supportive breast cancer apps, we chose to evaluate the Owise breast cancer app, version 1.0 (see [Figures 1](#) and [2](#)). This app was developed in 2013 by Px HealthCare, the Netherlands. We chose this app because it can be downloaded and used free of charge for iOS and Android platforms, and includes the following functionalities [9]:

1. Patient repository for information (eg, audio-recorded consultations and imaging).
2. Physical and psychological symptom registration (ie, pain, fatigue, mental mood, etc).
3. Timeline of treatment trajectory and appointments.
4. Personalized information about breast cancer and treatment according to Dutch breast cancer guidelines, tailored to tumor characteristics, age, and menopausal status.

A researcher briefly demonstrated these functions, after which patients were invited to use the app at their own convenience. There was no minimum amount of time to be spent using the app. This approach was chosen to understand which parts of the app patients would use based on their own needs.

**Figure 1.** Screenshot of the OWise app (day overview).

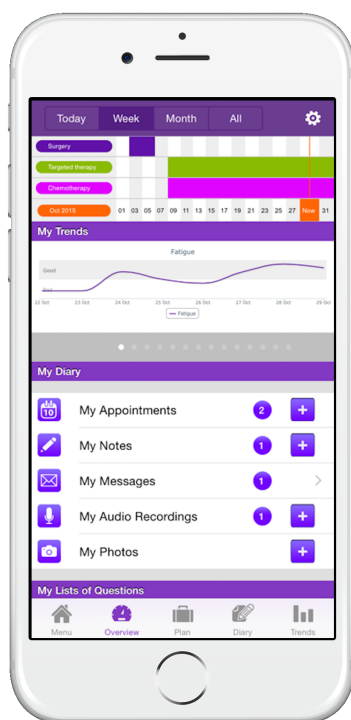
In-depth interviews were conducted using a predefined, semistructured interview guide (see [Multimedia Appendix 1](#)). This interview guide was developed by our team of breast cancer physicians, specialized breast cancer nurses, and clinical epidemiologists, and it was based on questions that were considered relevant from a clinical point of view. All interviews were conducted by one researcher (DAYA) from the breast cancer research team of the University Medical Center Utrecht, who was not involved in the clinical care of the participants. Interviews with patients were conducted every 2 weeks in the first 3 months, and monthly in the last 3 months, either face to face or by phone. Nurses and physicians were interviewed once, shortly after they were first exposed to the app, and two times approximately 1 and 3 months after patients had used the app in their presence several times.

The interview guide was also designed to assess which app functions patients found most useful and for what reason.

Questions for the medical team were designed to probe their opinions about the influence of the app on disease-related knowledge and disease-related behavior of patients during patients' visits. In addition, medical professionals' attitudes toward being recorded with the app were explored. The researcher interviewed each patient, physician, and nurse separately at all times. After each interview, a summary was transcribed and added to the participant's study file. Descriptive statistics were calculated using SPSS version 22 (IBM Corp) to summarize the data.

This study was approved by the Medical Ethics Committee of the University Medical Center Utrecht and was conducted according to the principles expressed in the Declaration of Helsinki. All patients gave written informed consent to participate in this study.



**Figure 2.** Screenshot of the OWise app (week overview).

## Results

### Overview

During the recruitment period, 40 patients visited our medical center consecutively, of which 21 (53%) were not approached for participation because the nurse felt the setting was inappropriate for discussing studies (eg, too emotional) or because the patients were not interested in participating in any kind of research. A total of 19 patients received study information, after which 4 (21%) declined study participation; 1 patient declined because she would be treated in another hospital, 2 patients felt the interviews would take up too much time, and 1 patient was not interested in using the app.

### Patients' Experiences

A total of 15 breast cancer patients with a mean age of 51 years (SD 10) participated in this study. The youngest patient was 30 years of age, while the oldest patient was 63 years of age. On average, each patient was interviewed eight times.

At baseline, patients were asked why they decided to participate in this study. The main reasons for participation were (1) an interest in this particular health app, (2) the hope of gaining benefit from using the app, (3) an interest in apps in general, and (4) an interest in participating in research to help future patients.

A total of 3 out of 15 patients (20%) expressed more specific reasons. One patient had received treatment for contralateral

breast cancer in the past and was particularly interested in recording conversations with her medical team. During her previous treatment, she found it difficult to remember all the information provided by the various different physicians. Another patient had recently lost her husband to cancer and found it difficult, due to her current emotional mental state, to process and remember new information. She hoped that by having her treatment-related information and audio-recordings all in one place, she would be more in control. The third patient was a full-time, nonmedical researcher and found it interesting to be on the other end of a study for a change. Prior to entering the study, 10 patients out of 15 (67%) had frequently used apps on their mobile devices, while 5 (33%) were relatively inexperienced with the use of apps.

Personalized information on breast cancer and treatment as provided by the app was used by 12 out of 15 patients (80%). Out of the 12 patients who used this information, 11 patients (92%) found it useful (see [Table 1](#)). All patients (n=15) used the audio-recording function to record consultations with their nurses and physicians, and 14 (93%) of them found this to be useful. Overall, 14 out of 15 patients (93%) would recommend the app to other patients.

The patient who would not recommend the app to others reported that it did not add much to the information as provided by the medical team and on the Internet. She did not feel comfortable recording medical consultations and registering symptoms. [Table 2](#) presents quotations regarding specific app functions as provided by patients.

**Table 1.** Patients' and health care providers' experiences with specific app functions.

Study participants	Characteristics and experiences with app	n (%)
<b>Patients</b>		
	<b>Age in years (n=15)</b>	
	30-39	3 (20)
	40-49	2 (13)
	50-59	8 (53)
	60-65	2 (13)
	Used information from the app	12/15 (80)
	Found it useful	11/12 (92)
	Used audio-recording function	15/15 (100)
	Found it useful	14/15 (93)
	Used symptom registration function	8/15 (53)
	Found it useful	4/8 (50)
	Would recommend app to other patients	14/15 (93)
<b>Physicians and nurses</b>		
	Found it useful for patients to record consultation	9/10 (90)
	Thought patients appeared to be better informed	2/10 (20)
	Would recommend this app to their patients	9/10 (90)

**Table 2.** Quotes from patients regarding specific app functions.

App functions	Supportive quotations (n=14)	Nonsupportive quotations (n=1)
Information about breast cancer and treatment (based on Dutch guidelines)	"A very useful overview of information, with links to all relevant websites in one place. I thought that was really helpful."	"To me the information in the app does not add much to the information that I can find on the Internet or as provided by my doctors."
Patient repository for information (eg, audio-recorded consultations)	"I shared the audio with my parents who could not be present at the consult. It was comforting to know that they heard the information firsthand from the surgeon instead of my own interpretation. At the same time, I heard important things during playback that I had missed during the initial consultation."  "I forgot important things the doctor said and it felt comforting to know that I could listen to the conversation again. From that moment on, I recorded every consult."  "I regretted not recording several important consultations, because the ones I did record I listened to several times."	"I can imagine it being helpful to some patients, but I personally do not need to listen to a consult again. I would feel uncomfortable having to ask every doctor if it's okay to record the conversation."
Symptom and feeling registration	"I used the symptom registration function on a daily basis during the first month until 2 weeks after the surgery. It helped me a lot to see the graphical overview of my symptoms on a weekly basis. I stopped using it when I started to feel better and my symptoms did not fluctuate anymore."  "The app gave me a familiar feeling in a difficult time of continuously changing faces and feelings, and registering my emotions in the app helped me to express feelings that I would have otherwise kept to myself."	"I'm a very grounded person. Breast cancer happened to me, but I do not want to think about it daily. I've never kept a diary in my life, so I have no desire to start one now."
Timeline	"In the timeline, I registered all my appointments. Keeping an overview of ongoing treatments was very difficult with so many different doctors and appointments, but the app helped me to keep that overview, which made me feel in control."	"I already have a calendar for all my other personal appointments, so I do not need an app for this. I do not feel the need to separate personal appointments from hospital appointments. I'll just deal with it all at the same time."

## Physicians' and Nurses' Experiences

The medical breast cancer team consisted of 2 breast surgeons, a medical oncologist, a radiation oncologist, a plastic surgeon, a gynecologist, a clinical geneticist, and 3 specialized breast cancer nurses. All 10 team members were recorded by patients at least once, and they all reported that being recorded did not influence consultation time. A total of 2 physicians out of the 10 team members (20%) indicated that they chose their wording more carefully. These 2 physicians indicated that they felt

uncomfortable while being recorded at first, but also that they got used to it over time. The audio-recording function was rated as useful by 9 out of 10 (90%) health care professionals. Of the 10 team members, 2 physicians (20%) had the impression that patients were better informed as a result of using the app. Overall, 9 out of 10 medical professionals (90%) would recommend the app to their patients. The 1 physician (10%) who would not recommend the app to patients believed the app did not add to the care and information as already provided by physicians and nurses (see [Textbox 1](#)).

**Textbox 1.** Quotes from health care providers about the app in clinical practice.

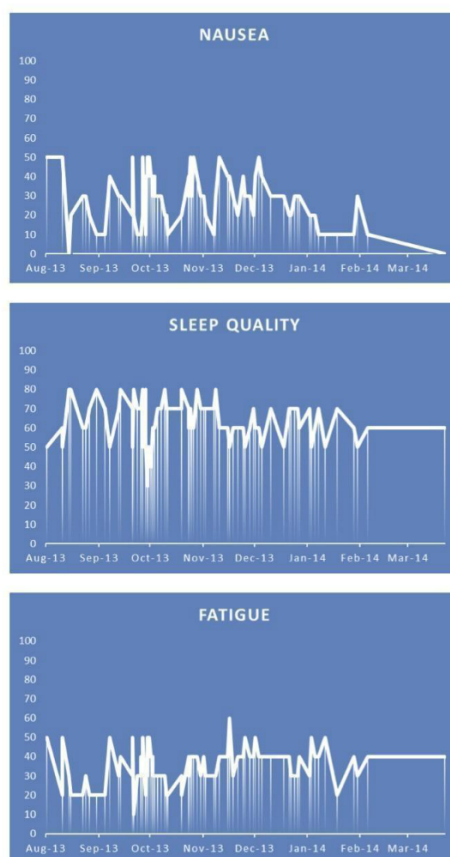
"A patient, who was hesitant at first to record the consult, called my office to thank me for letting her record it. She and her husband heard important things during playback that both of them missed during our conversation."

"I felt hesitant, and even a bit upset, while being recorded the first time. I noticed that I was paying closer attention to what I was saying. However, after a couple of times I did not notice the devices anymore and patients were so enthusiastic about it that I started to like it. I really think the app can be a very helpful tool, also for physicians."

"A patient mentioned that she forgot when, and how, she would get the results of her test. Several days later she received a letter from the hospital, but she was too afraid to open it. She wanted to call the office to ask about the content of the letter, but it was off-hours. She then remembered that she had recorded the consult and found answers to her questions, after which her anxiety went away. In this case, it was simply the letter confirming the next appointment, that I luckily had mentioned during the recorded consult."

"Personally, I don't think that health apps can add to the information we provide to our patients. We are able to provide patients with the information they need, when they need it, while also helping them understand what this medical information actually means."

**Figure 3.** Example of a graphical overview of patient-reported outcomes as obtained from the OWise app's symptom registration function. The levels of nausea, sleep quality, and fatigue range from minimum (0) to maximum (100). A vertical line corresponds with the input of data by the patient. This patient received chemotherapy between August 2013 and December 2013. This data was provided by Px HealthCare with written permission from the patient.



## Scientific Potential of Patient-Reported App Data

Out of 15 patients, 8 (53%) used the symptom registration function at least once during the first month after diagnosis: 1 patient used this function daily (923 data entries), 4 patients weekly (121-355 data entries), and 3 patients monthly (10-30 data entries). Out of 15 patients, 7 (47%) never used this function. Out of the 8 patients who used this function, 4 (50%) found it useful. An example of symptoms registered by one patient is presented in [Figure 3](#). This patient received neoadjuvant chemotherapy during the first 3 months of her treatment.

## Discussion

### Principal Findings

This study of a breast cancer support app shows positive experiences among patients and their medical team. The app functions patients found most useful were the option to record audio from consultations with their medical team, and the personalized information about disease and treatment. Physicians and nurses found the recording function most useful and would recommend the app to their patients.

Patients were asked to use the app at their own convenience, which made it possible to assess which functions of the app they wanted to use. This was based on their own needs in routine clinical practice. In this group of patients, the use of a symptom registration function varied from never to several times a day. With limited data entries in this small study group, we did not further explore the PROs that were generated from the app. We suggest that patients may need to be actively encouraged to regularly register their symptoms in the app. If this is done between hospital visits, results could then be shared during visits with their physicians and/or nurses. The medical team could then address symptoms that may have been left unnoticed otherwise, while researchers could evaluate these PROs in

clinical studies when patients consent to the use of their data for research purposes.

The app in this study stores all audio-recordings on the mobile device, but, in contrast to the standard recording function on mobile devices, only allows for playback within the app without the option to edit or share the file with others. As a result, audio files are not stored on external servers or in Internet clouds, which serves as protection for patient data, but also protects the recorded physician/nurse against uncontrolled sharing and editing of their words [10]. This feature was appreciated by several members of our medical team and increased their willingness to be recorded. We recommend using apps that incorporate these kinds of conditions and restrictions, to allow audio-recording in the consulting room with protection of all parties involved in the recording process.

In this study, we chose to collect data by frequent in-depth interviews in order to obtain a complete first impression on the aspects of the app that patients and the medical team (dis)liked or found useful. The implication of this approach was that we could only include a small number of patients, which limits generalizability of the results. The strengths of this study were that we included patients of all ages, with or without an interest in apps, but also included a multidisciplinary medical team, which allowed for an in-depth evaluation of the needs of a relatively wide range of patients and medical professionals.

### Conclusions

This qualitative evaluation of a supportive breast cancer app shows benefits for patients and their medical teams, especially because of the option to make audio-recordings of consultations and the availability of relevant information in the app. However, in this study group, the use of the feature to register symptoms varied between patients. We recommend that future studies aiming to use patient-reported app data for scientific research encourage patients to regularly register their symptoms within these apps to generate sufficient data.

## Acknowledgments

The authors would like to thank Px HealthCare for providing three iPads on loan to three patients, who did not own a mobile phone or tablet themselves, for use during this study and for providing study participants' data of PROs.

## Conflicts of Interest

David J Bruinvels is Medical Director at Px HealthCare, the company that created and owns the Owise breast cancer app. He is currently not employed by Px HealthCare and is a minor shareholder of Px HealthCare. The first and last author vouch for the integrity of this manuscript.

## Multimedia Appendix 1

Semistructured interview guide.

[[PDF File \(Adobe PDF File\), 20KB - cancer\\_v2i1e8\\_app1.pdf](#)]

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## Abbreviations

**FDA:** US Food and Drug Administration

**PRO:** patient-reported outcome

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Original Paper

# Predictors of Online Cancer Prevention Information Seeking Among Patients and Caregivers Across the Digital Divide: A Cross-Sectional, Correlational Study

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## Abstract

**Background:** The digital divide is a recognized public health problem caused by social determinants that exacerbate health disparities. Despite the “tectonic shift” in how most of the public obtains cancer information, underserved communities are at increased risk of being digitally marginalized. However, research that examines factors underlying eHealth information seeking in diverse health contexts is lacking.

**Objective:** The aim of this paper is to explore preferences and use of eHealth cancer prevention information (CPI) among patients and caregivers attending a minority-serving oncology clinic using the comprehensive model of information seeking as a theoretical framework. Specifically, the study examined the role of social determinants and prevention orientation in differences in preference and use of the Internet for CPI seeking among this diverse sample.

**Methods:** Survey methodology was used to identify social determinants and behavioral factors, including prevention orientation as correlates and predictors of respondents' (n=252) preferences and use of eHealth for CPI seeking.

**Results:** Less than half (112/252, 44.4%) of respondents said that if faced with the need to seek CPI, they would seek this information online. In the final logistic regression model, education, ethnicity, age, and prevention orientation made significant contributions to the model ( $P<.05$ ). Specifically, for each year increase in age, participants were 3% less likely to use the Internet for CPI seeking ( $P=.011$ ). Compared to college graduates, respondents who did not complete high school were 11.75 times less likely to cite the Internet as a CPI carrier ( $P<.001$ ) and those with a high school education were 3 times (2.99,  $P=.015$ ) less likely. In addition, the odds that a Spanish speaker would cite the Internet as a CPI carrier were one-fifth (22%) of non-Hispanic whites ( $P=.032$ ) and about one-quarter (26%) of English-speaking Latinos ( $P=.036$ ). Finally, with each one point increase on the prevention orientation scale, respondents were 1.83 times less likely to cite online CPI seeking ( $P=.05$ ).

**Conclusions:** Social determinants to health have profound influence on eHealth CPI seeking. Providers and policy makers should focus on meeting patients and family members' CPI needs following diagnosis and increase eHealth accessibility and availability of evidence-based CPI to diverse populations. Future research is needed to unravel further differences in eHealth CPI seeking, including those among Native Americans that emerged as an additional digitally underserved racial/ethnic group. Finally, additional factors underlying these differences should be explored to better tailor CPI eHealth information to diverse communities' information needs.

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## KEYWORDS

digital divide; Internet, information seeking behavior; minority health



## Introduction

### Overview

The exclusion of ethnic and racial minorities and vulnerable populations from accessing Web-based health information [1-3] exacerbates cancer-related health disparities. Despite a “tectonic shift” in how cancer patients and their families obtain information and make decisions about their health, including primary and secondary prevention [4], 1 in 5 American adults does not use the Internet. These nonusers are disproportionately likely to be senior citizens, Spanish speakers, adults with less than a high school education, people with low income [5], and cancer survivors [6]. In view of the mounting evidence on the prevalence and demographic predictors of online health information inequities in the general public [3], scholars noted the importance of examining the digital divide in communities that cope with specific health concerns [7].

The goal of this study is to examine use of the Internet for cancer prevention information (CPI) seeking among cancer patients and their families attending a minority-serving academic cancer center in New Mexico, United States, a minority-majority state with the lowest national rate of Internet access at home [8]. The need for this study stems from the importance of eHealth CPI for people diagnosed with cancer and their families. CPI is necessary to inform lifestyle- and screening-related behavior changes. Adhering to evidence-based preventive practices may reduce the likelihood of cancer reoccurrence following remission, reduce second primary cancer diagnosis among cancer survivors, improve overall health outcomes, and reduce anxiety among this population [9,10]. Although people diagnosed with cancer and their families consistently report that they are interested in CPI [11], these needs are rarely met in the medical encounter [12]. A recent study revealed that ethnic and racial minority patients and caregivers value CPI but are often blocked from seeking it [13]. It is likely that the digital divide contributes to the barriers they experience, but past studies did not explore use of the Internet for CPI seeking in this population.

Consistent with the theoretical framework of the comprehensive model of information seeking (CMIS) [14,15], this study aimed at understanding preferences and actual use of the Internet for CPI seeking among diverse patients and their families with the goal of informing a future intervention. Following the CMIS, this study examined factors that are consistent with social determinants to health and have been shown to distinguish between eHealth users and nonusers [16] as well as additional behavioral- and individual-level factors including past CPI-seeking behaviors and prevention orientation [17-19].

### Theoretical Background

The CMIS [14,15] provides a theoretical framework for this research developed to explain and predict cancer-related health information seeking and source utilization and has been tested in diverse settings [14,15,20-23] including online communication environments [24]. Integrating concepts from uses and gratification research, the health belief model, and a model of media exposure and appraisal, the CMIS proposes three primary levels of variables that influence cancer information seeking. Antecedent factors, such as demographics,

beliefs, and attitudes constitute the first level, factors related to the information sources comprised the second level, and the third level includes specific information-seeking behaviors [15,25]. According to this model, the antecedents determine the underlying imperatives to seek information; the perceived characteristics of the information carriers influence the intentions to seek information from particular carriers; and the information-seeking actions are the outcomes of the antecedents and the characteristics of the information carriers [21].

### Cancer Prevention Information Seeking Among Survivors and Caregivers

Whereas some patients might perceive CPI as irrelevant or stressful [26,27], review of the literature concluded that CPI constitutes an important information need, comprising 30% of patient information needs [11]. This information need is likely related to the increased risk of secondary diagnoses and reoccurrence following remission among cancer survivors [11]. Additionally, people diagnosed with cancer might also be interested in receiving information in order to support their families in preventing cancer or to better understand the etiology of their illness. Diagnosis of cancer in the family also leads to heightened perceptions of cancer risk and cancer worry among family members [28], which often result in CPI needs [29]. Obtaining CPI is necessary in making informed decisions about cancer prevention and can reduce anxiety [9], but only one-fifth of oncologists provide this information [12].

Cancer patients vary their source utilization in accordance with the type of information they seek [30]. It is therefore essential to examine use of the Internet for CPI seeking, but most studies to date focused on general cancer information seeking among cancer patients [6,22,31-33]. Additionally, studies that examined CPI seeking and source utilization following diagnosis recruited predominantly non-Hispanic white college graduates [22,30,34,35], and their findings might not be generalized to more diverse patient populations. A recent community-based study of CPI seeking among a diverse sample of cancer patients and their families documented that ethnic minorities and those with lower social economic status (SES) were less likely to seek CPI compared to other respondents despite equal or higher perceptions of its importance and motivation to receive it [13]. Experiencing barriers to online access might contribute to this disparity [6], but eHealth preferences and use of CPI seeking following diagnosis among diverse people diagnosed with cancer and their loved ones was not previously examined. According to the CMIS [14,15], information seeking along the cancer continuum involves different mindsets and is motivated by different needs. Therefore, it is important to better understand CPI seeking following diagnosis with cancer rather than assume it follows patterns identified in different populations or cancer information seeking contexts. Such an understanding is essential for designing health communication and education efforts for this population.

According to the CMIS, there are inherent differences in cancer information seeking among the general public and those who cope with a cancer diagnosis. Whereas the first type of information seeking is taking place “when someone is not confronted with the symptoms or disease, but may be mildly

concerned with prevention [21],” persons who seek information following diagnosis cope with a pressing and acute problem, which is “novel and fraught with emotional complications [21].” In view of this difference in information seeking that distinguishes those who seek CPI following cancer diagnosis from the general public, it is important to explore CPI seeking following cancer diagnosis. Use of the CMIS to examine use of the Internet for CPI seeking can shed more light on this important experience and its predictors.

### **Antecedents to Internet Use in Cancer Prevention Information Seeking**

Consistent with the CMIS, this study examines whether certain antecedents are related to seeking CPI online among cancer patients and their families who attend an ambulatory care oncology clinic at a National Cancer Institute (NCI)-designated minority-serving cancer center. The following factors were identified in past research that identified social determinants of CPI seeking online among the general population [36-39] and among those following diagnosis [40].

### ***Social Determinants of Online Cancer Prevention Information Seeking***

As previously mentioned, older adults, those with low SES or health status, and cancer survivors are less likely to seek health information online [25,41,42]. Ethnic minority cancer patients and their families have lower rates of accessing the Internet to seek cancer-related information compared to non-Hispanic whites [43]. According to national survey data, Latinos are considered the most digitally disadvantaged ethnic group in the United States [44]. In addition to having less access to the Internet, Latinos also hold different perceptions of its utility [45]. These disparities are related to inequalities in the propensity to seek CPI and lack of availability of Spanish language information resources [39]. Because English emerges as the most significant predictor of health information seeking among Latinos [46,47], it is important not to conflate Latino ethnicity with limited English proficiency and to examine experiences of monolingual Latino Spanish speakers as well as those who are fluent in English. Whereas national surveys document the digital divide among Latinos, telecommunication evidence suggests that Native American communities are the most digitally marginalized [48]. Because they are not included in most national surveys such as those conducted by the NCI [33,49-58] and the Pew Research Center [5,46,59,60], the impact of the digital divide on health information seeking among Native Americans remains largely unknown.

### ***Motivation to Seek Cancer Prevention Information***

In contrast to the role of social determinants of cancer health information-seeking behavior and the digital divide including race/ethnicity, education, income, and other demographic factors [33], not much is understood about the role of other psychosocial factors in seeking CPI online. A potential antecedent that can relate to CPI seeking online is motivation, an important variable in health information seeking [61]. Individuals’ motivation to be healthy leads to their interest in health issues and active engagement in information seeking, including selection of new information technologies [17]. Specifically, individuals’

prevention orientation, or health consciousness, is likely to influence online CPI seeking [62]. A construct of health orientation [17], prevention orientation measures the degree to which individuals feel that preventive behavior is important to them and worthy of engaging in. It is thought to be a personality construct that is influenced by specific health contexts [17]. Prevention orientation is related to different health behaviors including online support group participation [17,62] and CPI seeking among minority cancer patients and caregivers [13]. Research revealed that among the general population, health information seeking online is related to higher levels of health orientation [63]. However, it is unknown to what degree it is related to use of the Internet as a CPI carrier.

Following the CMIS [14,15] and previous studies that examined the manifestation of digital inequities in cancer information seeking as described above [22,25,64], the current research goal was to examine predictors of online CPI seeking among a diverse sample of people diagnosed with cancer and their families. Moreover, research indicated the importance of understanding individuals’ preferred sources, conceptualized as information sources they indicate they would use if faced by an information need as well as the information sources they actually use [33]. Therefore, this study aimed at understanding both correlates and predictors of preference for the Internet as a CPI carrier and differences among those who sought CPI online and those who sought it offline. To learn about eHealth CPI seeking among a diverse sample of people diagnosed with cancer and their families, the following research questions were posed:

RQ1: What are the factors associated with citing the Internet as a CPI carrier among cancer patients and their families?

RQ2: What are the factors associated with online and offline CPI seeking among cancer patients and their families?

## **Methods**

### **Overview**

This is a cross-sectional, correlational study using secondary data analysis of a study that examined CPI seeking among a diverse sample of people diagnosed with cancer and their families. Individuals were eligible to participate if they were 18 years of age or older and receiving care at a NCI-designated minority-serving cancer center in New Mexico (referred to as patients) or were accompanying a person receiving care (referred to as caregivers). The study was approved by the institutional review boards of the University of New Mexico and its cancer center, and informed consent was obtained from all participants.

### **Recruitment**

Direct recruitment approach [65,66] and the screening strategy for oversampling minority participants [67] were used to recruit hard-to-reach patient populations [65,66] in the context of ethnic-related health disparities [68-70]. Response rate was 91%. Patients and caregivers who declined cited reasons including lack of English/Spanish proficiency, emotional state, and lack of interest. Of the 252 individuals recruited, 105 were caregivers. The largest group (56/105, 53.3%) included spouses of patients, followed by adult children (29/105, 27.6%) and

other family members (20/105, 19.0%). One caregiver identified as a friend.

Participation included answering a survey in English (214/252, 84.9%) or in Spanish (38/252, 15.1%), according to participants' preference. A bilingual, bicultural research team member was available to answer questions and requests for clarification. Participants were offered to have the survey read by the

interviewer/research team member. A total of 54 participants preferred to have the survey read to them, and a team member read each question out loud, ensured that participants understood the questions, and filled in the participants' answers. Respondents received a \$10 gift card to a local grocery store as compensation for participation. Participants' demographic information is presented in [Table 1](#).

**Table 1.** Personal characteristics.

	N (%)
<b>Gender</b>	
Women	94 (37.3)
Men	157 (62.3)
<b>Patient/relative</b>	
Patient	144 (57.1)
Relative	108 (42.9)
<b>Marital status</b>	
Married/live with a partner	145 (57.5)
Not married	100 (39.7)
Missing	7 (2.8)
<b>Race/ethnicity</b>	
American Indian/Native American	17 (6.7)
Latino-Spanish speaking	36 (14.3)
Latino-English speaking	131 (52.0)
Other (African American & Asian)	10 (4.0)
Non-Hispanic white	58 (23.0)
<b>Education</b>	
Less than high school	50 (19.8)
High school graduate	59 (23.4)
Some college/training	83 (32.9)
College graduate	55 (21.8)
Missing	5 (2.0)
<b>Annual household income</b>	
<\$20,000	115 (45.6)
\$20,001-\$35,000	39 (15.5)
\$50,001-\$70,000	28 (11.1)
>\$70,001	29 (11.5)
Missing	3 (1.2)
<b>Medical insurance</b>	
Uninsured	48 (19.0)
Insured	202 (80.2)
Missing	
<b>Language of survey</b>	
English	214 (84.9)
Spanish	38 (15.1)

## Measures

### Antecedents

Sociodemographic questions pertained to gender, age, education, household income, marital status, and clinical information including self-reported health status. The following measures were used to examine perceptions and experiences that might influence CPI seeking online.

Behavioral-related measures consisted of prevention orientation, previous CPI seeking, past use of the Internet for CPI seeking, and health information-seeking experiences. All the survey measures have been tested in prior research and were reliable and valid, as described in the following sections.

Prevention orientation related to respondents' motivation to engage in healthy behaviors including health information seeking. It was measured by the prevention orientation subscale, which was previously tested and validated [17] and comprises five items. Examples include "Living life in the best possible health is very important to me" and "Eating right, exercising, and taking preventive measures will keep me healthy for life." Responses were measured on a scale ranging from 1 to 5 with 1 representing *strongly disagree* and 5 representing *strongly agree*. The Cronbach alpha for this measure was .88.

Past CPI-seeking behavior was measured using Health Information Trends Survey (HINTS) items [33,52]. Participants were asked whether they have looked for information about cancer prevention: "Have you ever looked for information about cancer prevention?" and "When was the last time you searched for information about how to prevent cancer?" Responses to the second question were coded as *prior CPI seeking* when respondents indicated a time when they sought CPI and *no prior CPI seeking* when they did not indicate such search. Cronbach alpha was assessed at .98.

Health information-seeking experiences were measured by examining respondents' evaluation of the difficulty of CPI seeking. The 6 HINTS items included statements such as "It took a lot of effort to get the information that I needed" and "The information I found was too hard to understand." This scale reliability has been previously tested [71] and determined to have a Cronbach alpha of .84.

### Outcome Measures

Selection of the Internet as a CPI carrier was the primary outcome measure. Following the HINTS instrument that examined cancer information seeking [72], we asked all respondents where they would go first for information about cancer prevention and asked those who previously sought CPI to indicate the information sources they used [72]. Responses to these open-ended questions were coded as a binary variable that referred to whether respondents listed the Internet as a CPI source or not. The coders were two doctoral research assistants, and they met for one training session that consisted of directions on coding the responses as *online* when participants' referenced the Internet. Such references included listing specific websites or mentioning the Internet as a general information source for CPI. Coders were instructed to code entries as *offline* when no reference to online sources was mentioned. Following this

session, they coded the responses individually and met again to compare their results. Inter-coder reliability was computed at 98%; the Krippendorff alpha was .96.

### Analysis

Analysis was conducted using SPSS version 22 software (IBM Corp). First, to determine the sample's demographic characteristics, chi-square tests were used to examine categorical variables and *t* tests were used to examine continuous variables. The main outcome of the analysis of the first research question was whether respondents cited the Internet as a CPI carrier they would turn to if faced with a CPI need. These results are listed in [Multimedia Appendix 1](#).

Missing values ranged from 0% to 5% in all variables, so listwise deletion was used for categorical variables and mean substitution was used for continuous variables. The final logistic model indicates those variables remaining statistically significant at the .05 level and is presented in [Multimedia Appendix 1](#).

The main outcome in answering the second research question included actual use of the Internet by respondents who sought CPI. Analysis of differences between online and offline CPI seekers was conducted using the *t* test and chi-square test as indicated.

## Results

### Selecting the Internet As a Cancer Prevention Information Carrier

To answer the first research question, which examined factors that distinguished respondents who cited the Internet as an information carrier they would turn to if faced with a CPI need from those who did not, analysis of the answers by all respondents to the survey ( $n=252$ ) was performed. Less than half (112/252, 44.4%) of respondents said that if faced with the need to seek CPI, they would seek this information online. Differences between respondents who cited the Internet as a CPI carrier and those who did not are described in the subsequent section and detailed in [Multimedia Appendix 1](#).

### Demographic Variables

Women (74/157, 47.0%) and men (38/93, 41.0%) did not differ significantly in citing the Internet as a CPI source, as indicated in the chi-square test ( $\chi^2_{1,N=251}=0.93, P=.36$ ). Family members (56/108, 52.0%) were more likely than patients (44/143, 39.0%) to report that they would use the Internet for CPI, with a chi-square test showing that this difference was statistically significant ( $\chi^2_{1,N=251}=4.01, P<.05$ ). Differences in marital status of respondents who cited the Internet as a CPI source (71/147, 48.1%) and those who did not (39/100, 39.0%) were not statistically significant as indicated in chi-square analysis ( $\chi^2_{1,N=247}=2.08, P=.15$ ).

Analysis of ethnic differences in citing the Internet as a CPI source revealed that non-Latino whites (35/78, 60%), followed by Latinos who answered the survey in English (64/128, 50.0%) were the most likely to select the Internet as a CPI source, compared to about one-third of Native Americans (6/17) and African Americans and Asians (3/10) and only 10% of Latinos



who filled in the survey in Spanish (4/38). Chi-square analysis revealed that ethnic differences in selecting Internet for CPI seeking were statistically significant ( $\chi^2_{4,N=251}=26.64, P=.00$ ).

Level of education attained was related to respondents' indication that they would use online CPI sources. Whereas only one-tenth (5/52) of those who did not graduate high school cited the Internet as a CPI carrier they would turn to, almost half (26/59, 44%) of high school graduates, over half (43/83, 52%) of those with some post high school education, and two-thirds (37/56, 67%) of college graduate respondents would use online CPI sources. Chi-square analysis revealed that differences in educational attainment between those selecting Internet for future CPI seeking and those who did not were statistically significant ( $\chi^2_{3,N=249}=38.96, P=.00$ ).

Income was also related to citing the Internet as a CPI source. Less than one-third (34/117) of those who have annual household income of less than \$20,000 said they would use the Internet for CPI seeking, but 71% of those in the highest income bracket in this study would seek CPI on the Internet (27/38). Additional differences are presented in [Multimedia Appendix 1](#).

Differences in income levels in citing the Internet as a CPI source were statistically significant ( $\chi^2_{4,N=251}=28.26, P=.00$ ). Respondents with medical insurance were more likely to cite the Internet as a CPI carrier (47.5%) than the uninsured (29.2%). Chi-square testing showed that this difference was statistically significant ( $\chi^2_{1,N=250}=5.30, P<.05$ ). Almost half of insured respondents (96/199) cited the Internet as a CPI source compared to 29% of uninsured respondents (14/48). Chi-square test revealed that this difference was statistically significant ( $\chi^2_{1,N=250}=5.30, P<.05$ ).

Language of survey was significantly associated with citing the Internet as a CPI carrier. Half of participants (108/213) who answered the survey in English cited the Internet as a CPI carrier they would turn to compared to only a tenth of respondents who answered in Spanish (4/38). The chi-square test showed that the difference was significant ( $\chi^2_{1,N=247}=5.70, P<.05$ ).

Participants who cited the Internet as a CPI source were significantly younger (mean 51.2 years [SD 12.56]) than those who would not use the Internet for CPI seeking (mean 55.8 [SD 12.99],  $t_{249}=-2.82, P<.01$ ). Time since diagnosis of those who cited the Internet as a CPI sources (mean 32.09 months [SD 4.24]) and of those who did not cite the Internet (mean 29.40 [SD 38.45]) was not statistically significant ( $t_{241}=0.52, P=.60$ ).

Individuals who cited the Internet as a CPI source had better self-reported health (mean 2.73 [SD 1.00]), compared to those who did not think they would use the Internet as a CPI source (mean 3.18 [SD 1.01]). A *t* test revealed that these differences were statistically significant ( $t_{248}=-3.52, P<.01$ ). Individuals who cited the Internet as a CPI carrier had lower levels of prevention orientation (mean 4.17 [SD 0.54]) compared to those who would not search CPI online (mean 4.34). These differences were statistically significant ( $t_{247}=-3.41, P<.01$ ).

Almost half of participants who sought CPI in the past believed that they would use the Internet for CPI seeking if faced with CPI need compared to 41% of those who did not previously sought CPI ( $n=46/113$ ), a difference that did not reach statistical significance as indicated in chi square analysis ( $\chi^2_{1,N=249}=1.48, P=.25$ ).

Participants who used the Internet in the past for CPI seeking were more likely to cite the Internet as a CPI carrier compared to those who did not previously use the Internet for CPI seeking. Only 28% (18/58) of those who did not use the Internet in the past to seek CPI believed that they would use it in the future, whereas a majority (46/64, 72%) of those who sought CPI online in the past responded that they would use it in the future. Chi-square analysis revealed that these differences were statistically significant ( $\chi^2_{(1,N=246)}=16.55, P=.00$ ).

### Predictors of Selecting the Internet for Cancer Prevention Information Seeking

Logistic regression analysis was conducted to answer the first research question and determine which independent variables predicted citing the Internet as a CPI carrier. Included were variables significantly related to differences in citing the Internet as a CPI carrier in the previous analysis (status as patient or caregiver, race/ethnicity, education, age, health status, and prevention orientation). Income and medical insurance were not included due to multicollinearity. A test of the full model against a constant only model was statistically significant, indicating that the predictors as a set reliably distinguished between participants who cited the Internet as a CPI carrier they would turn to and those who did not ( $\chi^2_{8,N=247}=71.7, P=.00$ , Nagelkerke  $R^2=.319$ ).

Education, ethnicity, age, and prevention orientation made significant contributions to the model ( $P<.05$ ). Specifically, the odds of citing the Internet as a CPI carrier are lower with age. For each year increase in age, participants are 3% less likely to use the Internet for CPI seeking ( $P=.011$ ). Education also contributed significantly to the model. Compared to college graduates, respondents who did not complete high school were 11.75 times less likely to cite the Internet as a CPI carrier ( $P=.00$ ), and those with a high school education were three times (2.99,  $P=.015$ ) less likely to cite the Internet as a CPI carrier compared to college graduates. The odds that a Spanish speaker would cite the Internet as a CPI carrier were one-fifth (22%) of that of non-Hispanic whites ( $P=.032$ ) and about one-quarter (26%) of English-speaking Latinos ( $P=.036$ ). Other ethnic/racial differences were not significant. Additionally, with each one point increase on the prevention orientation scale, respondents were 1.83 times less likely to cite online CPI seeking ( $P=.05$ ). Other variables did not contribute to prediction of CPI in a statistically significant way. The results are presented in [Multimedia Appendix 2](#).

### Actual Use of the Internet for Cancer Prevention Information Seeking

Of the 252 respondents to the survey, more than half (133, 52.8%) indicated they have previously sought CPI. These individuals were asked where they sought CPI, and their

responses were analyzed to understand the characteristics of online CPI seekers, defined as those who used the Internet to seek CPI, versus offline CPI seekers, those who used only non-Internet CPI sources. These differences are reported in [Multimedia Appendix 1](#). As indicated in the appendix, most CPI seekers (75/133, 56.3%) used the Internet to search for CPI.

The majority of women who sought CPI used the Internet (55/85, 65%) in contrast to a minority of men (20/48, 42%). These differences were statistically significant as indicated in chi-square analysis ( $\chi^2_{1,N=133}=6.62, P<.05$ ). However, family members who sought CPI were not significantly more likely to use the Internet (37/61, 61%) compared to patients (38/72, 53%) ( $\chi^2_{1,N=133}=0.83, P=.38$ ). Similarly, marital status was not related to CPI seeking online in a statistically significant way ( $\chi^2_{1,N=133}=1.08, P=.37$ ).

Examination of the relationship between ethnic identity and online CPI seeking indicated that non-Latino white CPI seekers were most likely to use the Internet (26/39, 67%), followed by Latinos who completed the survey in English (39/56, 59%). In comparison, a minority of Latinos who responded in Spanish (5/13, 39%), Native Americans (3/9, 33%) and African Americans/Asians (2/6, 33%) who sought CPI did so online. Chi-square analysis revealed that ethnic differences among online and offline CPI seekers did not reach statistical significance ( $\chi^2_{4,N=133}=6.81, P=.146$ ).

Online information seeking was positively associated with educational attainment. Among online CPI seekers, only one had less than high school education (7%). A minority of high school graduates sought CPI online (9/23, 39%). In contrast, a majority of participants with some post high school training or education (37/57, 65%) and of those who were college graduates (38/56, 71%) were online seekers. Chi-square analysis indicated that these differences were statistically significant ( $\chi^2_{3,N=132}=21.56, P=.00$ ).

Online information seeking was positively associated with annual household income. A minority (21/54, 39%) of CPI seekers with an annual household income less than \$20,000 used the Internet for CPI seeking compared to a vast majority (23/27, 85%) of CPI seekers with an annual household income above \$70,000. Chi-square analysis revealed that these differences were statistically significant ( $\chi^2_{4,N=132}=16.05, P<.01$ ). This information and information about additional income brackets is presented in [Multimedia Appendix 1](#). In addition, medically insured and uninsured CPI seekers were equally likely to seek CPI online, with 56.5% of CPI seekers using the Internet regardless of their medical insurance status ( $\chi^2_{1,N=133}=0.00, P=1.00$ ).

Although the majority of CPI seekers who answered the survey in English were online CPI seekers (70/120, 58.3%) compared to a minority of respondents who filled in the survey in Spanish (5/13, 39%), the results did not reach statistical significance ( $\chi^2_{1,N=133}=1.88, P=.24$ ). Online information seekers were younger (mean 52.7 [SD 12.30]) than offline CPI seekers (mean 56 [SD 11.90]), but a *t* test indicated that these results did not

reach statistical significance ( $t_{133}=-1.55, P=.123$ ). Time since diagnosis was longer (mean 32.9 [SD 38.22]) among online CPI seekers compared to offline CPI seekers (mean 26.72 [SD 35.22]). These results were not statistically significant ( $t_{133}=0.948, P=.345$ ). An additional factor that differed between online CPI seekers and offline CPI seekers was health status, with online information seekers reporting better health (mean 2.6 [SD 0.94]) compared to offline CPI seekers (mean 3.2 [SD 0.93]). This difference was statistically significant ( $t_{133}=3.52, P<.01$ ).

The analysis revealed that offline CPI seekers had higher levels of prevention orientation (mean 4.42 [SD 0.44]) compared to online CPI seekers (mean 4.27 [SD 0.50]), and this difference was statistically significant ( $t_{130}=-1.80, P<.05$ ). Finally, offline and online CPI seekers reported the same levels of difficulty in accessing information (mean 2.8 [SD 0.94 and 0.82, respectively],  $t_{130}=-0.04, P=.97$ ). The results are presented in [Multimedia Appendix 1](#).

## Discussion

### Principal Findings

The current study applied the CMIS to expand the knowledge on the digital divide in specific clinical settings [25] by examining eHealth use for CPI seeking among an ethnically and socioeconomically diverse sample of people diagnosed with cancer and their caregivers who attend a minority-serving academic cancer center in New Mexico. Borrowing from the CMIS framework, this study examined factors related to social determinants of health and motivation as potential antecedents to CPI seeking. According to the CMIS, certain antecedents determine the type of information sources and channels used as well as overall information behavior. The findings revealed the importance of social determinants as antecedents to CPI eHealth seeking in this population. Consistent with patterns identified in past research on health information behavior and the digital divide [22,25], certain demographic factors, including race/ethnicity, educational attainment, household income, age, gender, and health status are related to the propensity to seek cancer information online. In the regression model, younger age, higher levels of education, being non-Hispanic white or English-speaking Hispanic compared to Spanish-speaking Latino, and reporting better health status were significant predictors of CPI eHealth seeking. These factors have been shown to predict disparities following cancer diagnosis in other cancer-related topics [1,6]. Therefore, these findings demonstrate how disparities in use of the Internet are merely one factor within an overall inequity in health information seeking and contribute to the literature that documents how the “double divide” is blocking those who need this information the most from accessing it.

Further, this study contributes to past research that suggested that the CMIS is a useful framework for understanding cancer patients' information source selection and usage on the cancer continuum [24]. This model was originally applied to selection of mass media sources [14], but a growing body of research applies this framework to understand use of online cancer



information sources [24,31]. The current study reveals the importance and utility of integrating factors related to social determinants to the CMIS in exploring cancer information behavior of diverse populations. An additional strength of the CMIS is its structural flexibility. Applying the CMIS in diverse contexts allows for examination of specific predictors of information behavior. The model highlights the importance of incorporating a variety of factors to account for information seeking across different contexts and the fact that the specific patterns of relationships among variables in the model are contingent on the context [21]. Therefore, the current findings point at the importance of examining CPI seeking of underserved cancer patients and their families rather than assume that their information seeking parallels those of the general public. For instance, in contrast to studies utilizing CMIS that reported no significant correlation between antecedents and characteristics of cancer information sources among the general public [14], this study documented the importance of social determinants in predicting online CPI.

Applying the CMIS framework also led to a deeper understanding of the differences between actual CPI versus hypothetical selection of sources. Clearly, not all individuals are able to seek information or to enact on their preferred information sources. Past research documented some discrepancies between cancer information sources that individuals indicate they would select for actual use [73]. This study examined information preferences along with self-reports of actual use. Participants' perceptions of whether they would use the Internet for CPI seeking were largely consistent with reports of use among CPI seekers, with some exceptions. Ethnicity, income, education, and health status were related both to the rates of citing the Internet as a potential CPI source and reports of its use among CPI seekers. However, some differences were noted. First, although men and women did not differ in a statistically significant way in citing the Internet as a CPI source they would use, women who sought CPI were significantly more likely to use the Internet than men who sought CPI. In addition, although having medical insurance was related to citing eHealth as a CPI source, online and offline CPI seekers were equally likely to have medical insurance. Similarly, family members were more likely to cite the Internet as a CPI source, but family members did not differ significantly from patients choosing to be online versus offline CPI seekers. These findings point at the importance of examining information source preferences as well as actual use.

Exploring different psychosocial factors as predictors of information seeking is an important part of studies utilizing the CMIS [14,15] as well as other research of cancer information behavior. An intriguing finding in the current study relates to the negative correlation between prevention orientation and online CPI seeking. In other words, participants who indicated use of the Internet for CPI seeking scored lower on prevention orientation than those who did not report Internet use. This finding conflicts with past studies that indicated the importance of psychosocial factors on health information behavior following cancer diagnosis [34]. Prevention orientation was positively associated in past studies with seeking CPI even after controlling for other factors [13]. This finding further underscores the

importance of considering both context and specific predictors because certain psychosocial factors might be associated differently with certain cancer information behaviors based on the context and content of the information and the information sources utilized. Future studies and in particular studies using a long attitudinal design should examine whether online CPI seeking increases skepticism regarding the importance of prevention and how it might influence cancer prevention behavior such as diet, exercise, and screening practices.

These findings also contribute new insights into the dynamics of the digital divide. Age was a key factor that discriminated between those citing the Internet as a CPI source and those who did not in both bi-variate and multivariate analyses. However, this difference is smaller than previously reported. Specifically, persons who cited the Internet as CPI carrier were on average only 4 years younger than those who did not compared to 10 years' difference reported in past studies [25]. Moreover, difference in age among online and offline CPI seekers was smaller and did not reach statistical significance. This finding is consistent with the prediction that age differences in Internet use would decline over time as older adults increasingly use the Internet [25]. The findings indicate a trend toward persistence of the digital divide in CPI seeking because respondents who previously sought CPI online were more likely to indicate that they would seek CPI online in the future. Future studies should explore the role of intervention in decreasing the digital divide and the impact of such intervention on CPI behavior and prevention-related behaviors such as participation in screening and lifestyle changes.

The results also revealed better self-reported health status among those who cited eHealth as a CPI source versus those who did not. Previous research reported conflicting findings regarding the relationship between health status and online health information seeking [74,75]. It is possible that lower health status is related to seeking treatment information online whereas those who feel healthier focus more resources on CPI seeking. Alternatively, it is possible that those with better health have better access to the Internet or that respondents who seek CPI online are better able to maintain their health. This relationship should be explored in future studies using larger cohorts and following them over time.

### Practical Implications

These disparities in CPI seeking online are particularly concerning because comprehensive cancer centers charged with targeting communities with prevention initiatives do not have overarching strategies to disseminate CPI to cancer survivors and their families [76]. Researchers reported that when barriers to access are removed, the benefits of online information seeking are extended to individuals from underserved communities [24]. Therefore, programs should be designed that consider CPI sources available to the target audiences. While many patients and family members turn to the Internet to seek this information, those who are disfranchised and need this information the most are least likely to receive it.

Since interventions are likely to be conducted in specific geographic communities [77], it is essential that research incorporates understanding of CPI seeking among clinical

populations in certain locales that necessitate effective recruitment strategies. In contrast to past research that used nationally or state representative phone-based [25,33,49,51,52,54,55,57,58] or mailed surveys [30,34,58], this study employed direct recruitment methods in a specific geographic community [65,66], an approach that has been shown to include individuals from underserved communities [70,78]. This approach facilitated a high response rate among this hard-to-reach population of patients and caregivers. Future interventions should apply similar recruitment methods and measure their effectiveness in engaging individuals.

### Limitations and Future Research

Due to this study's focus on a specific geographical region, its sample consisted entirely of patients and caregivers who attend a minority-serving cancer center in New Mexico. Whereas this focus enriches understanding of specific communities and allows for design of community-based interventions, this sample may not be representative of cancer patients from other regions along certain dimensions, such as the health and digital disparities they experience. Despite sample size that exceeded the initial power analysis to detect differences in this sample, the large proportion of ethnic minority respondents who did not seek CPI likely rendered certain differences between online and offline CPI seekers statistically insignificant. This limitation is concerning as Native Americans are underserved and underresearched in both digital access and health information research. The current findings point to the disparities experienced by Native American respondents, and more research

is needed to provide insight on actual use of eHealth for CPI seeking among Native American cancer patients and their families.

Further, this study relied exclusively on self-reported data, which have documented shortcomings including recall bias and social desirability influences. Triangulation of data revealed consistency in participants' accounts of their experiences in information seeking, but ultimately the study reports on respondents' perceptions only. Future research should examine the association between CPI-seeking behavior and additional factors that were not explored in this or in previous studies. For instance, this study did not focus on comparisons between CPI seeking among individuals who cope with different types of cancer, which is associated with differences in seeking general cancer information among patients [34] and might also be related to differences in CPI seeking. In addition, Internet access was not measured in a secondary data analysis; therefore, the reasons behind the reported disparities in eHealth CPI seeking are unknown. Future studies should examine Internet access as well as additional factors that might influence eHealth use including digital and health literacies. This study followed past research that examined disparities in information seeking in binary terms [22,25], a methodological choice that introduced an additional limitation. The digital divide consists of a spectrum of inequalities in use of the Internet [5], and research should examine the nuances of CPI seeking and use of eHealth as well as the relationship between CPI seeking, the specific types of CPI sought, sources used, and outcomes such as knowledge and prevention practices.

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### Conflicts of Interest

None declared.

### Multimedia Appendix 1

Online and offline CPI seeking among cancer patients and relatives.

[[PDF File \(Adobe PDF File\), 38KB - cancer\\_v2i1e2\\_app1.pdf](#)]

### Multimedia Appendix 2

Logistic regression analysis predicting digital divide in citing the Internet as CPI carrier among cancer patients and relatives.

[[PDF File \(Adobe PDF File\), 85KB - cancer\\_v2i1e2\\_app2.pdf](#)]

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## Abbreviations

**CMIS:** comprehensive model of information seeking

**CPI:** cancer prevention information

**HINTS:** Health Information Trends Survey

**NCI:** National Cancer Institute

**SES:** social economic status

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Original Paper

# Interest in Health Behavior Intervention Delivery Modalities Among Cancer Survivors: A Cross-Sectional Study

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## Abstract

**Background:** Effective, broad-reaching channels are important for the delivery of health behavior interventions in order to meet the needs of the growing population of cancer survivors in the United States. New technology presents opportunities to increase the reach of health behavior change interventions and therefore their overall impact. However, evidence suggests that older adults may be slower in their adoption of these technologies than the general population. Survivors' interest for more traditional channels of delivery (eg, clinic) versus new technology-based channels (eg, smartphones) may depend on a variety of factors, including demographics, current health status, and the behavior requiring intervention.

**Objective:** The aim of this study was to determine the factors that predict cancer survivors' interest in new technology-based health behavior intervention modalities versus traditional modalities.

**Methods:** Surveys were mailed to 1871 survivors of breast, prostate, and colorectal cancer. Participants' demographics, diet and physical activity behaviors, interest in health behavior interventions, and interest in intervention delivery modalities were collected. Using path analysis, we explored the relationship between four intervention modality variables (ie, clinic, telephone, computer, and smartphone) and potential predictors of modality interest.

**Results:** In total, 1053 respondents to the survey (56.3% response rate); 847 provided complete data for this analysis. Delivery channel interest was highest for computer-based interventions (236/847, 27.9% very/extremely interested) and lowest for smartphone-based interventions (73/847, 8.6%), with interest in clinic-based (147/847, 17.3%) and telephone-delivered (143/847, 16.9%) falling in between. Use of other technology platforms, such as Web cameras and social networking sites, was positively predictive of interest in technology-based delivery channels. Older survivors were less likely to report interest in smartphone-based diet interventions. Physical activity, fruit and vegetable consumption, weight status, and age moderated relationships between interest in targeted intervention behavior and modality.

**Conclusions:** This study identified several predictors of survivor interest in various health behavior intervention delivery modalities. Overall, computer-based interventions were found to be most acceptable, while smartphones were the least. Factors related to survivors' current technology use and health status play a role in their interest for technology-based intervention versus more traditional delivery channels. Future health behavior change research in this population should consider participants' demographic, clinical, and lifestyle characteristics when selecting a delivery channel. Furthermore, current health behavior interventions for older cancer survivors may be best delivered over the Internet. Smartphone interventions may be feasible in the future following further adoption and familiarization by this particular population.

**KEYWORDS**

cancer survivor; technology; smartphone; behavioral intervention; physical activity; diet

## Introduction

Currently, there are an estimated 14.5 million cancer survivors in the United States; they comprise approximately 4% of the population [1]. This number has nearly doubled in the past 15 years [2] and is projected to increase by another 4 million over the next decade [1]. This growing number of cancer survivors has brought to the forefront a host of physiological (eg, lymphedema [3], sexual dysfunction [4], and fatigue [5]) and psychological (eg, anxiety [6] and depression [7,8]) sequelae that follow a cancer diagnosis and its treatment. These consequences and other unique health aspects of surviving cancer increase patients' risk for health conditions [9]. As an example, second primary cancers among survivors account for 16% of all incident cancer diagnoses and can be attributed to a variety of factors, including both treatment-related issues and lifestyle behaviors [10-12]. Despite this heightened risk, the incidence of risky health behaviors remains high in this population. Data collected in 2009 from the Behavioral Risk Factor Surveillance System indicate that 15.1% of cancer survivors are smokers, 27.5% are obese, and 31.5% do not engage in any form of leisure-time physical activity [13]. More recent estimates indicate that over 30% of adult cancer survivors are obese [14]. There is a clear need for effective behavior change interventions for this population.

The ultimate public health impact of any behavior change intervention is influenced by intervention efficacy as well as reach, adoption, implementation, and maintenance [15]. Interventions that use new technologies, such as smartphones or Web-based tools, have greatly increased reach compared to traditional face-to-face interventions [16-18]. Though technology-based interventions have demonstrated efficacy [19-21], they are typically implemented in younger, healthier populations, rather than older adults with cancer. About 60% of cancer survivors are over the age of 65 years [1]—an age group whose adoption of technology is growing but still lags behind that of the general population [22]. Previous research has shown mixed findings for survivor preferences between more traditional delivery modalities (eg, face to face or telephone) versus technology-based platforms (eg, computer or phone), depending on the behavioral target of the intervention (eg, physical activity or diet) and other demographic and health variables [23,24]. For example, Eakin et al found that breast cancer survivors participating in their telephone-based exercise intervention were more likely to report interest in the same intervention being delivered face to face versus the Internet (83% vs 76%) [25]. Age has also been shown to be predictive of delivery preference [26] and use [27,28]. Increasingly, specific information is needed to understand cancer survivors' preferences for intervention modalities in order to design programs that produce the greatest public health impact. This need is particularly important given the rapid changes in broad-reaching technology today.

The purpose of this study was to investigate cancer survivors' interest in four health behavior intervention delivery modalities and to identify the factors that are predictive of interest in new technology (ie, interventions delivered via computers or smartphones) and traditional channels of delivery (ie, interventions that are clinic or telephone-based). Specifically, we were interested in whether interest in different health behavior interventions predicted interest in intervention delivery modality while controlling for demographic characteristics and current health behavior status.

## Methods

### Recruitment

The data in this study were collected in 2010 via a cross-sectional survey mailed to 1917 early-stage breast, colorectal, and prostate cancer survivors [29]. All survey recipients were 18 years of age or older and had completed their primary cancer treatment at the University of Texas MD Anderson Cancer Center (Houston, Texas) within the previous 20 years. We employed a stratified sampling plan to assure representation across the cancer continuum and time from diagnosis (ie, 0-6 months, 6-12 months, 1-5 years, and 5+ years). Patients were selected who had no history of other cancers (with the exception of non-melanoma skin cancer), had no evidence of metastatic disease at the time of recruitment, and who were residents of Harris County or adjacent counties in Southeastern Texas. A reminder postcard and up to three follow-up mailings of the survey were mailed to non-respondents.

### Measures

The survey was meant to inform future planning for lifestyle interventions for cancer survivors and included questions about current health behavior practices (eg, diet and physical activity) and the level of interest in lifestyle interventions and delivery preference. Demographic data regarding patients' education and marital status were collected. Body Mass Index (BMI) was calculated based on participants' reported height and weight. Participants were also asked yes/no questions regarding their access to and use of computers, social networking sites, and Web cameras. Participants' daily consumption of fruits and vegetables was assessed using the National Cancer Institute's Multifactor Screener, which assesses patients' dietary habits and intake of 16 different food types in the previous 30 days [30]. Physical activity was measured using a 3-item modified version of the Godin Leisure Time Exercise Questionnaire [31]. This measure produces a weekly leisure activity score based on participants' weekly frequency of strenuous, moderate, and light physical activity. In addition, participants were asked to rank their interest in learning more about certain health behavior topics (ie, exercise, nutrition, and weight control) on a 5-point Likert scale, ranging from "extremely interested" to "not at all interested." Finally, participants were asked to rate their interest in receiving this information through a number of different

modalities, including clinic-based programs (classes), telephone calls with a health counselor, computer-based programs (eg, using the Internet or a Web camera), and smartphones (eg, iPhone). Again, participants were asked to rate their interest on the Likert scale described above.

### Statistical Analyses

All analyses were conducted using Mplus software version 7.2 [32]. Full information maximum likelihood was used to estimate missing data. In addition, *t* tests and chi-square analyses were used to compare demographic information between those with and without missing data. Given the large sample size for this study, path analysis was used to account for correlations between exogenous and endogenous variables [33]. The four intervention modality variables (ie, clinic, telephone, computer, and smartphone) were regressed onto 14 predictors and 13 interaction terms. The predictor variables consisted of interest in different types of interventions (eg, healthy eating, weight control, and exercise), demographic variables, and diet and physical activity. Interaction terms were created by

mean-centering the hypothesized lower-order continuous predictors (eg, age, BMI, physical activity, and fruit and vegetable consumption) and multiplying them by each of the four intervention modality variables (ie, clinic, telephone, computer, and smartphone). Standard errors were estimated via bias-corrected bootstrap with 2000 bootstrap samples, which has been shown to increase power and decrease bias due to non-normally distributed outcomes [34].

### Results

A total of 1917 patients were identified for this survey study; of these, 37 had incorrect addresses and nine were deceased. Out of a possible sample of 1871 patients, 1053 responded to the survey, for a response rate of 56.3%. From these responses, 847 were included in the analysis (206 were excluded because they were missing data for categorical exogenous variables, which cannot be estimated by the full maximum likelihood method). Survey respondents' characteristics are reported in Table 1.

**Table 1.** Participant characteristics.

Demographic characteristic	Participant data (N=847)
<b>Cancer type, n (%)</b>	
Breast	429 (50.7)
Colorectal	86 (10.2)
Prostate	332 (39.2)
Mean years since diagnosis, mean (SD)	4.6 (3.1)
Age in years, mean (SD)	61.7 (11.1)
Sex, female, n (%)	471 (55.6)
BMI (kg/m <sup>2</sup> ), mean (SD)	27.8 (5.5)
Mean daily fruit and vegetable servings, mean (SD)	5.1 (2.0)
<b>Education, n (%)</b>	
Less than 6 <sup>th</sup> grade	14 (1.7)
6 <sup>th</sup> -11 <sup>th</sup> grade	42 (5.0)
High school graduate	113 (13.3)
Trade/Tech/Vocational/Some college	204 (24.1)
College graduate/post grad	474 (56.0)
<b>Physical activity, median minutes/week</b>	
Light	27.5
Moderate	30
Strenuous	0
<b>Technology use and access, n (%)</b>	
Own a computer	751 (88.7)
Access to Internet in home	528 (62.3)
Use social networking sites	257 (30.3)
High-speed Internet in home	493 (58.2)
Use a Web cam	200 (23.6)

The mean age of participants was 61.7 (SD 11.1) years, with 55.6% (471/847) being female. The mean reported time since a patient's primary cancer diagnosis was 4.6 (SD 3.1) years. The average BMI for this sample was 27.8 (overweight), with an average of 5.1 reported fruit and vegetable servings per day, and a median of 30 reported minutes of moderate physical activity per week. Analyses were conducted to compare basic demographic variables between participants who were excluded because of missing data and included participants. No significant differences were detected for sex, cancer site, years since diagnosis, BMI, fruit and vegetable consumption, and physical

activity. However, a significant difference was found for age: the mean age of those with missing data was 67.2 years, and the mean age of those with no missing data was 61.7 years ( $P<.001$ ). Since age was included in the full information maximum likelihood model used to estimate missing data, the results are unlikely to be biased [35].

Survivor interest in intervention types and modalities is presented in Table 2. Most notably, participants' interest in smartphone-based interventions was the lowest, with 69% "not at all interested," while computer-based interventions received the highest percentage of "very" and "extremely" interested.

**Table 2.** Percentage of participants interested in intervention types and delivery modalities.

Interest variable	Not at all interested, %	A little interested, %	Somewhat interested, %	Very interested, %	Extremely interested, %
<b>Intervention type</b>					
Getting in shape (exercise)	18.4	14.5	20.7	26.2	20.2
Eating better to stay healthy	16.2	11.1	18.1	29.4	25.3
Weight control	22.7	12.2	15.5	25.9	23.8
<b>Delivery modality</b>					
Clinic-based program	48.4	13.8	15.3	9.3	8.0
Telephone calls with a health counselor	49.2	16.1	12.6	9.6	7.3
Computer-based program	36.6	10.2	20.7	17.2	10.7
Smartphone	68.9	6.6	6.8	4.1	4.5

Table 3 shows the results for each regression model. The results of the regression analysis of interest in clinic-based interventions indicated that there were two statistically significant predictors: (1) fruit and vegetable consumption and (2) the interaction term between BMI and interest in getting in shape (exercise). Probing this interaction revealed that all simple slopes were positive and significant ( $B=1.158$ ,  $P=.002$ ;  $B=1.032$ ,  $P<.001$ ; and  $B=0.906$ ,

$P<.001$ , for one standard deviation above the mean BMI, the mean BMI, and one standard deviation below the mean BMI, respectively), indicating that as BMI increased, the relationship between interest in getting in shape and interest in a clinic-based (ie, face-to-face) intervention was stronger. Figure 1 shows this interaction.

**Table 3.** Predictors of each regression of intervention modality and  $R^2$  in each model.

Predictor	Intervention type, unstandardized beta coefficient (standard error)			
	Clinic	Telephone	Computer	Smartphone
<b>Demographics</b>				
Age	-0.006 (0.004)	-0.002 (0.004)	-0.004 (0.004)	-0.021 (0.004) <sup>c</sup>
BMI	-0.001 (0.008)	-0.005 (0.008)	0.006 (0.008)	-0.009 (0.007)
Sex	0.123 (0.238)	0.106 (0.259)	-0.271 (0.253)	-0.009 (0.211)
Cancer site	-0.210 (0.124)	-0.124 (0.134)	0.078 (0.131)	0.027 (0.111)
Education	0.055 (0.048)	-0.036 (0.051)	0.095 (0.050)	0.045 (0.042)
<b>Technology use and access</b>				
Have computer	-0.049 (0.151)	-0.342 (0.167) <sup>a</sup>	0.596 (0.150) <sup>c</sup>	-0.316 (0.139) <sup>a</sup>
Have access to Internet	-0.045 (0.033)	0.006 (0.032)	-0.018 (0.032)	0.024 (0.032)
Use social networking sites	0.107 (0.100)	0.047 (0.100)	0.392 (0.100) <sup>c</sup>	0.184 (0.094) <sup>a</sup>
Use Web camera	0.100 (0.100)	0.050 (0.104)	0.287 (0.097) <sup>b</sup>	0.397 (0.103) <sup>c</sup>
<b>Behavioral goals</b>				
Getting in shape (exercise)	0.395 (0.057) <sup>c</sup>	0.231 (0.063) <sup>c</sup>	0.249 (0.068)	0.092 (0.053)
Eating better to stay healthy	0.070 (0.051)	0.152 (0.064) <sup>a</sup>	0.334 (0.067) <sup>c</sup>	0.055 (0.054)
Weight control	0.071 (0.055)	0.151 (0.054) <sup>b</sup>	-0.050 (0.062)	0.089 (0.050)
<b>Current behavior</b>				
Godin score, physical activity (PA)	0.002 (0.002)	0.002 (0.002)	0.003 (0.002)	0.004 (0.002) <sup>a</sup>
Daily servings of fruits and vegetables (FV)	0.045 (0.019) <sup>a</sup>	0.043 (0.019) <sup>a</sup>	0.054 (0.019) <sup>b</sup>	0.014 (0.019)
Age × PA	<0.001 (<0.001)	<0.001 (<0.001)	<0.001 (<0.001)	<0.001 (<0.001)
Age × getting in shape (exercise)	-0.003 (0.005)	0.005 (0.006)	0.001 (0.006)	-0.001 (0.005)
Age × eating better to stay healthy	-0.007 (0.004)	-0.006 (0.006)	-0.007 (0.004)	-0.010 (0.004) <sup>b</sup>
Age × weight control	0.005 (0.004)	-0.002 (0.005)	<0.001 (0.004)	0.000 (0.004)
BMI × getting in shape (exercise)	0.023 (0.011) <sup>a</sup>	0.023 (0.012) <sup>a</sup>	-0.009 (0.013)	0.018 (0.009) <sup>a</sup>
BMI × eating better to stay healthy	-0.013 (0.011)	-0.003 (0.011)	0.017 (0.013)	-0.006 (0.010)
BMI × weight control	0.002 (0.009)	-0.002 (0.008)	-0.001 (0.011)	-0.006 (0.009)
PA × getting in shape (exercise)	-0.005 (0.003)	-0.008 (0.003) <sup>a</sup>	-0.010 (0.004) <sup>b</sup>	<0.001 (0.002)
PA × eating better to stay healthy	0.001 (0.003)	0.002 (0.003)	0.006 (0.004)	-0.002 (0.002)
PA × weight control	0.004 (0.002)	0.004 (0.003)	0.001 (0.003)	0.004 (0.002)
FV × getting in shape (exercise)	-0.030 (0.030)	0.051 (0.031)	0.071 (0.033) <sup>a</sup>	-0.012 (0.024)
FV × eating better to stay healthy	0.025 (0.027)	0.010 (0.030)	-0.008 (0.027)	-0.012 (0.020)
FV × weight control	0.010 (0.026)	-0.053 (0.027) <sup>a</sup>	-0.040 (0.027)	0.018 (0.020)

<sup>a</sup> $P < .05$ .<sup>b</sup> $P < .01$ .<sup>c</sup> $P < .001$ .

The results of the regression of telephone intervention interest showed that there were five statistically significant predictors. Survivors with no computer access were more likely to be interested in telephone-based interventions. Interest in diet interventions was a positive predictor of interest in telephone intervention. The interaction term between BMI and interest in

getting in shape and the term between physical activity and interest in getting in shape were significant predictors of interest in telephone-based interventions. The term between BMI and interest in getting in shape was similar to that for clinic-based interventions. Probing the interaction of physical activity by interest in getting in shape revealed that the slope for one

standard deviation below the mean Godin Score was positive and significant ( $B=-0.133$ ,  $P=.376$ ;  $B=0.038$ ,  $P=.695$ ;  $B=0.209$ ,  $P=.001$ ), indicating that as physical activity decreased, the relationship between interest in exercise interventions and telephone-based programs became stronger (see [Figures 2 and 3](#)). The interaction term between fruit and vegetable consumption and interest in weight management interventions was also a significant predictor of interest in telephone-based interventions. Probing this interaction revealed that none of the simple slopes were significant indicating that the slopes were different from one another but none were significant ( $B=-0.224$ ,  $P=.260$ ;  $B=-0.117$ ,  $P=.425$ ;  $B=-0.011$ ,  $P=.914$ ). See [Figure 4](#).

The results of the regression analysis of interest in computer-based interventions revealed six significant predictors. Survivors who had a computer, used social networking sites, and used a Web camera were more likely to be interested in a computer-based intervention. Interest in diet interventions was also a positive predictor. Two significant interaction terms were found. The interaction term between physical activity and interest in getting in shape was negative and significant. Probing the interaction revealed that only the simple slope for one standard deviation below the mean physical activity score was significant ( $B=0.221$ ,  $P=.001$ ), indicating a stronger positive relationship between interest in getting in shape and interest in a computer-based intervention among participants with lower levels of physical activity (see [Figure 5](#)). The interaction between fruit and vegetable consumption and interest in getting in shape was also significant. Probing this interaction revealed that all of the slopes were significant and positive ( $B=0.751$ ,  $P=.002$ ;  $B=0.608$ ,  $P<.001$ ; and  $B=0.466$ ,  $P<.001$  for one standard deviation above the mean fruit and vegetable consumption score, the mean score, and one standard deviation

below the mean score, respectively), indicating that as the number of fruits and vegetables consumed increased, the relationship between interest in getting in shape and interest in a computer-based intervention became stronger (see [Figure 6](#)).

The results of the regression analysis of interest in smartphone interventions revealed six significant predictors. Survivors who did not own a computer, who used social networking sites, and who used a Web camera were more likely to be interested in smartphone-based interventions. Those who engaged in higher levels of physical activity were also more likely to express an interest in this intervention modality. The interaction term between age and interest in healthy eating was significant. Probing this interaction revealed that all simple slopes were negative and significant ( $B=-0.683$ ,  $P=.023$ ;  $B=-0.572$ ,  $P=.026$ ; and  $B=-0.460$ ,  $P=.031$  for one standard deviation above the mean age, the mean, and one standard deviation below the mean), indicating that as age increased, the negative relationship between interest in a diet intervention and interest in a smartphone-based intervention became stronger (see [Figure 7](#)). The interaction term between BMI and interest in getting in shape was significant. Probing this interaction showed that all simple slopes were positive and significant ( $B=0.689$ ,  $P<.001$ ;  $B=0.5912$ ,  $P=.021$ ; and  $B=0.492$ ,  $P=.018$  for one standard deviation above the mean BMI, the mean, and one standard deviation below the mean), indicating that as BMI increased, the relationship between interest in getting in shape and interest in a smartphone intervention became stronger (see [Figure 8](#)).

The correlations among the outcome variables are presented in [Table 4](#). All outcome variables were significantly correlated, with the highest correlations being between clinic and telephone intervention interest ( $r=.539$ ) and computer and smartphone intervention interest ( $r=.368$ ).

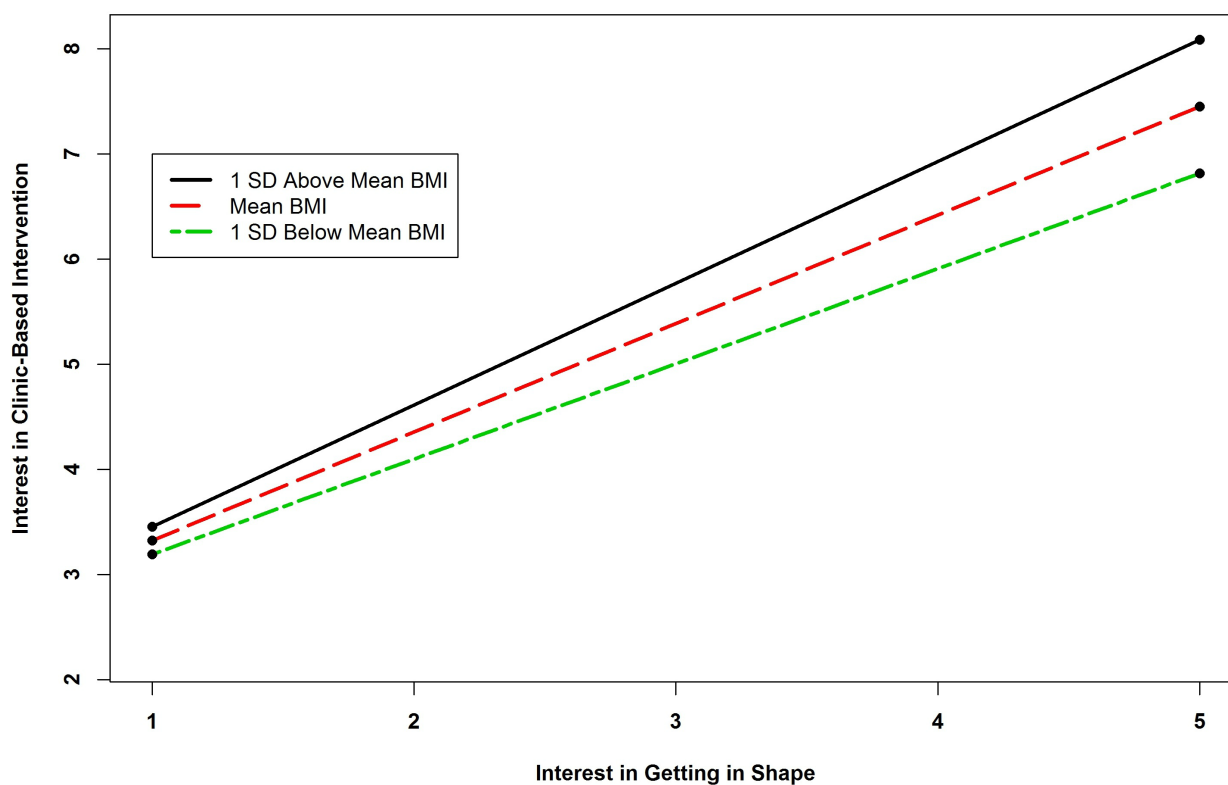
**Table 4.** Correlations of interest in intervention modalities<sup>a</sup>.

Intervention modality	Clinic	Telephone	Computer	Mobile phone
Clinic	–			
Telephone	.539	–		
Computer	.217	.315	–	
Smartphone	.199	.257	.368	–

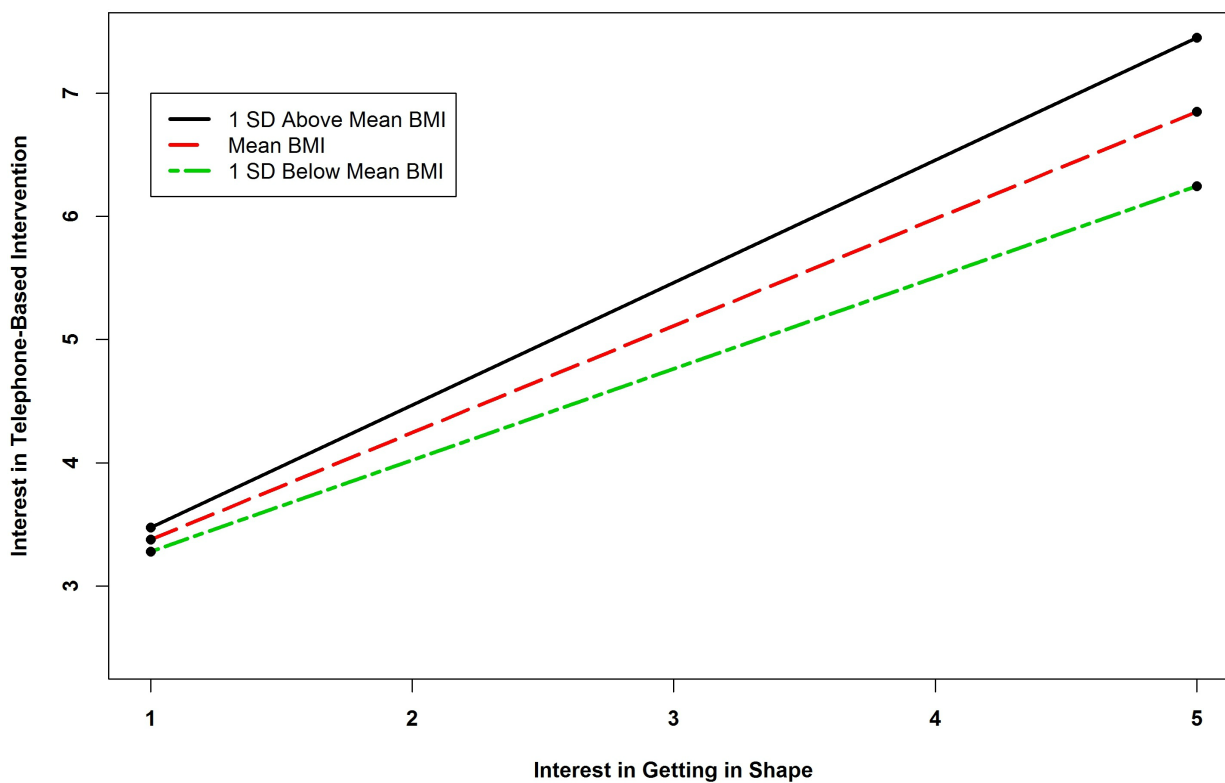
<sup>a</sup> All  $P$ s<.001.



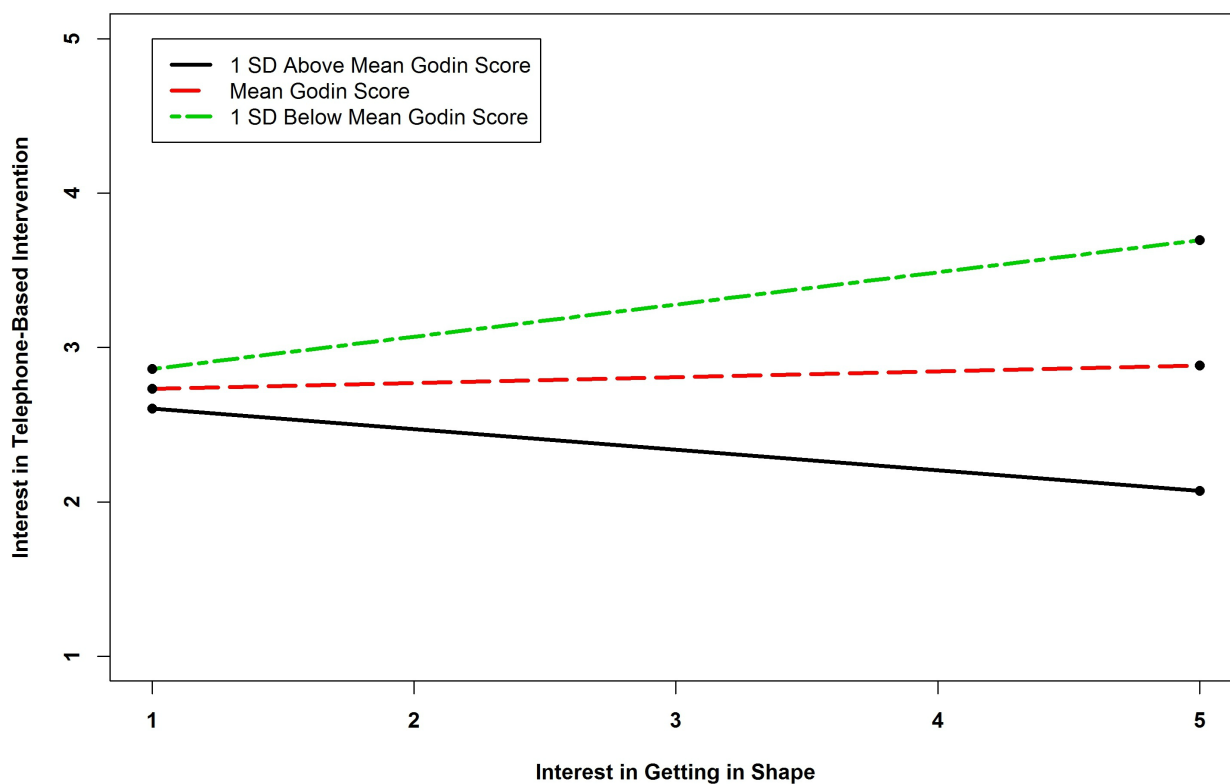
**Figure 1.** Simple slopes showing relationship between BMI and interest in getting in shape interaction and interest in clinic-based intervention.



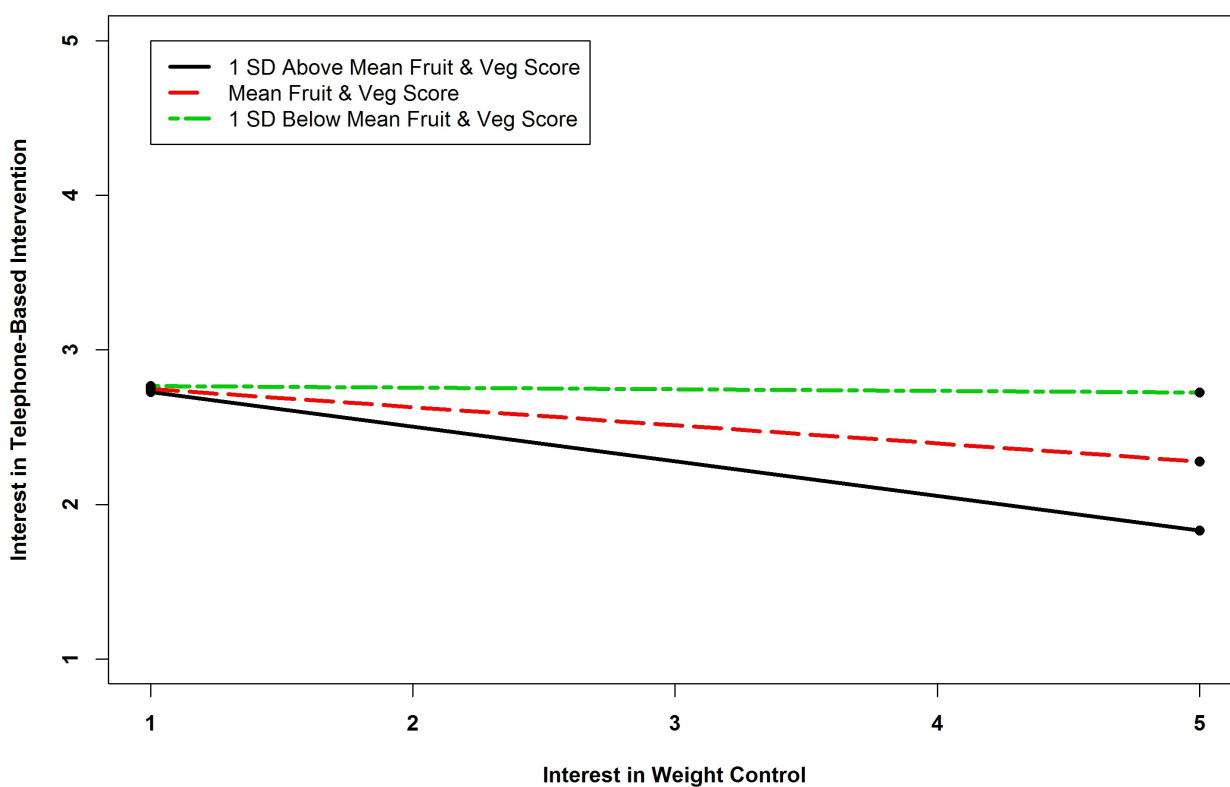
**Figure 2.** Simple slopes showing relationship between BMI and interest in getting in shape interaction and interest in telephone-based intervention.



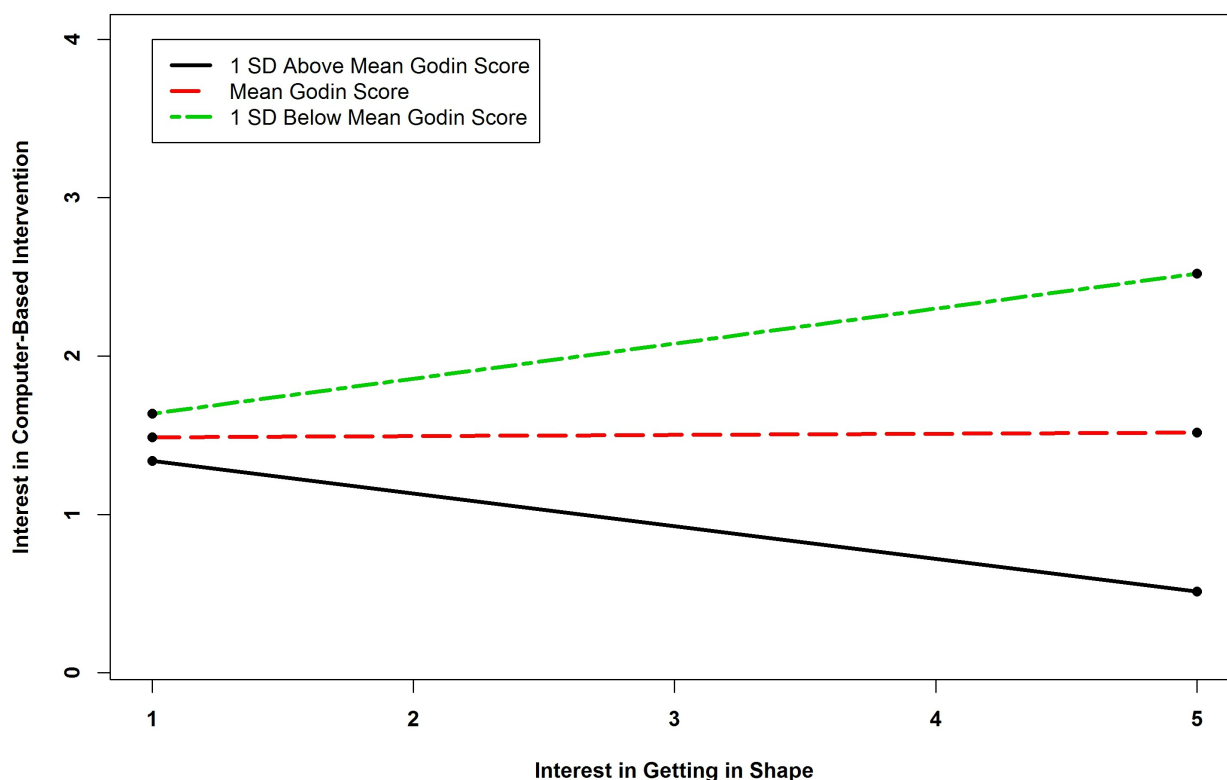
**Figure 3.** Simple slopes showing relationship between physical activity and interest in getting in shape interaction and interest in telephone-based intervention.



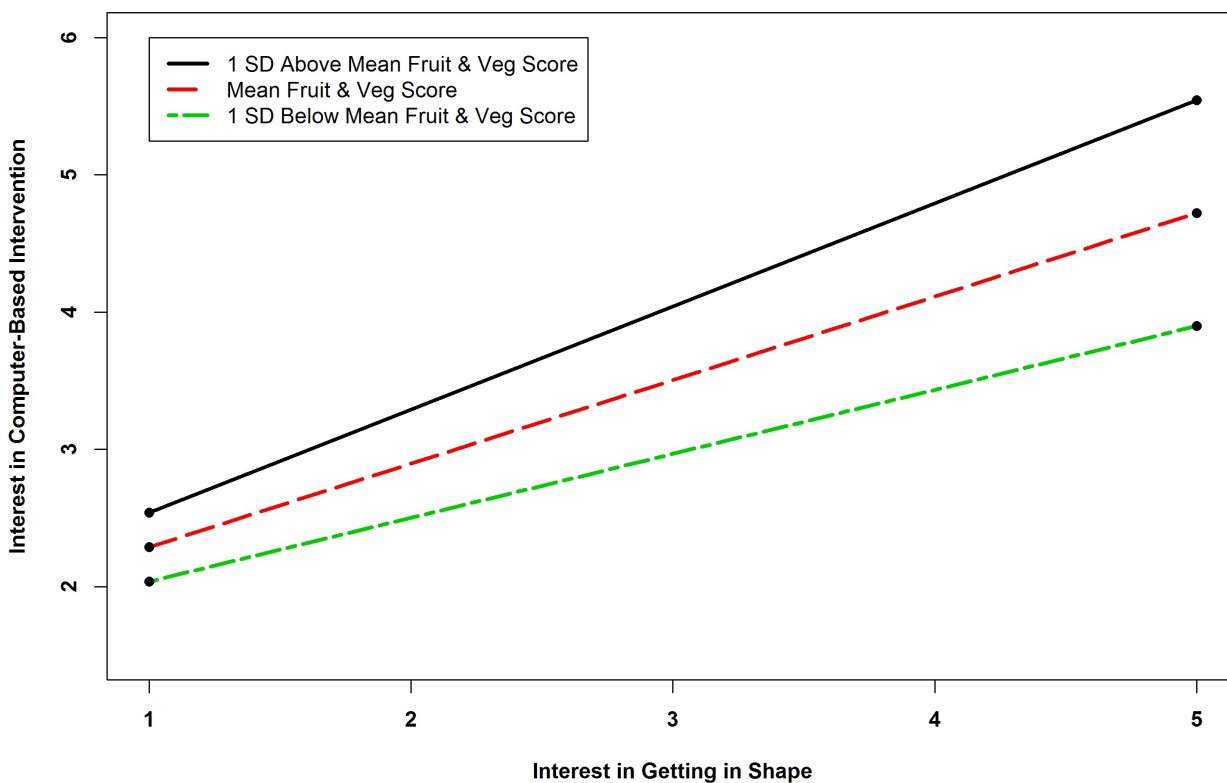
**Figure 4.** Simple slopes showing relationship between fruit and vegetable consumption and interest in weight control and interest in telephone-based intervention.



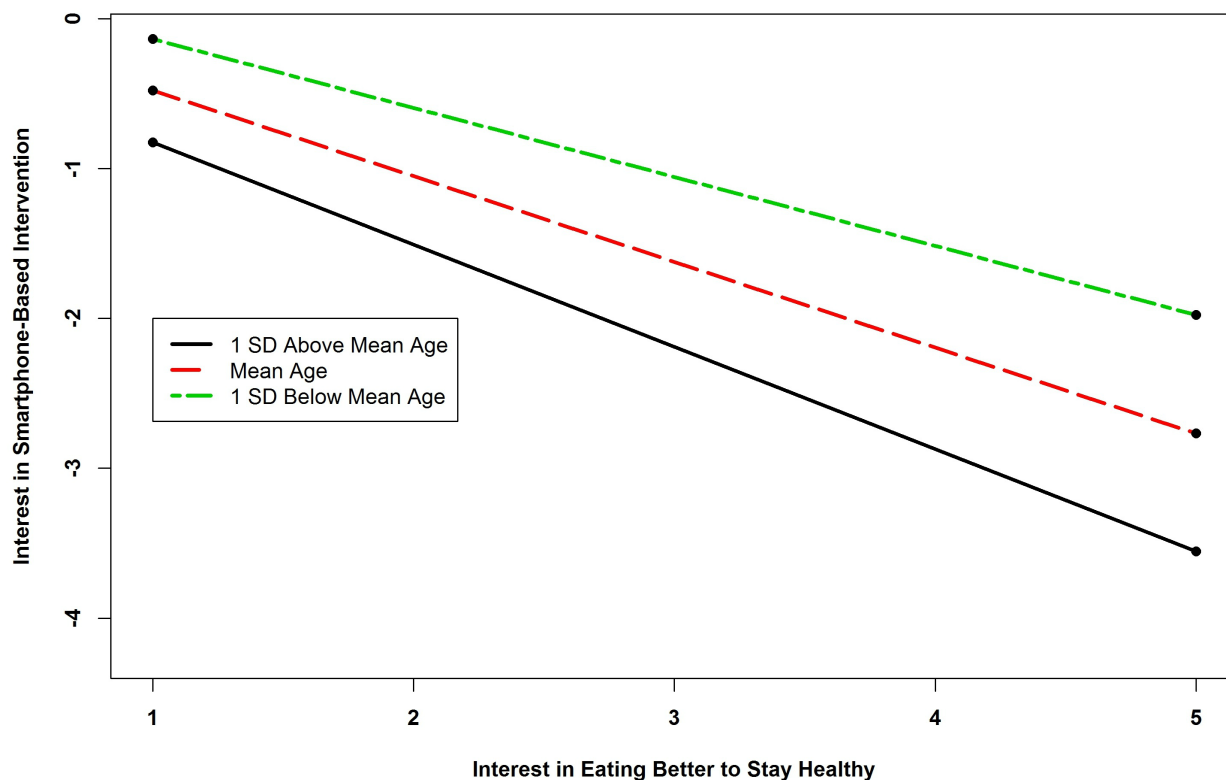
**Figure 5.** Simple slopes showing relationship between physical activity and interest in getting in shape and interest in computer-based intervention.



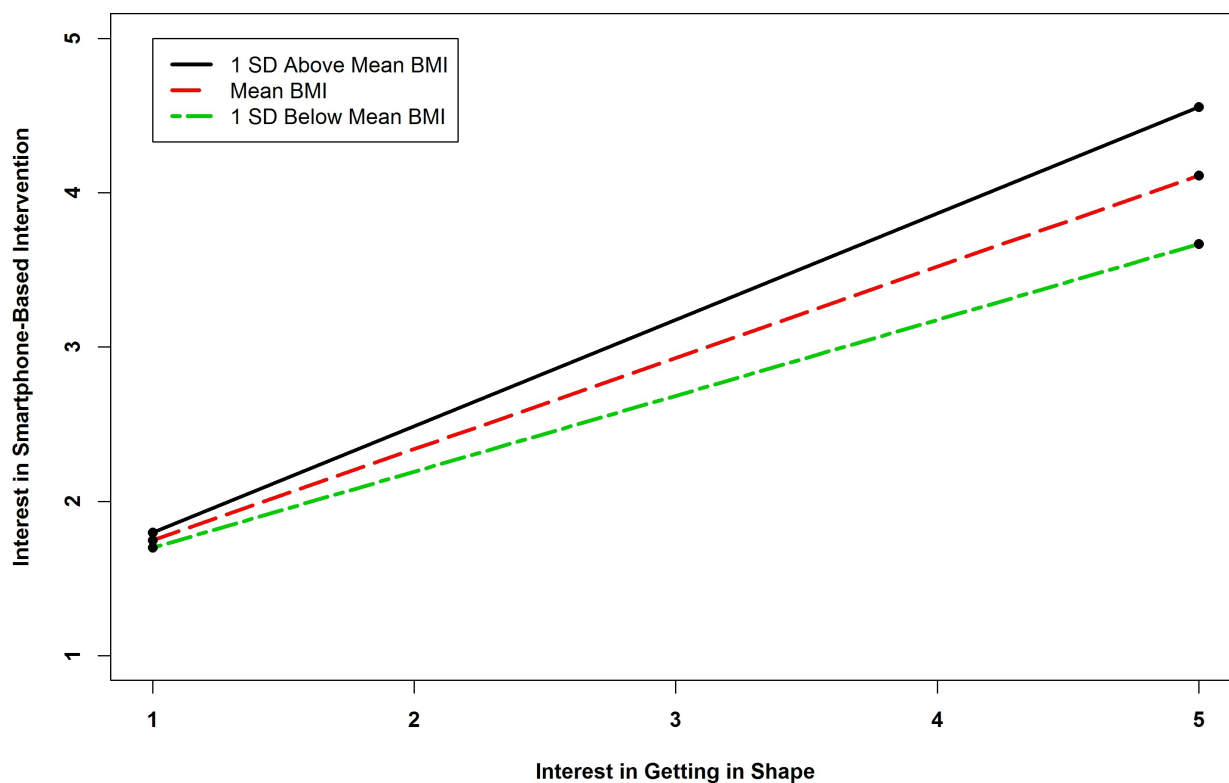
**Figure 6.** Simple slopes showing relationship between fruit and vegetable consumption and interest in getting in shape interaction and interest in computer-based intervention.



**Figure 7.** Simple slopes showing relationship between age and interest in healthy eating interaction and interest in smartphone-based intervention.



**Figure 8.** Simple slopes showing relationship between BMI and interest in getting in shape interaction and smartphone-based intervention.



## Discussion

### Principal Findings

In this study, we investigated cancer survivors' use of various forms of technology, as well as their interest in the delivery modality of health behavior change interventions. The purpose was to better understand what factors predict interest in newer forms of technology, such as smartphones, versus more traditional channels of delivery (eg, face-to-face, clinic-based interventions). The results indicate a low level of interest in interventions delivered via smartphone, with nearly 70% of the sample reporting no interest at all in this modality. This finding is expected, given that the average age of survey respondents was over 60 years, which is the age group with the lowest reported rate of ownership of smartphones [36]. In contrast, computer-based programs received the highest rating for "very" to "extremely" interested, indicating a higher level of overall interest in and acceptability of health interventions delivered through this medium. This interest is further supported by the high level of computer ownership in the sample (88.7%) and access to the Internet in the home (62.3%). Despite these high levels of preference for and ownership of computers, a relatively low number of participants reported using Internet-based social networking sites (30.3%) or Web cameras (23.6%), indicating that interventions using these technologies may reach only a small portion of cancer survivors who have a computer and access to the Internet.

Several predictors in the model were shown to be significant in predicting interest in technology-based interventions. Use of other technology-based platforms, such as social networking sites and Web cameras, positively predicted interest in interventions using broad-reaching technologies, such as computers and smartphones. Participants who did not have a computer were more likely to be interested in smartphone interventions. These individuals are part of a growing "smartphone-dependent" population in America that tends to be of low income and educational attainment [37]. In addition, participant age played a role in a significant interaction term for this modality, indicating that for some types of behavioral interventions (ie, diet) smartphone delivery may be of less interest to older survivors. When targeting cancer survivors for intervention, it is important that current technology use and age be taken into consideration. Some cancer survivors may be more amenable to the use of smartphones for interventions, such as those who already use various technology platforms or are younger.

We explored 13 interaction terms in this study. Of these, eight showed significant moderation. No one health behavior or demographic moderated the relationship between intervention type and modality alone. This highlights the complexity of the relationship between survivor interest in intervention modality, behavioral intervention targets, and current health behaviors. For example, the relationships between interest in getting into shape and clinic-based, telephone-based, and smartphone-based interventions were positive and significant across all BMI categories, though this interaction was not significant for computer-based interventions, which had received the highest

overall interest rating. This demonstrates that although generally computers may be a modality of high interest for health behavior intervention in this population, when specifically looking at exercise interventions, other broad-reaching modalities may be a better fit for both reach and retention. It should be noted that this relationship was strongest for those who were obese, suggesting this is particularly relevant for those with a high need for this type of behavioral intervention. Additionally, individuals with lower physical activity levels reported a positive relationship between interest in getting in shape and interest in computer-based interventions. However, this relationship was negative for individuals with higher levels of physical activity. This information would be clinically relevant when recommending a computer-based exercise intervention to a survivor, such that individuals with low levels of physical activity may show stronger preference towards a computer-based exercise intervention, while those with higher levels may prefer the intervention delivered by a different modality. In this way, current health behaviors, as with current technology use, are also important factors to consider when targeting cancer survivors for intervention. It should be noted that these findings are independent of computer ownership.

These findings support those of previous research regarding health behavior change interventions among cancer survivors and these survivors' interest in traditional versus technologically mediated channels of delivery. In their formative research for a mobile-enabled Web app to promote physical activity in older cancer survivors, Hong et al [27,28] found that while participants were enthusiastic regarding participation in an online health intervention, less than 10% reported accessing the Internet through their smartphones. In a design survey, 80% of 92 interview participants [27] reported that they would participate in an online physical activity program, but only 56% of pilot participants indicated that they would continue using the program after the intervention had completed [28]. In addition, participants typically accessed the app via a desktop or laptop computer, with only 9% accessing it through a smartphone [28]. Our findings support the results of this formative work, indicating that overall interest in health behavior interventions is low in this population and Web apps accessed via the computer may be preferable to those accessed via smartphone.

### Strengths and Limitations

There were several strengths of this study. Not only was interest in multiple intervention modalities evaluated in this at-risk population, but specific behavioral predictors of this interest were also evaluated, allowing the intervention modality to be better targeted in the future. Evaluating the relationships that exist between interest in health behavior interventions and the delivery modality allows for greater specificity, instead of defaulting to a "one size fits all" approach for intervention delivery. These data allow us to analyze which types of interventions are better suited for delivery by a particular modality, and to whom. In addition, the large sample size facilitated the use of statistical methods that were amply powered to detect these relationships.

A limitation of this study was that the cross-sectional design only allowed participants to indicate an interest in various types



of interventions, rather than actual participation. Therefore, predictor variables are only suggestive of having predictive value in future studies. Although survivors may have reported high interest levels, a longitudinal follow-up study is needed to determine whether this interest translates into actual engagement. Also, participants were able to rate their interest in each modality separately; thus, preferences between modalities could not be fully assessed. In the future, asking patients to rank order their preference between modalities would facilitate a better understanding of their “top choice” for intervention delivery. In addition, while most individuals who received the mailed survey responded, the percentage of those who did not respond may have biased our data. Finally, the data were collected in 2010. Since this time, smartphone use in the general population has nearly doubled. However, this is not the case for older adults in America—who are the focus of this paper—who have had a much slower trajectory of smartphone uptake [37].

## Conclusions

These results provide a better understanding of the individual factors that predict acceptance of health behavior intervention modalities among cancer survivors. Research has found substantial support for the efficacy of broad-reaching channels of delivery for health behavior intervention with cancer survivors [38]. As this population is growing, it is important to consider not only the most effective way to reach these individuals but also the most efficient and acceptable method of providing health behavior interventions. Future research in health behavior change intervention among cancer survivors should take into account multiple factors when choosing the channel of delivery for intervention, including age, experience and comfort with technology, and health behavior and conditions. Given the delayed adoption of technology among cancer survivors who tend to be older, it is likely that the use of smartphone-based interventions may be more acceptable in the coming years.

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## Conflicts of Interest

None declared.

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## Abbreviations

**BMI:** Body Mass Index

**FV:** daily servings of fruits and vegetables

**PA:** physical activity

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Original Paper

# Pilot and Feasibility Test of a Mobile Health-Supported Behavioral Counseling Intervention for Weight Management Among Breast Cancer Survivors

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## Abstract

**Background:** Health behavior and weight management interventions for cancer survivors have the potential to prevent future cancer recurrence and improve long-term health; however, their translation can be limited if the intervention is complex and involves high participant burden. Mobile health (mHealth) offers a delivery modality to integrate interventions into daily life routines.

**Objective:** The objective of this study was to evaluate the effects of a one-group trial with a pre-post evaluation design on engagement (use and acceptability), physiological (weight), behavioral (diet and physical activity), and other secondary outcomes.

**Methods:** The 10-week intervention consisted of mHealth components (self-monitoring of selected diet behaviors via daily text messages, wireless devices to automatically track weight and steps) and 4 motivational interviewing-based technology-assisted phone sessions with a nonprofessionally trained counselor. Participants were overweight breast cancer survivors who had completed treatment and owned a smartphone. Weight was measured objectively; diet and physical activity were measured with brief self-reported questionnaires.

**Results:** Ten women participated; they had a mean age of 59 years (SD 6), 50% belonged to a racial or ethnic minority group, 50% had some college or less, and 40% reported using Medicaid health insurance. Engagement was high: out of 70 days in total, the mean number of days recording steps via the wristband pedometer was 64 (SD 7), recording a weight via the scale was 45 (SD 24), and responding to text messages was 60 (SD 13); 100% of participants completed all 4 calls with the counselor. Most (90%) were very likely to participate again and recommend the program to others. Mean weight in pounds decreased (182.5 to 179.1, mean change -3.38 [SD 7.67]), fruit and vegetable daily servings increased (2.89 to 4.42, mean change 1.53 [SD 2.82]), and self-reported moderate physical activity increased in metabolic equivalent of task (MET) minutes per week (2791 to 3336, mean change 545 [SD 1694]).

**Conclusions:** Findings support the conduct of a fully powered trial to evaluate the efficacy of mHealth as a feasible intervention modality for breast cancer survivors. Future research should employ accelerometer-based physical activity assessment and consider development of an all-in-one app to integrate devices, messaging, and educational content and other mHealth approaches to support behavioral counselors conducting weight management interventions.



**Trial Registration:** ClinicalTrials.gov NCT02387671; <https://clinicaltrials.gov/ct2/show/NCT02387671> (Archived by WebCite at <http://www.webcitation.org/6hGEuttbZ>).

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## KEYWORDS

telemedicine; survivors; breast neoplasms; health behavior; body weight

## Introduction

Owing to multiple factors including improved treatment, the 5-year survival rate in the United States for women with breast cancer for 2003-2009 is 90%, up from 75% in 1975-1977 [1]. There are >3.1 million female breast cancer survivors in the United States [1]. Increasing attention is now being focused on how to increase quality of life, prevent future cancer recurrence, and reduce risk of chronic diseases, such as cardiovascular disease and diabetes [2].

For people who have already completed treatment and are either disease free or whose cancer is stable, the 2012 Nutrition and Physical Activity Guidelines for Cancer Survivors from the American Cancer Society recommend the following: (1) achieving a healthy weight; (2) moderate-vigorous physical activity of 150 minutes per week and strength training 2 times per week; and (3) eating a diet that is high in vegetables, fruits, and whole grains [2]. However, translation of these findings into population-wide, inexpensive, sustainable programs has to date proven largely unrealized. Key questions remain in terms of how interventions should be optimally designed for maximum effectiveness and reach to the entire cancer survivor population. This is particularly true for populations that face health disparities, those who belong to low-income or racial/ethnic minority groups, as these populations often experience less favorable cancer outcomes and higher rates of obesity compared with other populations [3,4].

Mobile health (mHealth) involves the use of any mobile technology, such as mobile phones and wireless sensors, to deliver and share personalized health information [5]. Mobile health holds immense promise to deliver behavioral interventions that are embedded into individuals' daily routines, that are highly personalized to individuals' behaviors, health conditions, and daily routines, and have the potential to reach diverse populations. Smartphone ownership is now higher among black, non-Hispanic (70%) and Hispanic (71%), populations compared with white (61%) populations [6]. In concordance with the promise of mHealth intervention modalities, an increasingly large body of literature now exists that has been examined in multiple systematic reviews covering particular mHealth strategies [7,8] (eg, apps, text messaging) and health topics [9,10] (eg, weight, physical activity, nutrition). A systematic scoping review focused on weight management published in late 2015 revealed that half of the 457 articles reviewed were published within the past 2 years [10]. Bennett and colleagues [11] also reviewed the use of electronic health (eHealth) interventions for weight management among racial/ethnic minority populations and found that interventions featuring more advanced features of eHealth technology and the use of mHealth technologies are needed. Although more

research is needed to summarize and recommend best practices, intervention designers can use information from these reviews to help inform the design of future interventions, including which mHealth strategies to select, how to implement them, and how to combine human behavioral counselors with mHealth components.

Although there is much that can be learned from this body of literature that can be applied to the optimal design and development of interventions, there are very few published studies using technology (mobile or Web-based) to deliver interventions to cancer survivors. This is important because cancer treatment can result in a range of circumstances that affect diet and physical activity behaviors of cancer survivors, including changes in taste and smell, physical discomfort such as lymphedema, and changes in social support structures [2]. A systematic review conducted by Goode et al [12] analyzed print, telephone, and Web-based interventions for diet, physical activity, or weight management among cancer survivors. Of 27 studies, 3 were delivered using the Web (1 of which was via the social media platform Facebook) and none were delivered via text message. In addition, none of the studies specifically targeted minority race or ethnic groups. The review concluded with support for broad-reach methods, specifically telephone based, and the need to integrate newer technologies, such as texting and mobile technologies, to deliver interventions with potential for broad reach to diverse populations of cancer survivors. Although some studies have since been published [12] or are in development [13] that have some mHealth components such as texting or use commercial weight loss applications [14], published studies evaluating interventions with multiple mHealth components for weight management and related behaviors among cancer survivors are limited.

Given the body of evidence for the importance of lifestyle behaviors for cancer survivors and the increasingly large literature on mHealth interventions, the time is ripe to deliver mHealth interventions to adult cancer survivors. Our approach is to use multiple mHealth strategies to augment a human counselor-delivered behavioral intervention to address weight management-related behaviors. The purpose of this study was to evaluate a weight management mHealth intervention for breast cancer survivors on the following feasibility and preliminary efficacy outcomes: engagement (use and acceptability); physiological (weight); behavioral (diet and physical activity); and psychological and other outcomes (self-efficacy, perceived stress, social support, sleep, loss of control over eating, fatigue). The selection of these outcomes served to provide a detailed picture of the effects of the intervention directly both on weight and weight-related behaviors and factors that influence these behaviors. The feasibility data served to help the research team decide if this



intervention approach is suitable for further testing and refinement in future studies [15].

## Methods

### Study Design

We conducted a one-group pilot study with a pre-post evaluation design to evaluate the feasibility and preliminary efficacy of a human counselor-delivered behavioral intervention incorporating multiple mHealth strategies targeting weight management behaviors among breast cancer survivors (ClinicalTrials.gov NCT02387671). The protocol was approved by the Boston University Medical Center Institutional Review Board.

### Formative Feedback

Before the start of the pilot study, we conducted individual interviews with 4 women from our target population to obtain feedback on mHealth intervention design features. Informed consent was obtained from participants at the start of the interview. Interview participants had a mean age of 62.3 years (SD 7.5) and body mass index (BMI) of 33.5 kg/m<sup>2</sup> (SD 5.0); 1 (25%) reported being Hispanic, 2 (50%) black or African American, and 1 (25%) white. Suggestions for features of an mHealth intervention included providing educational/culturally relevant resources, offering information on opportunities for social support (ie, recommending local support groups), and encouraging the use of mobile phone apps and programs to search the Internet for more information. Concerns included participants believing recalls of food intake could be inaccurate and maintaining an appropriate number of interactions between the counselor and participants. Additionally, the need for a thorough orientation to any mHealth strategies (devices, apps, the agenda for counseling sessions) was noted. We refined our intervention approach in response to the findings.

### Recruitment and Participants

Recruitment methods included contacting individuals on a university-maintained registry of people interested in research, postings on a university website for those looking for research studies, postings on university-wide emails, recontacting individuals from the interviews described above, announcements at the hospital-based breast cancer survivor support group, posting paper flyers, and posting notices on Craigslist and in a local newspaper. Through all methods, individuals were asked to call or email the study team to request further information. When the individual contacted the study team, she was screened for eligibility. Eligibility criteria were 18 years of age or older, able to speak and read English, female, 2 years or more since

breast cancer diagnosis (self-reported) and 6 months or more since end of cancer treatment (surgery, radiation, or chemotherapy), self-reported overweight or obese (BMI greater than 25 kg/m<sup>2</sup>, as assessed by self-reported height and weight), be an owner of an Android or iOS-platform smartphone, and have WiFi at home. Exclusion criteria included contraindications for physical activity, pregnancy, presence of a pacemaker or other internal medical device, and medical conditions (dementia, active cancer, anorexia) or any other condition in the opinion of the study team deemed to make the participant unsuitable for inclusion in the study. For eligible individuals, a staff member then scheduled an in-person baseline study visit at our research office space at an academic medical center. At this visit, a staff member measured their height and weight, asked whether they would be willing to share Fitbit account information (log-in/password) with the study team, and observed their ability to navigate programs on a smartphone to verify eligibility. Individuals who had a BMI of 25.0 kg/m<sup>2</sup> or greater according to measured height and weight, were willing to share Fitbit account information, and appeared able to navigate programs on their smartphone (from the research staff members' perspective) were eligible to participate. We chose these eligibility criteria in order to compose a sample that would be similar to a sample targeted in a future, larger-scale, randomized controlled efficacy trial, yet also be feasible to obtain within the parameters of a small-scale pilot study (for example, it was determined that it would not be feasible to provide smartphones to individuals who did not already own one). This sample also served to target breast cancer in early survivorship phases or later such that cancer treatment-related physical effects have decreased for most women [16].

Eligible participants were asked to provide their informed consent to participate and were enrolled into the intervention and asked to complete a paper-and-pencil baseline questionnaire. Participants were recontacted 10 weeks after baseline to complete a follow-up paper-and-pencil questionnaire. Participants received US \$20 for completing each questionnaire and received the wristband pedometer and scale devices to keep.

### Intervention

After enrollment, participants engaged in a counselor-delivered intervention with multiple mHealth components [17] over 10 weeks (Textbox 1). Participants engaged in self-monitoring nutrition behaviors; automatic (ie, passive) weight and behavioral monitoring via a scale and wristband pedometer; and received technology-assisted phone counseling from a behavioral health counselor.

**Textbox 1.** Description of intervention components.

## Intervention component

## 1. Self-monitoring

Daily text messages sent to ascertain participants' dietary intake immediately after enrollment and for the next 10 weeks. Each message was the same and contained 5 questions that prompted a yes or no response or a numerical value. Responses from the messages were recorded and conveyed to the health counselor to assist in the counseling sessions. Messages corresponded to content in the telephone counseling sessions.

## Questions:

- Did you eat more than one high-calorie snack?
- Did you eat food from a restaurant or fast-food place?
- Did you drink more than one sugary drink?
- Did you eat until you were uncomfortably full?
- How many servings of fruits & vegetables did you eat?

## 2. Automatic weight and behavioral monitoring

*Weight scale*

Participants were asked to record their body weight daily using Fitbit Aria [18,19].

*Wristband pedometer*

Participants were asked to wear the wristband daily to track their steps and hours of sleep by wearing the Fitbit Flex wristband. Weight, steps, and sleep recordings were synchronized through WiFi (weight) or via cellular Bluetooth (steps & sleep) connections to the participants' Fitbit app installed on their mobile phone.

## 3. Technology-assisted counseling

*Counselor training*

A behavioral health counselor conducted telephone sessions with participants. The counselor underwent training in study-specific protocols (eg, recording phone calls) and motivational interviewing techniques, such as viewing and discussing a series of 4 training videos, practicing and receiving feedback on counseling with a structured call guide. Before interacting with participants, the study director rated a recorded telephone session between the counselor and a volunteer for attaining a sufficient level of motivational interviewing spirit and empathy (eg, asking permission, supporting the participant and not confronting or giving advice). The coach had a bachelor's degree in nutrition.

*Counseling session topics and ordering*

Participants engaged in 4 phone calls with the study counselor, one every other week. The first and second calls focused on physical activity, sleep, and fatigue. The third and fourth calls focused on 2 out of 4 possible nutrition topics chosen by the participant. The 4 nutrition topics were sugary beverages, fruits and vegetables, snacking, and cooking/preparing meals/eating out. This approach was intended to bring about small decreases in daily energy intake by making small daily behavioral changes, such as substituting no-calorie beverages for sugary beverages. This "small changes" approach has demonstrated efficacy in multiple populations, including overweight or obese adults [20] and multicultural socioeconomically disadvantaged adults [21,22].

*Counseling session content*

The counselor used a structured, yet flexible, guide to conduct the sessions that followed principles of motivational interviewing [23], the Social Contextual Model [24], and was adapted from a guide used in a previous study [25]. The guide was built in Excel and used embedded logic to flow from section to section. The calls included 6 sections: introduction (introduce the topic of the call, review privacy information); provide feedback on current behavior compared with recommendations, obtain information on participant's behavior (eg, what type of physical activity she enjoys); assess importance & confidence in changing the behavior; assess influences on their behavior (eg, finances, stress, family/friends/neighborhood); assess motivation to change behavior; if motivated, conduct collaborative goal setting, and if not, prompt discussion of what it would be like to change). In each subsequent call, the counselor checked in about what was discussed in the previous call. Participants' data collected during self-monitoring were used to guide the counseling sessions. All calls were recorded.

*Resources*

The counselor had a list of weblinks for resources around each topic area (such as sleep, fatigue, fruits and vegetables, and so on) The resources were compiled from sources that were both reputable and user-friendly. Examples included choosemyplate.gov, mayoclinic.org, and cdc.gov. Resources were sent to the participants if the participant requested them.

*Asynchronous messages*

During interim weeks between calls, the counselor maintained contact with the participants through 3 asynchronous text messages per week to monitor their progress in the study. The messages served several purposes:

- The counselor would monitor whether participants were tracking behaviors (self-monitoring and automatic weight and behavioral monitoring). If participants were not tracking all behaviors at least 5 days per week, the counselor would try to resolve any issues with tracking (eg, device difficulties, confusion on how or what to track). If they were meeting the 5-day-per-week target, the counselor encouraged them to keep up the good work.

- The counselor would check in on any goals the participant had set during the counseling calls (eg, “Hi, it looks like you have not yet reached your goal of walking 10,000 steps 7 days per week. Do you have any questions about this goal? Have you been experiencing any difficulties?” or “Just checking in on the goal you set to plan out your meals every Sunday evening. How has that been going? Have you experienced any successes? Any difficulties?”).
- The counselor would send a message to the participant 2 days before each counseling call as a reminder of the upcoming call.
- The participants and counselor also used asynchronous messages as needed to ask/answer questions, comments, or requests for information.

## Measures

Our measures comprised both feasibility (engagement and acceptability) and outcomes (physiological, behavioral, and secondary variables), because it is important to both demonstrate the feasibility of the intervention approach and emulate the evaluation approach of a future larger-scale efficacy trial.

### Engagement and Acceptability

We collected data on number of calls completed, duration of calls, number of responses received to text messages, and valid days of wearing the wristband pedometer and recording a weight on the scale. Daily step counts of <100 and >50,000 were considered invalid. We also asked open- and closed-ended questions on the appeal of the intervention, perception of the number of calls received, perceptions of setting and meeting health goals, how likely they would be to participate again, and suggestions for improving the intervention.

### Evaluation Outcomes

#### Physiological

Weight and height were measured using a protocol in which participants removed shoes or footwear, outer garments, and so on and stood with their back against a wall [26]. The same procedure was used at 10 weeks. Height measurements were recorded to the nearest ¼ inch, rounding down [27]. Height was measured at baseline only.

#### Behavioral

Diet was measured by an 18-item food frequency questionnaire, the PrimeScreen, which has been compared for reliability and validity against a full-length food frequency questionnaire and biomarkers [28]. Correlation coefficients for comparability between dietary components of the PrimeScreen and a full-length food frequency questionnaire range from .36 for other vegetables to .82 for eggs and for nutrient estimates range from .48 for folate, .58 for fiber, to .59 for saturated fat. Correlation coefficients for comparability between PrimeScreen and biomarkers were .33 for vitamin E and .43 for both beta-carotene and lutein/zeaxanthin. Participants indicate the frequency with which they eat each food, with 5 response category options, ranging from less than once a week to twice or more per day. Foods were then grouped into categories: fruits and vegetables, 6 items; whole grains, 1 item; red and processed meats, 2 items; whole fat dairy foods, 1 item; and high calorie, 3 items. A composite diet score was calculated, with a score from 0 (worst) to 100 (best) assigned for intake from each of the 5 food categories and then averaged [29].

Sugary beverage intake was evaluated via the 15-item Beverage Questionnaire (BEVQ-15) [30], which assesses frequency of past-month consumption of common sugary drinks including

sweetened juice drinks, soda, and energy drinks. Of note, 100% fruit juice is not included as a sugary drink. The BEVQ-15 has shown adequate reliability and validity with 4-day food intake records (Spearman  $r$  value = .673 for grams of total sugar-sweetened beverages).

Fast-food intake was assessed via a 1-item question: “In the past 7 days, how many times did you eat fast food? Include meals eaten at work, at home, or at fast food restaurants, carryout or drive-through, such as food you get from Dunkin’ Donuts, McDonald’s, Panda Express, or Taco Bell,” which was based on a question derived from a large population-based survey [31]. Response options were as follows: less than once per week, once per week, 2–4 times per week, nearly daily, and twice or more per day.

Physical activity was measured using the International Physical Activity Questionnaire (IPAQ) [32,33]. This tool provides an internationally relevant measure of physical activity, which has undergone extensive validity and reliability testing. The IPAQ covers all areas of moderate and vigorous physical activity in everyday life, with questions in regard to job-related physical activity; transportation physical activity; housework and family care physical activity; recreation, sport, and leisure time physical activity; and time spent sitting.

#### Psychological and Other Secondary Variables

Self-efficacy was assessed separately for fruit and vegetable intake and physical activity, asking the participants to rate their confidence that they can perform these behaviors under a variety of circumstances [34]. We used the 4-item Perceived Stress Scale [35] (sample question: “In the last month, how often have you felt that you were unable to control the important things in your life?”), with response options ranging from 0 (never) to 4 (very often). Social support was assessed using the question “How much can you rely on family or friends for support and encouragement?” with answer options a lot, somewhat, and not at all [36]. Sleep was evaluated using the question “How often during the past 4 weeks did you get enough sleep to feel rested upon waking up?” with response options never, rarely, sometimes, often, and very often [37]. Perceived loss of control over eating was evaluated using the validated 7-item Loss of Control over Eating Scale-Brief, with 5 response options ranging from 1 (never) to 5 (very often) [38]. Fatigue was evaluated using a scale of 0–10 with 0 being “no fatigue” ranging up to 10 as fatigue “as bad as you can imagine” [39,40].

#### Statistical Analysis

All surveys and measurements for outcomes were conducted in person and collected on paper. Surveys were then entered in duplicate into REDCap [41] by two individuals and compared for accuracy. Data were examined descriptively using

frequencies, means, and medians. Analysis was conducted using SAS version 9.3 (Cary, NC).

## Results

### Participant Flow Through the Study

In response to our recruiting efforts, 27 individuals were screened for eligibility. Fourteen were excluded for not meeting the eligibility criteria; the most frequent reasons for being ineligible were not having home WiFi and/or a smartphone (n=9) and not being overweight/obese (n=3). Three individuals were eligible but declined to participate, because of perceived need for more assistance with using the devices, perceptions that the intervention would offer a prescribed diet and exercise program, and not being able to enroll until a later date. Therefore, 10 participants were enrolled. Recruitment methods

for enrolled participants were hospital-based breast cancer support groups (n=4), the patient registry (n=3, of whom 2 gave formative feedback), hospital-wide email (n=2), and the newspaper advertisement (n=1). All participants completed both the baseline and follow-up surveys.

### Participant Characteristics

Characteristics of participants are listed in [Table 1](#). Approximately half reported belonging to a minority race/ethnic group and 40% reported financial limitations as reflected by being covered by Medicaid insurance or receiving food assistance benefits within the past 2 years. The majority accessed the Internet on their mobile phone but less frequently used their mobile phone for health-related purposes. Self-reported breast cancer stage was early or 0-I (60%) and stage II or above (40%). Mean self-reported years since diagnosis was 7.1 (SD 4.0).

**Table 1.** Participant characteristics.

Characteristic	N=10
Age in years, mean (SD)	58.6 (6.1)
<b>Ethnicity/race, n (%)</b>	
Hispanic white	1 (10)
Non-Hispanic black	3 (30)
Non-Hispanic white	5 (50)
Other	1 (10)
<b>Highest level of education, n (%)</b>	
High school graduate/GED <sup>a</sup> or lower	2 (20)
Some college/university	3 (30)
College/university graduate or higher	5 (50)
<b>Work for pay, n (%)</b>	
Yes	6 (66.7)
No	3 (33.3)
<b>Type of insurance, n (%)</b>	
Medicaid (ie, public insurance) only or in combination	4 (40)
Private insurance	5 (50)
Medicare (ie, public insurance for older adults) & private	1 (10)
<b>Delayed taking medication due to cost, n (%)</b>	
Yes	2 (20)
<b>Household receives food stamps, n (%)</b>	
Yes	4 (40)
<b>Always had enough money to buy food, n (%)</b>	
Yes	9 (90)
<b>Use the Internet at least occasionally, n (%)</b>	
Yes	10 (100)
<b>Send or receive email at least occasionally, n (%)</b>	
Yes	10 (100)
<b>Access the Internet on a mobile handheld device, n (%)</b>	
Yes	9 (90)
<b>Use mobile phone to download apps, n (%)</b>	
Yes	9 (90)
<b>Have apps to track health, n (%)</b>	
Yes	4 (40)
<b>Receive text updates or alerts about health or medical issues, n (%)</b>	
Yes	0 (0)
<b>Social support</b>	
A lot	5 (50)
Somewhat	5 (50)
Not at all	0 (0)

<sup>a</sup>GED=General Education Diploma



## Engagement and Acceptability

Out of 70 opportunities (7 days a week  $\times$  10 weeks) to record self-monitoring and automatic behavioral monitoring data, mean number of responses was 60 (SD 13), median 64 (range 24-68) for responding to text messages; 64 (SD 7) for recording a step measurement, median 52 (range 3-67); 45 (SD 24) for recording a weight measurement, median 67 (range 52-70); and 43 (SD 19) for recording a sleep measurement, median 47 (range 9-63).

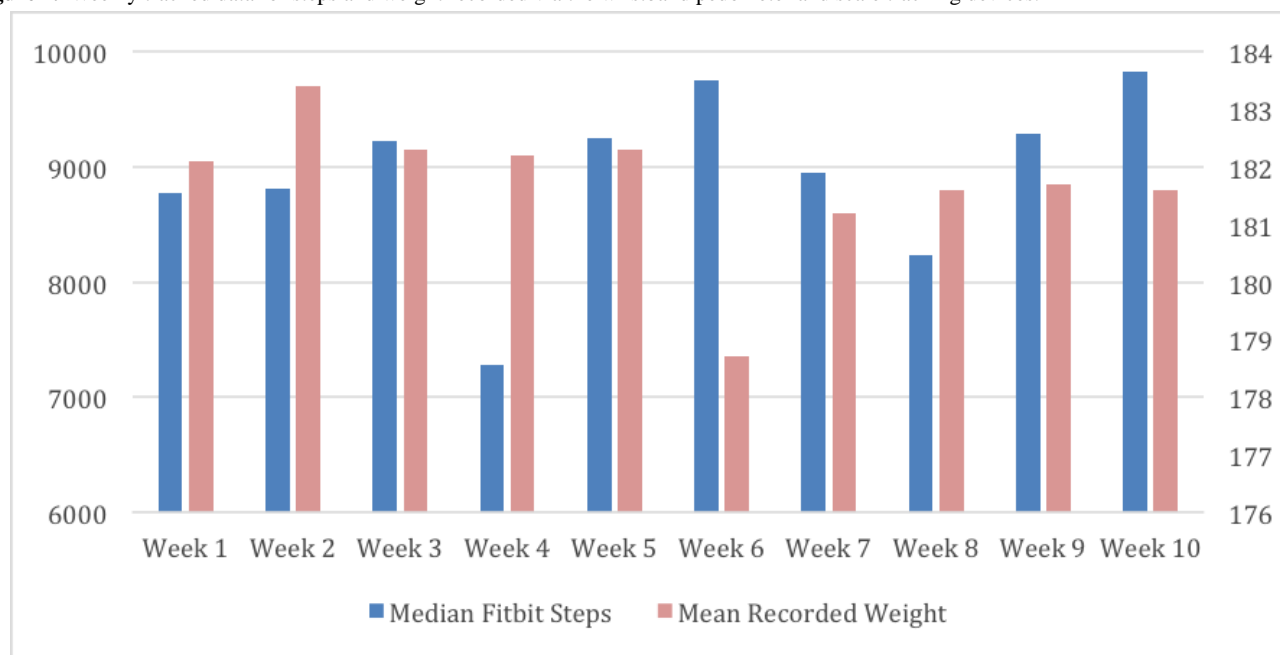
All participants completed all 4 counseling calls. Mean duration of calls 1 to 4 was 29 (SD 9), 22 (SD 11), 28 (SD 14), and 24 (SD 13) minutes, respectively. Of 20 nutrition-related calls completed (2 per participant), there were 8 calls about fruits and vegetables, 6 about cooking, 5 about snacking, and 1 call about sugary drinks. To illustrate the data collected during the intervention, median number of recorded steps and mean weight are presented in [Figure 1](#).

For acceptability, 9 participants reported setting health goals during the last 3 months and all participants reported meeting

some ( $n=8$ ) or all ( $n=2$ ) of their personal goals. All participants rated the calls as very helpful in setting personal goals to change their health habits and felt the number of calls was “just right.” Whereas 2 participants responded that the number of text messages/emails from their counselor was “too many,” the other 8 felt the number was “just right.” Nine of 10 participants responded that it is “very likely” that they would participate again or recommend the program to others. However, 7 of 10 participants responded that it is “somewhat unlikely” or “not at all likely” that they would participate again if they had to pay for the program.

Written feedback included participants’ difficulty with using the devices (including seemingly erratic weight and sleep readings) and desire for self-monitoring diet behaviors in a more streamlined fashion. Participants noted the calls and the wristband pedometer and scale devices were helpful in setting and achieving goals.

**Figure 1.** Weekly tracked data for steps and weight recorded via the wristband pedometer and scale tracking devices.



## Evaluation Outcomes

As listed in [Table 2](#), there were beneficial changes in physiological and behavioral outcomes, including weight, nutrition behaviors (daily servings of fruits and vegetables and the composite diet score), and physical activity. Those reporting “often” or “very often” to feeling rested upon waking in the past 4 weeks increased from 5 at baseline to 7 at follow-up.

Other variables showed minimal changes (such as self-efficacy) or nonbeneficial changes (such as intake of sugar-sweetened beverages). For fast-food consumption, 6 stayed at the same response, 2 increased from  $< 1$  time per week to 1 time per week, 1 decreased from once per week to  $< 1$  time per week, and 1 skipped this question at baseline. Beneficial changes were also reported for perceived fatigue, loss of control eating, and perceived stress.

**Table 2.** Change in behavioral, psychological, and other outcomes from baseline to 10-week follow-up.

Outcome	Baseline mean (SD) median (range)	Follow-up mean (SD) median (range)	Change mean (SD) median (range)
Weight, pounds	182.5 (24.9)	179.1 (23.4)	-3.38 (7.67)
<b>Diet behaviors, servings/day</b>			
Fruits & vegetables	2.89 (1.79)	4.42 (1.91)	1.53 (2.82)
Whole grains	0.30 (0.31)	0.32 (0.30)	0.03 (0.33)
Whole fat dairy	0.34 (0)	0.31 (0)	-0.03 (0.28)
Red meat	0.51 (0.42)	0.62 (0.76)	0.11 (0.92)
High calorie	0.36 (0.31)	0.51 (1.07)	0.15 (0.86)
Diet composite score	60.16 (9.19)	66.91 (8.80)	6.76 (13.31)
Sugar-sweetened beverages, fluid ounces	8 (7)	13 (15)	5 (13)
Low physical activity, MET-minutes/week <sup>a</sup>	1967 (3189) 830 (0-10,584)	3076 (2685) 2473 (0-8262)	1108 (3636) 1029 (-6552 to 8064)
Moderate physical activity, MET-minutes/week <sup>a</sup>	2792 (4475) 660 (0-14,175)	3336 (4422) 1755 (0-14,160)	545 (1694) 345 (-3090 to 3360)
Vigorous physical activity, MET-minutes/week <sup>a</sup>	1776 (4103) 0 (0-13,200)	2568 (3751) 1080 (0-11,040)	792 (5565) 0 (-10,320 to 10,560)
<b>Self-efficacy</b>			
Fruits & vegetables	3.1 (0.6)	2.9 (0.6)	-0.3 (0.6)
Physical activity	3.0 (1.1)	2.9 (1.0)	-0.1 (0.8)
Fatigue	4.4 (2.1)	2.6 (1.6)	-1.8 (0.8)
Loss of control eating	1.9 (0.8)	1.4 (0.5)	-0.5 (0.7)
Perceived stress	5.1 (3.3)	4.7 (3.2)	-0.4 (3.3)

<sup>a</sup>MET=Metabolic Equivalent of Task

## Discussion

This mHealth-supported behavioral counseling intervention for weight management was feasible to implement, as demonstrated by high levels of engagement with the intervention components (self-monitoring, automatic behavioral monitoring, and counseling phone sessions) and high levels of acceptability with intervention components. In our study, out of 70 opportunities to answer self-monitoring text messages, the mean number of responses was 60, or 86%. Our findings compare favorably with other reported engagement outcomes in the literature. For example, in a study among overweight or obese women from racial/ethnic minority groups, one intervention component included daily text messages prompting self-monitoring with an accompanying feedback message. Among 26 intervention group participants, the adherence rate for responding to the message was 49% (SD 28) [18]. In another intervention using a wearable pedometer (the clip-on Fitbit) among women, mean number of days of wear-time was 106 out of 112 days (94%) [42], which is comparable with our data in which out of 70 opportunities to log a step count via Fitbit wristband pedometer, the mean number of times that participants recorded their steps was 64, or 91%. Taken together, our study has comparable outcomes with other research using mHealth strategies for

weight or weight-related behaviors, such as physical activity. It is possible that high levels of engagement with intervention components are the result of the integration of mHealth into participants' daily lives, allowing for simpler and more frequent self-monitoring.

In addition, there were several beneficial physiological, behavioral, and other variables. Notably, weight change decreased by a mean of 3.38 pounds, which reflects a 2% loss of baseline weight. Although this is lower than the generally accepted clinically meaningful weight loss level of 5%, our intervention was of a shorter duration (10 weeks) and of a moderate intensity level that may be able to be sustained over the long term. Combined with changes in diet and physical activity as well as changes in other variables such as fatigue and sleep, participation in the intervention led to multiple beneficial changes that could be further examined in a larger trial.

About half of our participants were reflective of a population facing health disparities (ie, low income or belonging to a racial/ethnic minority group). Others have examined the use of mHealth strategies among health disparity populations. For example, Smith and colleagues [43] examined the preferences of African American breast cancer survivors for lifestyle modification and found that peer-led sessions and incorporation

of support groups would be important components of intervention strategies. The integration of human-based intervention components such as counselor-delivered phone calls with technology-related approaches was also supported by the weight management study conducted among breast cancer survivors by Spark and colleagues [44]. We ultimately decided to involve human coaching because it is not yet established that fully automated eHealth/mHealth interventions have comparable efficacy with interventions that utilize human counselors [11]. Thus, future directions for mHealth interventions for breast cancer survivors from health disparity-facing groups could investigate optimal ways of integrating human-based components, such as behavioral counseling, into mHealth-based interventions. The scalability of this approach can be broadened as community health workers/patient navigators are increasingly integrated into health care systems [45] and can support telephone-based delivery of behavioral interventions. This approach can become even more widely implemented as devices become more available across population groups (eg, among low-, medium-, and high-resourced groups) and data from these devices become better integrated with electronic medical records.

Limitations to our pilot study design include a lack of a control group and a small sample size. Although it is appropriate for sample sizes for pilot studies to be based on practical considerations based on recruitment and budgetary limitations [46], a larger sample size may have expanded our capacity to generate feasibility data. In addition, our eligibility criteria requiring ownership of a smartphone and home WiFi is also a limitation in that it may have led to bias in our sampling design [47]; our criteria may have excluded members of our target

population (for example, women from low-income groups without access to home WiFi). These design decisions were made to enable the functionality of the weight scale (which relied on a WiFi connection) and because providing smartphones was beyond the financial resources of the study. However, in future work, we will select newer devices that do not rely on WiFi connectivity, and examine the option of providing lower-cost smartphones to those who do not own one. Another limitation is the lack of objective assessment of physical activity at baseline and follow-up time points via accelerometry. Our self-reported data on physical activity likely reflect an overestimation of physical activity, yet may still be useful in exploring the direction of change from baseline to follow-up time points. Similarly, the data on steps/day as measured by the wristband pedometer during the intervention period also reflected moderately high levels of physical activity. Moreover, other research has shown that the Fitbit Flex wristband pedometer can underestimate step count in treadmill walking and running [48]. Taken together, future studies may consider eligibility criteria in which participants have lower levels of physical activity upon entry to the study. Future research will also systematically capture cancer stage and treatment details from the medical record.

In conclusion, our findings demonstrate that a pilot test of an mHealth-supported behavioral counseling intervention conducted among breast cancer survivors was feasible and demonstrated some positive physiological and behavioral changes. Future work could examine this intervention approach in a larger study, powered to detect significant changes in weight, and further investigate optimal ways to integrate behavioral counseling with mHealth strategies.

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## Authors' Contributions

LMQ and DMM contributed to the study design and LMQ, DMM, and MP contributed to the implementation, interpretation of results, and writing of the manuscript. EQ conducted data analyses and contributed to the writing of the manuscript.

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## Conflicts of Interest

None declared.

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## Abbreviations

**BEVQ:** Beverage Questionnaire



**BMI:** body mass index

**IPAQ:** International Physical Activity Questionnaire

**mHealth:** mobile health

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Original Paper

# The Effects of Physical Activity on Health and Quality of Life in Adolescent Cancer Survivors: A Systematic Review

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## Abstract

**Background:** There are numerous published controlled trials assessing the safety and the benefits of physical activity (PA) for child and adult cancer survivors. However, trials exclusively comprised of adolescent cancer survivors aged 13-19 years, who may experience different health and quality of life (QOL) effects as a function of their developmental status, are lacking. Rather, some trials have included both adolescent and child cancer survivors together.

**Objective:** The aim of this systematic review was to synthesize the findings from randomized controlled trials (RCTs) and controlled clinical trials (CCTs) investigating the effects of PA on health and QOL outcomes in samples comprised of >50% adolescent cancer survivors to summarize the current state of evidence, identify knowledge gaps, and highlight areas in need of additional research within this population.

**Methods:** Using a search strategy developed for this review, 10 electronic databases were searched for RCTs and CCTs that reported on the effects of PA on at least 1 health and/or QOL outcome in samples comprised of >50% adolescent cancer survivors.

**Results:** From the 2249 articles identified, 2 CCTs met the predetermined eligibility criteria and were included in this review. Combined, 28 adolescents (of 41 participants) who were receiving active treatment participated in the 2 studies reviewed. A total of 4 health and QOL outcomes (ie, bone mass, fatigue, grip strength, QOL) were assessed pre- and post-PA intervention.

**Conclusions:** On the basis of the 2 studies reviewed, PA appears to be safe and feasible. PA also shows promise to mitigate reductions in bone mass and might be a viable strategy to improve fatigue, grip strength, and QOL. High-quality controlled trials with larger samples exclusively comprised of adolescent cancer survivors that assess a wide range of outcomes are needed to determine the effects of PA on health and QOL outcomes in this population.

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**KEYWORDS**

exercise; controlled clinical trial; randomized controlled trial; review; treatment effectiveness

## Introduction

Each year in North America, more than 7500 adolescents are diagnosed with cancer [1,2], thereby becoming a “cancer survivor” as the National Cancer Institute defines a cancer survivor from the point of diagnosis onward [3]. Accordingly, a cancer survivor is a person who may be awaiting treatment,

be actively receiving treatment (ie, on-treatment), or have completed treatment (ie, off-treatment). Approximately 80% of adolescents will live at least 5 years after they are diagnosed with cancer [4]. Although this rate reflects a relatively good prognosis, adolescent cancer survivors often report negative side effects (eg, fatigue, pain [5]) and have an increased risk of disability, morbidity, and premature mortality [6-10]. Furthermore, they may have impaired psychological and social

functioning [11,12], which can hinder their health and quality of life (QOL [13,14]).

There have been several trials testing the effects of physical activity (PA) on health and QOL outcomes among cancer survivors [eg, 15-18], and several reviews have summarized the findings [eg, 19-22]. Combined, this work shows that PA can help to reduce the risk of disability (eg, physical limitations, neurocognitive impairments), morbidity (eg, obesity, diabetes, cardiovascular diseases, second cancers, organ dysfunctions), and premature mortality. This work also shows that PA may decrease some of the negative side effects reported by cancer survivors, as well as improve health and QOL across different domains of functioning (ie, physical, psychological, emotional, social [15-22]). In recognition of these benefits, several cancer organizations recommend that cancer survivors incorporate PA into their daily lives [23,24], and many groups have developed PA guidelines for cancer survivors [25,26]. Notwithstanding the contributions of existing trials and reviews, none have focused exclusively on adolescent cancer survivors [15-22], preventing the development of age-appropriate PA guidelines for this population.

The Public Health Agency of Canada defines adolescents as individuals aged 13-19 years [27]. This life stage is characterized by the onset of puberty, a period when a number of biological, physical, psychological, emotional, social, and cognitive changes occur [28,29]. A diagnosis of cancer during this time may cause deviations from normative developmental changes [30]. For example, chemotherapy and radiation can result in precocious puberty, gonadal dysfunction, and infertility [31,32]. These treatments may also result in growth hormone deficiency, which has been related to decreased muscle mass, reduced PA tolerance, and impaired growth [33]. Furthermore, some of the physical challenges associated with cancer and its treatments markedly reduce PA levels [34], which may partly explain the increased odds of adolescent cancer survivors being obese by 2.59 for females and 1.86 for males compared to their siblings without a history of cancer [35]. These biological and physical challenges and changes can negatively impact adolescents' body image and adversely affect their physical, psychological, emotional, and social functioning [36]. Thus, cancer and its treatments may affect adolescents' psychological, social, and cognitive development, which can impair their ability to master necessary skills in these areas [37-39]. It can also lead to psychological, social, and cognitive maladjustment such as anxiety, depression, poor social relations, and lower educational and/or occupational attainment [37-39]. It is therefore imperative to determine if PA can be used as a strategy to reduce the negative effects of cancer on adolescents' normative biological, physical, psychological, emotional, social, and cognitive development.

Given that adolescence is a time of tremendous growth and development [28,29], which can be challenged by cancer, the findings from PA trials and reviews focused on younger and older cancer survivors should be extrapolated cautiously and efforts should be made to examine the effects of PA on these outcomes in adolescent cancer survivors specifically. Hence, the aim of this systematic review of the literature was to synthesize the findings from randomized controlled trials (RCTs)

and controlled clinical trials (CCTs) investigating the effects of PA on health and QOL outcomes in adolescent cancer survivors to summarize the current state of evidence in this population, identify knowledge gaps, and highlight areas in need of additional research.

## Methods

The review was carried out following established criteria for the good conduct and reporting of systematic reviews (ie, Preferred Reporting Items for Systematic Review and Meta-Analyses, Cochrane Handbook for Systematic Reviews of Interventions, Consolidated Standards of Reporting Trials, Guidance on the Conduct of Narrative Synthesis in Systematic Reviews [40-45]). The full review protocol is published elsewhere [46].

### Search Strategy

First, 10 electronic databases were searched (ie, CINAHL, Cochrane Central Register of Controlled Trials, EMBASE, LILACS, MEDLINE, PEDro, Physical Education Index, PsycINFO, PubMed, SPORTDiscus) for articles published in English in peer-reviewed scientific journals from database inception to November 2015. A combination of Medical Subject Heading terms and keywords covering the target population (eg, adolescent, young person, teen, cancer patient), intervention (eg, exercise, PA, physical fitness), and comparison condition (eg, control group, usual care) were used after consultation with an expert librarian (YL). Of note, these search terms were revised and refined after conducting an initial search. The rationale for this is presented in the published systematic review protocol [46], along with additional details on the specific search strategy and how it was developed. Next, the reference lists of all relevant articles identified in the electronic databases were searched to identify additional studies.

### Selection of Studies

Both authors screened the titles and abstracts of all studies identified during the search using the following predetermined eligibility criteria: (1) reported the effect(s) of PA on at least 1 health and/or QOL outcome, (2) used a RCT or CCT study design, (3) had at least pre- and post-intervention assessments, and (4) had a sample comprised of >50% cancer survivors aged 13-19 years. The latter criterion was based on precursory knowledge that no PA trials have been conducted with samples exclusively comprised of adolescent cancer survivors. For the purpose of this review, an intervention was considered as anything greater than 1 PA session. Studies were excluded if they had multiple program features that could be attributed to the outcomes reported or if they had insufficient details on the target population, intervention, comparison condition, and/or outcomes (after the study authors were contacted by email and it was determined that the requested data were unavailable). The inter-rater agreement between both authors on the eligibility of studies was >95%, representing a high level of agreement [47]. In instances of disagreement during the review process, consensus was reached through discussion with 2 independent researchers (AJ and CO).

## Data Extraction

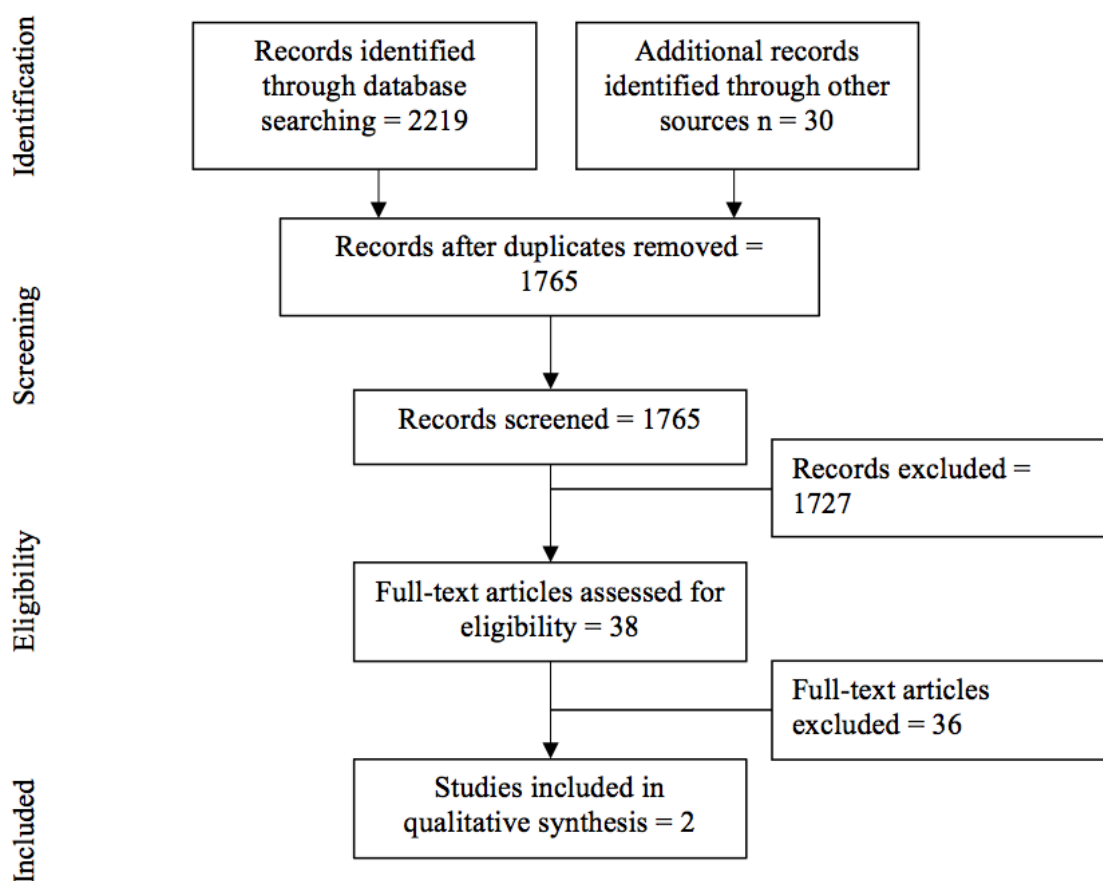
Both authors extracted the following information from the eligible articles: (1) study characteristics (ie, year of publication, country, study design), (2) sample characteristics (ie, number of participants randomized, age, type(s) of cancer diagnosed, treatment status), (3) intervention characteristics (ie, supervision, setting, length, frequency, duration, intensity, activity types(s)), (4) outcome measures, and (5) outcomes (ie, health, QOL). Additional relevant information such as the use of theory and whether intention-to-treat analysis was performed were also recorded. In cases where details were missing, authors were contacted by email.

## Results

As illustrated in [Figure 1](#), a total of 2249 articles were identified during the search, of which 2219 were from the electronic search

and 30 were from the manual screening of reference lists. After 484 duplicates and 1727 articles that did not meet eligibility criteria were excluded, 38 full-text articles were considered potentially relevant. Both authors independently reviewed the full-text articles and determined that 36 studies were not eligible for review for the following reasons: study was not published in English (n=1), no full-text was available (n=12), no control group (n=3), no PA intervention (n=6), multiple program features (n=1), protocol article (n=2), no health and/or QOL outcome reported (n=1), and age criteria not met (n=10). For those studies that were excluded because of the age criteria, participants were either above the defined age range [48-55] or samples were comprised of ≤50% adolescents [56,57]. This left 2 articles that met the predetermined eligibility criteria [58,59].

**Figure 1.** Flow chart of search results.



## Study Characteristics

[Multimedia Appendix 1](#) provides an overview of the characteristics of the reviewed studies. Müller et al [58] published their CCT in 2014 and Rosenhagen et al [59] published their CCT in 2011. Both studies were conducted in Germany [58,59].

## Sample Characteristics

There were a total of 41 participants between the 2 studies. Müller et al [58] included 21 participants (mean age = 14.0 years; 67% (ie, 14 of 21) were aged 13-19 years), who were diagnosed with malignant bone tumors in the lower extremity and were currently receiving adjuvant treatment. Rosenhagen et al [59] included 20 participants (mean age = 15.3 years; 70% (ie, 14 of 20) were aged 13-19 years), diagnosed with mixed

cancer during the isolation phase of peripheral blood stem cell transplant.

### Intervention Characteristics

Both interventions varied considerably with regard to the type of PA intervention and reported characteristics. Thus, each intervention is described separately. Müller et al [58] delivered an in-hospital PA intervention during participants' inpatient stay (range = 8-12 inpatient stays) over a 6-month period. PA sessions were offered from Monday to Friday. Participants who were not able to leave the ward to attend the session had the opportunity to complete the PA session in their hospital room. Participants were advised to attend the PA sessions at least every second day while admitted as an inpatient. Sessions lasted 15-45 minutes and included aerobic activity (ie, stationary bicycling, walking or jogging on the treadmill, using an elliptical trainer), strength training (ie, multiple joint exercises such as squats, lunges, rowing), balance and flexibility training, and sports games (eg, football, basketball, table tennis) at moderate-to-vigorous intensity. Borg's Rating of Perceived Exertion Scale was used to monitor PA intensity. All sessions were supervised by 2 trained sports therapists [58].

Rosenhagen et al [59] delivered an in-hospital PA intervention during participants' inpatient stay over a 5- to 7-week period. PA sessions were offered 3 times/week in participants' hospital room. Sessions lasted 50 minutes and included moderate-intensity aerobic activity (ie, stationary bicycling) and strength training using barbells, balls, and participants' own body weight (eg, squats, side steps, balancing on 1 leg). A heart rate monitor was used to ensure participants engaged in PA at the intended intensity. Trained sports therapists supervised each session [59].

### Intervention Outcomes

The results of the PA interventions are presented in [Multimedia Appendix 2](#). The 4 health and QOL outcomes that were assessed included: (1) bone mass, (2) fatigue, (3) grip strength, and (4) QOL. PA levels, intervention acceptance, intervention adherence, and adverse events were the non-health or QOL outcomes that were reported.

#### Health and QOL Outcomes

Müller et al [58] assessed bone mass with dual-energy X-ray absorptiometry, Lunar Prodigy System (enCore 2006, Software version 10.51.006; GE Healthcare, Madison, WI, USA). Changes analyzed using multivariate analysis of covariance showed decreases in bone mineral content (BMC), bone mineral density (BMD), and height-corrected lumbar spine Z-scores over the course of the intervention and at follow-up in both groups. Despite decreases in BMC, BMD, and height-corrected Z-scores in both groups, these declines were attenuated (nonsignificantly) in the intervention group compared with the control group. There was no significant difference between groups in BMC over the course of the intervention and at follow-up. There were significant differences in lumbar spine BMD and height-corrected lumbar spine Z-scores in the intervention group compared with the control group post-intervention; however, this difference was no longer significant at follow-up [58].

Rosenhagen et al [59] assessed fatigue and found that participants' symptoms of fatigue improved, albeit not statistically significantly, over the course of the study for those assigned to the PA intervention. It is not possible to determine if fatigue differed between the intervention and control groups as no comparisons between groups were made [59].

Rosenhagen et al [59] assessed grip strength using a hand-held dynamometer (JAMAR; Homecraft Ltd, Kirby-in-Ashfield, Nottinghamshire, UK). On average, grip strength increased nonsignificantly from baseline to day 14, but returned to baseline levels post-intervention. It is not possible to determine if grip strength differed between the intervention and control groups as no comparisons were made between groups [59].

Rosenhagen et al [59] assessed QOL using participant reports on the German version of the KINDL and its associated oncology subscale [59,60]. Over the course of the study, participants in the intervention group reported a nonsignificant U-shaped trend in general QOL, that is, levels decreased from baseline to day 14 and then increased from day 14 to post-intervention. Cancer-specific QOL increased nonsignificantly over time in the intervention group. It is not possible to determine if general or cancer-specific QOL differed between groups as no comparisons were made between groups [59].

#### Other Outcomes

Müller et al [58] assessed daily PA levels using accelerometers (StepWatch 3<sup>TM</sup> Activity Monitor; Orthocare Innovations, Washington, DC, USA). Post-intervention (ie, 6 months after baseline) and follow-up (ie, 12 months after baseline) levels of PA were assessed in the intervention and control group. At post-intervention, the intervention group engaged in more PA (16.9 minutes/day) than the control group (1.7 minutes/day), and the effect size for this difference was large. Also, at follow-up, both the intervention and control group increased their levels of PA. However, the intervention group continued to engage in more PA (25.2 minutes/day) than the control group (8.0 minutes/day), and the effect size for this difference was large [58].

Rosenhagen et al [59] assessed participants' acceptance of the intervention by asking participants to discuss their general opinion of the inpatient PA intervention during semi-structured interviews. For those assigned to the intervention group, they were asked to think about the PA intervention they participated in, whereas for those assigned to the control group, they were asked their opinion after receiving a description of the PA intervention delivered to those in the intervention group. Overall, participants in the intervention group held positive opinions, whereas the control group expressed skepticism about participating in such an intervention because of the additional burden they perceived it would have [59].

Müller et al [58] assessed adherence and operationalized it as the number of times the intervention was received (mean = 34.5 ± 8 PA sessions) out of the total amount of times the intervention was to be delivered (mean = 44.8 PA sessions). They reported an adherence rate of 77% [58]. Rosenhagen et al [59] did not report on adherence. No adverse events were reported in either



of the PA interventions, leading the authors of the 2 studies included in this review to conclude that their PA interventions were safe [58,59].

## Discussion

### Principal Findings

This systematic review summarizes the best available evidence regarding the effects of PA on health and QOL outcomes for samples comprised of >50% adolescent cancer survivors. A total of 2 CCTs were identified that had mixed samples of children and adolescents [58,59]. Although there was a lack of statistical significance for most outcomes, trends in the data show that PA may be a useful strategy to improve health and QOL in adolescent cancer survivors. Specifically, the studies found that bone mass, fatigue, grip strength, and QOL were maintained or improved in the PA intervention group. Simple inspection of mean values demonstrated that PA may confer clinically meaningful changes (ie, experienced as relevant by the participants). Indeed, researchers have suggested that the smallest change in a treatment outcome that patients would identify as important signifies a clinically meaningful effect [61].

Given the evidence that PA can improve symptoms of fatigue in adult cancer survivors [62,63], Rosenhagen et al [59] tested whether a PA intervention could improve symptoms of fatigue in child and adolescent cancer survivors. Although fatigue scores improved over the course of the intervention, the change was not statistically significant. This is in contrast to the overwhelming evidence that PA does improve symptoms of fatigue in adult cancer survivors [62,63], and the emerging evidence with samples comprised of both children and adolescents. For example, Yeh et al [57] delivered a 6-week home-based PA intervention using active video games to a sample of child and adolescent cancer survivors (ie, 32% adolescents, 7 of 22 participants). Participants reported improved mean fatigue scores in the intervention group over the course of the intervention; however, these changes did not result in statistically significant differences between the intervention and control group when intention-to-treat analysis (which considers the outcomes of all participants regardless of whether they received their assigned treatment) was used [57]. In contrast, when per-protocol analysis (which considers only the outcomes of participants who received their assigned treatment) was used, general fatigue scores were significantly different between the intervention group and the control group at 1-month follow-up [57]. Given the divergent findings both across studies and within studies depending on the analytical approach, more research is necessary to determine the efficacy of PA to improve symptoms of fatigue in adolescent cancer survivors. Furthermore, researchers should explore how improvements in symptoms of fatigue may in turn promote other positive physical and psychosocial outcomes (eg, emotional well-being, social engagement, cognitive functioning) in adolescent cancer survivors.

Although the included studies had samples comprised of 67% [58] and 70% [59] adolescents, it must be underscored that no published controlled trials examining the effects of PA in a

sample exclusively comprised of adolescent cancer survivors aged 13-19 years were identified when this review was conducted. Both studies reviewed had survivors as young as 6 and 8 years. This is an important consideration that should be taken into account when interpreting the findings from the included studies. Moving forward, researchers seeking to study the effects of PA on health and/or QOL outcomes in adolescent cancer survivors could conduct trials at multiple sites to enroll larger samples of adolescents. Researchers could also consider reporting results for adolescents separately in cases where they have mixed samples that include children and/or adult cancer survivors. For example, although not reviewed herein because adolescents comprised a minority of the sample (ie, 38% adolescents, 11 of 29 participants), Hinds et al [56] separated data for the adolescent cancer survivors in their enhanced-activity intervention. However, the authors only reported the *P*-values for the total sample in the Results section, thereby making it difficult to determine if there were significant differences in the outcomes of interest (ie, sleep efficiency, fatigue) for adolescents.

In line with a previous systematic review conducted with pediatric cancer survivors aged 2-21 years [19,20], the reviewed studies had small sample sizes [58,59]. It is therefore plausible that the authors of the included studies did not detect statistically significant effects because they lacked sufficient statistical power. It is also possible that the intensity and duration of PA was insufficient to produce change in the outcomes assessed. In addition, given the evidence that long-term involvement in PA may be needed to affect health (ie, fatigue, strength) and QOL outcomes [64-66], the interventions may not have been long enough to affect the studied outcomes. Accordingly, it is possible that increasing the dose of PA, and offering interventions lasting longer, may yield statistically and clinically significant effects on health and QOL. Both studies included reported on the effects of PA for adolescent cancer survivors who were undergoing treatment [58,59]. Considering that treatments are associated with severe declines in physical, psychological, emotional, social, and cognitive functioning [5-14], it is conceivable that small improvements, or even maintenance, may translate into clinically important differences in health-related outcomes for this population.

The effects of PA on a wider range of health and QOL outcomes cannot be established as the CCTs included in this review focused mainly on physical health outcomes (ie, bone mass, fatigue, grip strength [58,59]). Considering that adolescence is a time of tremendous biological, physical, psychological, emotional, social, and cognitive development [28,29], it is especially important to assess outcomes in each of these areas to determine if PA can help promote optimal development for adolescent cancer survivors. For instance, biological changes (eg, impaired growth, weight gain or loss, early or delayed sexual maturation [30-35]) may lead some adolescent cancer survivors to feel physically different from their peers, heightening their experiences of body dissatisfaction, which may manifest as social anxiety, psychological distress, and avoidance of health protecting behaviors such as PA [36,67]. In addition, psychological, social, and cognitive development (eg, establishing autonomy and independence, building social

skills and coping resources) may be negatively impacted by cancer and its treatments [37-39]. It is therefore necessary to determine if PA can facilitate the development of positive health behaviors, improve body image, mitigate psychosocial maladjustment (eg, anxiety, psychological distress, depression, social skills/functioning), and address cognitive limitations (eg, fine motor, visual-spatial and nonverbal skills, attention, concentration).

Although for the most part, PA was not shown to significantly affect adolescent cancer survivors' health and QOL at the conventional 5% level of significance, it is important to balance the lack of evidence based on the reviewed CCTs with the previously mentioned limitations of each. Combined with evidence from case-series studies linking PA to improvements on various outcomes in this population (eg, [68]) and the overwhelming evidence for the benefits of PA in pediatric and adult cancer survivors [19-22], it seems prudent to recommend that adolescent cancer survivors engage in PA, especially given the lack of adverse events in the reviewed studies. Indeed, based on previous reviews with pediatric [19,20] and adult cancer survivors [21,22], the low dropout rates, high adherence to the intervention protocols, and ability to recruit participants in the studies reviewed, it can be concluded that PA is not only safe but also feasible for adolescent cancer survivors undergoing treatment. As such, health care providers may recommend PA to their patients without fear of harm, provided they take into account contraindications that would make PA potentially inadvisable for certain patients (eg, cardiopulmonary disease, neurological problems, impairments in general performance limiting mobility [25,26]). To date, few resources exist for health care providers who want more information regarding the safety and benefits of PA for adolescent cancer survivors [26]. Thus, many groups are developing resources. For example, based on the findings of this review, and recommendations from other research and resources [15-26], the authors of this manuscript are developing a PA pamphlet that health care providers may give to adolescent cancer survivors. In the meantime, health care providers can encourage adolescent cancer survivors to engage in PA. Health care providers should also take into account adolescents' past PA behavior, current physical condition, contraindications, and PA preferences and may also consider referring adolescent cancer survivors to a PA specialist who has received training in cancer and PA.

### Limitations

The limitations of the current review should be taken into account. First, although the strength of conducting a systematic review is the ability to integrate and pool existing data to draw firm conclusions and determine effect sizes [69], the lack of

studies and the variability in the interventions and outcomes reported in the studies reviewed prevented this. Second, publication bias was not assessed, and no attempts were made to identify unpublished studies. Third, details were missing in the studies reviewed. The authors of the studies reviewed responded to emails requesting additional information about their study; however, to facilitate systematic reviews and meta-analyses and to ensure rigor and transparency in research, researchers should adhere to existing guidelines for the conduct and reporting of trials (eg, Consolidated Standards of Reporting Trials, Transparent Reporting of Evaluations with Nonrandomized Designs [44,70]). Fourth, the search strategy used may not have identified all trials published on this topic. In an attempt to minimize this, the reference lists from previously published articles retrieved in the database search were scanned. Finally, adolescent cancer survivors were defined as individuals with cancer in their teenage years (ie, 13-19 years), which is in line with the range used by the Public Health Agency of Canada [27], other researchers [71], and an existing review of symptom clusters in adolescent oncology [12]. As a result, studies containing samples fitting different definitions or those with samples comprised of  $\leq 50\%$  of boys and girls aged 13-19 years were excluded.

On the basis of the current review, there is insufficient evidence available to conclude that PA affects adolescent cancer survivors' health and QOL. The lack of RCTs and CCTs stands in stark contrast to the extant literature providing evidence for the effects of PA on health and QOL in younger [19,20] and older cancer survivors [21,22]. More high-quality research exploring the effects of PA on health and QOL outcomes in samples containing only adolescent cancer survivors is necessary because PA could offer a cost-effective, non-pharmacological, self-managed strategy to help adolescents manage the burden of cancer. To improve the quality of evidence-based medicine, studies should use RCT or CCT designs, have adequate sample sizes to detect minimal clinically important differences, and ensure intervention dosage is sufficient to elicit changes in the desired outcomes (ie, frequency, intensity, type, duration). Furthermore, studies should also assess the effects of PA on a broad range of biological, physical, psychological, emotional, social, and cognitive health outcomes. Finally, using the Physical Exercise Across the Cancer Experience framework [72] may ensure adolescents at different phases of the cancer trajectory (eg, during treatment, survivorship, palliation) are included in PA trials. This framework could not only help guide researchers seeking to examine the effects of PA across the entire cancer experience but also help answer questions about the optimal time to implement PA interventions for adolescent cancer survivors.

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## Authors' Contributions

AW and JB conceptualized and designed the systematic review protocol, performed the systematic literature searches, screened and selected studies, and extracted and interpreted the data. They were involved in all aspects of drafting, revising, and finalizing this manuscript. Furthermore, both approved the order of authorship.

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Characteristics of the included physical activity interventions.

[[PDF File \(Adobe PDF File\), 35KB - cancer\\_v2i1e6\\_app1.pdf](#)]

## Multimedia Appendix 2

Measures and outcome results from the included physical activity interventions.

[[PDF File \(Adobe PDF File\), 37KB - cancer\\_v2i1e6\\_app2.pdf](#)]

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## Abbreviations

**BMC:** bone mineral content  
**BMD:** bone mineral density  
**CCT:** controlled clinical trials  
**PA:** physical activity  
**QOL:** quality of life  
**RCT:** randomized controlled trial

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Original Paper

# Assessment of Cancer Survivors' Experiences of Using a Publicly Available Physical Activity Mobile Application

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## Abstract

**Background:** Regular participation in physical activity (PA) is associated with improved physical and psychosocial outcomes in cancer survivors. However, PA levels are low during and after cancer treatment. Interventions to promote PA in this population are needed. PA mobile apps are popular and have potential to increase PA participation, but little is known about how appropriate or relevant they are for cancer survivors.

**Objective:** This study aims to (1) assess recruitment, study uptake, and engagement for a publicly available PA mobile app (GAINFitness) intervention in cancer survivors; (2) assess cancer survivors' attitudes towards the app; (3) understand how the app could be adapted to better meet the needs of cancer survivors; and (4) to determine the potential for change in PA participation and psychosocial outcomes over a 6-week period of using the app.

**Methods:** The present study was a one-arm, pre-post design. Cancer survivors (N=11) aged 33 to 62 years with a mean (SD) age of 45 (9.4), and 82% (9/11) female, were recruited (via community/online convenience sampling to use the app for 6 weeks). Engagement with the app was measured using self-reported frequency and duration of usage. Qualitative semi-structured telephone interviews were conducted after the 6-week study period and were analyzed using thematic analysis. PA, well-being, fatigue, quality of life (QOL), sleep quality, and anxiety and depression were self-reported at baseline and at a 6-week follow-up using the Godin Leisure Time Exercise Questionnaire (GLTEQ), the Functional Assessment of Cancer Therapy-General (FACT-G), the Functional Assessment of Chronic Illness Therapy (FACIT)-Fatigue Scale Questionnaire, the Health and Quality of Life Outcomes (EQ5D) Questionnaire, the Pittsburgh Sleep Quality Index (PSQI), and the Hospital Anxiety and Depression Scale (HADS), respectively.

**Results:** Of the people who responded to the study advertisement, 73% (16/22) agreed to participate and 100% (11/11) of the participants who started the study completed all baseline and follow-up outcome measures and the telephone interview. On average, participants used the app twice a week for 25 minutes per session. Four themes were identified from the qualitative interviews surrounding the suitability of the app for cancer survivors and how it could be adapted: (1) barriers to PA, (2) receiving advice about PA from reliable sources, (3) tailoring the application to one's lifestyle, and (4) receiving social support from others. Pre-post comparison showed significant increases in strenuous PA, improvements in sleep quality, and reductions in mild PA. There were no significant changes in moderate PA or other psychosocial outcomes.

**Conclusions:** All participants engaged with the app and qualitative interviews highlighted that the app was well-received. A generic PA mobile app could bring about positive improvements in PA participation and psychosocial outcomes among cancer

survivors. However, a targeted PA app aimed specifically towards cancer survivors may increase the relevance and suitability of the app for this population.

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## KEYWORDS

cancer survivors; mobile applications; mHealth; physical activity; sleep

## Introduction

It is estimated that 1 in 2 people born in the United Kingdom (UK) after 1960 will develop cancer during their lifetime [1]. However, improvements in early detection, diagnosis, and treatment mean that cancer mortality is falling, with 50% of people being diagnosed with cancer now surviving more than 10 years. The rising incidence and falling mortality of cancer has led to an increase in the number of cancer survivors. In the context of cancer, “a person is considered to be a survivor from the time of diagnosis until the end of life” [2]. In the United Kingdom, there are currently over 2 million people living with or beyond a cancer diagnosis; this has doubled in the last 40 years and continues to increase by 3% each year [3].

Fatigue [4], poor sleep quality [5], reduced quality of life (QOL) [6,7], pain [8], physical side effects (eg, lymphedema) [9,10], depression, anxiety and/or fear of cancer recurrence [11-14] are common among cancer survivors as a consequence of diagnosis, treatment, and side effects. The Living With and Beyond Cancer (LWBC) Program was formed in partnership between the UK Department of Health, the National Health Service (NHS), and a large national cancer charity, Macmillan Cancer Support, to improve the overall care and support needs of the growing population of cancer survivors. One key area of focus for the LWBC Program is to promote participation in physical activity (PA) among cancer survivors due to the accumulating body of evidence illustrating the benefits of PA for this population. Evidence includes an increased chance of survival (both cancer-specific [15-17] and all-cause survival [16,17]), reduced risk of cancer recurrence [16], improved physical and psychological health and consequences of treatment (eg, fatigue [18-22], sleep disturbance [18,23], pain [18], muscle strength [22,24-26], physical functioning [27], well-being [18], QOL [18-20,22,28,29], anxiety and depression [22,30]) and a reduced risk of comorbidities (eg, hypertension, cardiovascular disease, and diabetes) [31]. Much of this research has involved breast, prostate, and colorectal cancer survivors and so the evidence is strongest for these cancer types. Evidence of the benefits of PA for survivors of other cancer types (eg endometrial [32-36], hematological [37], and head and neck [26] cancers) is emerging.

Despite the benefits of PA, only 35% of cancer survivors engage in at least 2 hours of PA per week compared to 45% of those without a history of cancer [38]. The majority of cancer survivors do not meet the recommended minimum guideline of 150 minutes of moderate to vigorous PA per week, although this varies by cancer type [39]. Furthermore, PA levels fell and sedentary behavior rose in those who received a cancer diagnosis compared to those who did not in the English Longitudinal Study of Ageing [40]. The fall in PA participation as a result

of cancer is likely due in part to the experienced deterioration in health and well-being and common side effects, such as cancer-related fatigue [41]. Fatigue is one of the most commonly reported and debilitating side effects of cancer treatment and can continue for many months or years after completion of treatment [4,42].

The majority of PA interventions involve considerable contact between health care practitioners and fitness professionals delivering the PA program to participants. They often use face-to-face delivery methods and/or frequent structured support with a health professional or member of the research team [43-47]. Many of these intervention studies demonstrate promising results in improving participation in PA and provide evidence of the associated benefits. However, such approaches also face the challenge of being resource-intensive, expensive, and limited in terms of the number of cancer survivors who are able to access them. Therefore, a low-cost and broad-reaching strategy is warranted.

The rising use of mobile phones and mobile technology has afforded the opportunity to develop a relatively low-cost approach to intervention delivery with the potential to reach a large number of users. The most recent Ofcom report (2015) [48] revealed that 66% of UK adults own a mobile phone, a 27% increase since 2012, demonstrating the rapidly rising number of mobile phone owners. The report also revealed that 49% of 55 to 64 year olds and 17% of people aged over 65 own mobile phones, a number which is accelerating rapidly and expected to continue. Many people use mobile apps to support or motivate a healthy lifestyle [49], and previous studies have found mobile health (mHealth) interventions using apps to be successful in a range of health contexts including weight loss [50] and management of diabetes [51]. PA apps are particularly popular, with an estimated 1 in 5 mobile phone users having installed at least one PA app on their mobile device [52]. Despite the vast number of PA apps available for download (eg, via the App Store or Google Play), there are very few specifically aimed at improving PA participation among cancer survivors. Cancer survivorship apps currently available to the public tend to relate to cancer-related information, accessing and storing plans for treatment and follow-up care, patient health records, symptom tracking and monitoring, and connecting cancer survivors for peer-support. There is a lack of cancer-related apps that are supported by scientific evidence [53]. While some of the survivorship apps mention PA, currently there are very few with a specific focus on improving PA participation among cancer survivors, particularly outside of the research context. In a mixed-methods study by Hong and colleagues involving 112 cancer survivors, the researchers collected data to inform the design of a website (also accessible via mobile devices) to promote PA among older cancer survivors (iCanFit) [54]. The

researchers found this group welcomed the idea of using their mobile phone and the Internet to improve their PA participation, as well as to set and track their fitness goals online. A pilot of the iCanFit program with a sample of older cancer survivors (aged 60 to 78) revealed significant improvements in participants' QOL and participation in PA [55]. These findings demonstrate the acceptability and ability of Internet- and mobile-based interventions to promote PA among older cancer survivors.

Currently there are few mobile apps specifically aimed at promoting PA among cancer survivors, particularly outside of the research context. Therefore the aims of this study are (1) to assess recruitment, study uptake, and engagement for a publicly available PA mobile app intervention amongst breast, prostate, and colorectal cancer survivors; (2) to assess the attitudes of breast, prostate, and colorectal cancer survivors towards a publicly available PA app; (3) to understand how a PA app for the general population could be adapted to better meet the needs of cancer survivors; and (4) to determine the potential for change in PA and psychosocial outcomes (fatigue, well-being, sleep quality, QOL, anxiety and depression) which could be tested in a future randomized controlled trial (RCT).

## Methods

### Study Design

This study uses a one-arm pre-post design with a 6-week follow-up using both qualitative and quantitative techniques. Techniques were selected to ascertain qualitative feedback for intervention development and to model the data collection and intervention process, and outcomes in accordance with the Medical Research Council (MRC) guidance for development of complex interventions [56].

### Participant Recruitment

Participants were recruited via posters, short recruitment messages on the Cancer Research UK forum, and social media cancer support groups using online and community-based methods. Eligibility criteria included adults aged 18 years or older who have received a diagnosis of breast, prostate, or colorectal cancer and who have finished primary curative treatment. As the mobile app was only available on the iOS operating system, participants were also required to own an iPhone to test the application during the study period. The recruitment period lasted 10 weeks.

### Mobile Application

The app chosen for this study was GAINFitness; a free, self-guided PA app aimed towards the general population. GAINFitness is currently available for download on the iOS operating platform via the Apple App Store. The authors have

no association with the developers of GAINFitness. GAINFitness was selected as it provides a PA program based on the user's goals, current fitness level, and equipment they have access to. Moreover, the app incorporates many features that are common among popular PA apps available for public use. On the first use of the app, users are asked a series of questions to tailor the recommended PA program. First, users are asked to identify their fitness goal, the usual location of their PA (eg, at home, the gym, or on-the-go), their desired duration of a workout, and whether they prefer a balanced workout or wish to focus on a particular muscle group (Figure 1). Users are then asked to identify the pieces of equipment they have access to (Figure 2) so that exercises using appropriate equipment are recommended. The app also tailors the program according to the user's PA preferences (Figure 3). They are asked to select a free "fitness pack" on the type of PA to perform (cardiovascular fitness, strength training, yoga, pilates). There are other packs available for purchase via the app, which participants could download if they chose to. The PA program is then tailored to the user's fitness level. The user is required to identify the level of difficulty for their exercises, the "flow tempo" so they can increase the length of time for breaks between each exercise, and whether they would like to include a "warm-up" and "cool-down". The tailoring of the recommended PA program distinguishes GAINFitness from many other PA apps available on the App Store as it is appropriate for users with low baseline PA levels as well as those who are regularly active. Finally, users are asked to identify the days of the week and time of day for their workouts to be completed, and to set a workout reminder (Figure 4). This information is incorporated to set users a 4-week plan tailored to their current PA level, ability, and preferences. After the 4 weeks, the goal can be continued or amended. The tailored workout routines are comprised of individual exercises which participants viewed via video demonstrations, written "Trainer Tips" and spoken instructions on how to perform the exercises correctly (Figure 5). Push notifications were also delivered to the user's device when a scheduled workout was missed.

To the best of our knowledge, no other study has used GAINFitness as a PA intervention nor is there any published literature regarding its development or theoretical basis. Attempts to contact the developers regarding its development and theoretical underpinnings were unsuccessful. However, the Behavior Change Taxonomy [57] was used to identify behavior change techniques (BCTs) incorporated within the app. BCTs included goal setting (behavior), action planning, review behavior goals, feedback on behavior, self-monitoring of behavior, instruction on how to perform behavior, demonstration of the behavior, graded tasks, prompts and cues, and social reward.



Figure 1. Identify exercise goal, location, duration, and muscle group.

GAINFITNESSCancel

Let's build your 4-week GAIN Plan!

Goal

HealthFat LossMuscle

Location

HomeGymOn the Go

Duration - Minutes

1015202530

Muscle Focus

Balanced

Next

Figure 2. Identify accessible exercise equipment.

< Back

☒Dumbbells

☒Kettlebells

☐Exercise Ball

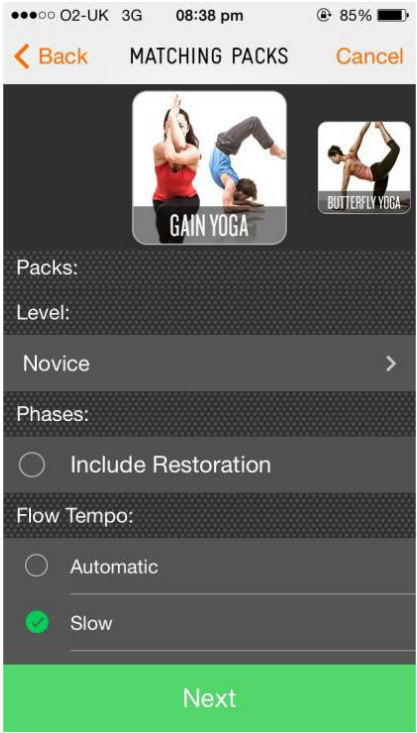
☐Exercise Band

☐Pull-up Bar

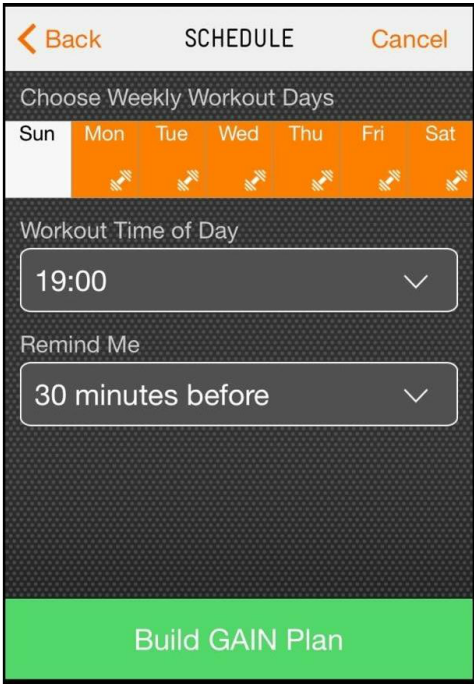
☒Sturdy Table

☒Running Space

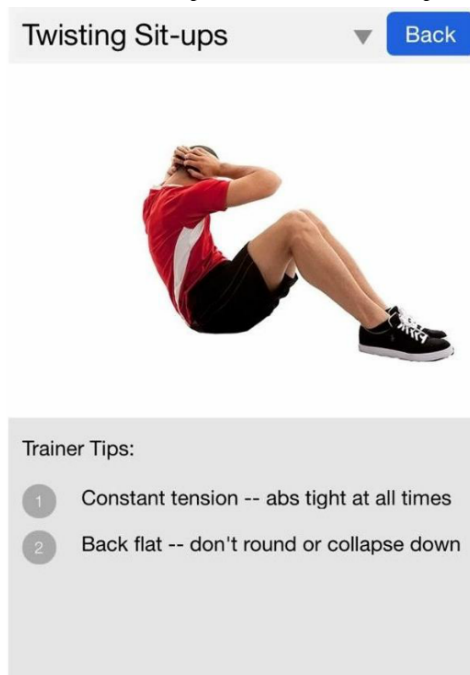
**Figure 3.** Identify preferences for fitness pack, fitness level, warm up and cool down preferences, and breaks between exercises.



**Figure 4.** Identify workout schedule and reminders.



**Figure 5.** Still image from motion video demonstration and trainer tips instructions on how to perform each exercise.



### Qualitative Interviews

Semi-structured interviews were conducted via telephone after the 6-week study period. The interviews aimed to gain in-depth data about the participants' opinions and experiences having used the app, whether they felt it was appropriate for cancer

survivors, and if appropriate, how it could be better adapted to suit their needs. Interviews were recorded with permission of participants, guided by a semi-structured interview schedule (Textbox 1), and were transcribed verbatim. The interviews lasted between 15 to 25 minutes. Two conducted in Polish were translated into English.

**Textbox 1.** Qualitative semi-structured interview topics.

Broad interview topic and discussion points

App features

- Which features of GAINFitness did participants like and dislike
- Features that could be improved and/or were missing
- Thoughts about specific features (eg, video instructions)

Types of workout

- Which workout packs they chose to use
- Their opinions of the types of packs which were available
- Which packs were most suited for them in context of cancer

Workout plan

- Did they use the tailored workout program
- Their experience and opinions of using this (or not)

Tailoring to cancer survivors' needs

- How appropriate the app/exercise program was in promoting PA to cancer survivors
- How could and/or should an app motivate cancer survivors to increase PA (if at all)

Technical experience

- How easy to use was the app
- Any technical issues experienced
- Thoughts about app settings and using the app on a mobile phone from a technical perspective (eg, battery life)

Physical activity

- Thoughts about whether participants felt using app increased their PA
- Stability of those changes (if changes were made)

Pain and injuries

- Did participants experience any pain, injuries or discomfort while exercising using the app

Visuals and layout

- Participants' opinions of the visual/aesthetic aspect of the app (e.g. layout, color scheme)

Outcomes

- Thoughts about whether participants noticed any changes in physical activity, quality of sleep, fatigue, mood, well-being
- Stability of those changes (if any)

Lifestyle

- How did using the app fit in with their lifestyle and needs in the context of cancer

General comments

- Overall opinions of the app
- Whether they're intending to continue using the app
- Any other comments

## Outcome Measures

### *Socio-Demographic and Cancer Outcomes*

In the baseline survey, participants were asked to report standard demographics including age, gender, education level and ethnicity, and weight and height to calculate body mass index (BMI). The questionnaire also included questions on cancer type, cancer stage at diagnosis, type of treatment(s), and time since primary treatment ended (in months).

### *Engagement With the Mobile App*

As the authors have no connection with the developers of GAINFitness, we were unable to obtain objective app usage data (eg, frequency and duration). Instead, participants were asked to complete a log sheet to assess engagement with and usage of the mobile app during the 6-week period. Each time participants used the app they reported the date, duration, and type of each workout (eg, yoga, strength training for legs). Participants reported this information to a research assistant each week via telephone.

### *Physical Activity and Psychosocial Outcomes*

Participants completed measures to assess PA and psychosocial outcomes at baseline (0 weeks; T0) and at 6-week follow-up (T1). All measures are valid, reliable, and have been used in previous studies with cancer survivors [44,47,58-60]. PA was assessed using an adapted version of the Godin Leisure-Time Exercise Questionnaire (GLTEQ), which asks participants to report the frequency of performing “strenuous”, “moderate” and “mild” physical activities in the previous week [61]. Strenuous PA includes vigorous activities during which the heart beats rapidly, such as running or long-distance cycling. Moderate PA is considered to be not exhausting and includes activities such as fast walking or easy swimming, whereas mild PA is considered to be of minimal effort and include activities such as yoga or easy walking. The GLTEQ has been previously used in oncology settings [62]. The GLTEQ does not ask about the duration of an exercise session thus a question was added to allow for the calculation of the total number of minutes per week in each type of activity (as recommended by Livingstone [63]). Cancer-related fatigue was assessed using the Functional Assessment of Chronic Illness Therapy (FACIT)-Fatigue Scale Questionnaire [64]. QOL was assessed using the Health and Quality of Life Outcomes (EQ5D) Questionnaire [65], and well-being was assessed using the Functional Assessment of Cancer Therapy-General (FACT-G) Questionnaire [66]. Participants’ sleep quality was analyzed using the Pittsburgh Sleep Quality Index (PSQI), with scores greater than 5 indicating poor sleep quality [67]. Participants’ anxiety and depression scores were assessed using the Hospital Anxiety and Depression Scale (HADS) [68].

## Procedure

On response to study advertisements, participants were contacted to obtain informed consent and were provided with a participant identification (ID) number to enter for the online surveys. Study participants were emailed a URL link to the T0 survey and 6 weeks later to the T1 survey. Both surveys had a “welcome” and “thank you” page. The T0 survey collected information on standard demographics, weight and height, PA, and psychosocial outcomes whereas the T1 survey collected information on PA, weight and height, and psychosocial outcomes only. All questions were mandatory and respondents were able to review and change their answers prior to submission if required. Internet Protocol (IP) addresses and participant ID numbers were used to check for duplicate surveys. Participants completed the log sheets each time they used GAINFitness. After the 6-week period of using the app, participants were telephoned to take part in the qualitative interview (T1). Ethical approval for the study was obtained from University College London Ethics Committee (Reference: 6510/00).

## Analyses

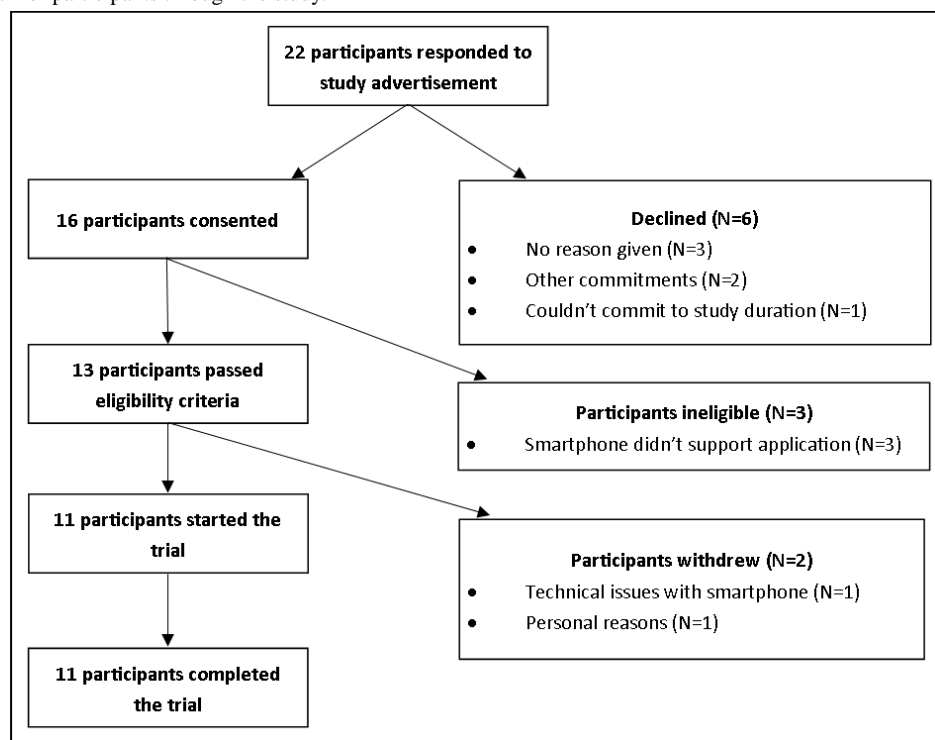
Recruitment success and engagement with the study was evaluated by the number of participants who agreed to participate and completed the study. Self-reported frequency and duration of app use was calculated from log sheets. Changes in T0 and T1 PA and psychosocial outcomes were analyzed using non-parametric tests. Results were considered significant at an alpha level of .05. Qualitative interview data were transcribed verbatim and analyzed using thematic analysis. Initial line-by-line codes were generated and secondary coding involved identifying links between codes to allow for creation of “themes”. Themes were reviewed and defined as coding progressed, and patterns within the data reported.

## Results

### **Recruitment and Study Uptake**

The flow of participants through the study is shown in Figure 6. Of the cancer survivors that responded to the study advertisement (N=22), 6 (27%, 6/22) declined participation (Figure 6). The remaining 16 survivors were screened for eligibility. Of those, 3 (19%, 3/16) did not meet eligibility criteria as their mobile phone did not support the app. A total of 13 participants entered the study, and 1 withdrew before baseline measures were taken due to technical issues with their mobile phone and another withdrew for personal reasons. All 11 remaining participants who completed baseline measures completed the trial (100%, 11/11).



**Figure 6.** Flow diagram of participants through the study.

### Participant Characteristics

Of the 11 participants who took part in the study, 7 (64%, 7/11) were breast cancer survivors, 2 (18%, 2/11) were colorectal cancer survivors, and 2 (18%, 2/11) were prostate cancer survivors. Participants were mostly female (82%, 9/11), and white British (82%, 9/11). Participants' age ranged from 33 to 62 years with a mean (SD) age of 45 (9.4). The majority of participants (73%, 8/11) had a BMI in the "normal" range (19-24 kg/m<sup>2</sup>); however one participant was underweight (BMI 17.5 kg/m<sup>2</sup>), and two were overweight (BMI > 25 kg/m<sup>2</sup>) (Table 1).

At baseline, participants spent a mean (SD) of 72.73 (89.90) minutes in strenuous PA per week, 224.55 (233.38) minutes in moderate PA, and 163.64 (102.50) minutes in mild PA. Participants' mean (SD) PSQI score at baseline was 9.27 (6.72) indicating that, on average, participants suffered from poor sleep quality [69]. Participants' mean fatigue scores of 36.20 (11.82) were below the reference score of 40.10 (10.40) for the general population, suggesting they suffered from cancer-related fatigue. The majority of participants (82%, 9/11) met the recommended weekly guideline of PA (minimum 150 minutes per week of moderate and strenuous PA).

**Table 1.** Baseline characteristics of study participants (N=11).

Characteristic	n (%)
Gender	
Female	9 (82)
Male	2 (18)
Ethnicity	
White British	9 (82)
Polish	2 (18)
Body mass index (BMI; kg/m <sup>2</sup> )	
Healthy	8 (73)
Underweight	1 (9)
Overweight	2 (18)
Education level	
Below degree level	5 (45)
Undergraduate degree	3 (27)
Postgraduate degree	3 (27)
Cancer type	
Breast	7 (64)
Colorectal	2 (18)
Prostate	2 (18)
Cancer stage at diagnosis	
Stage 2	6 (55)
Stage 3	4 (36)
Stage 4	1 (9)
Treatments undergone <sup>a</sup>	
Chemotherapy	8 (73)
Radiotherapy	7 (64)
Medication	5 (45)
Surgery	7 (64)
Hormonal treatment	2 (18)
High intensity focused ultrasound	1 (9)

<sup>a</sup>Percentages do not equal 100% as most participants experienced more than one type of treatment.

## Qualitative Interview Findings

All participants completed telephone interviews at the 6-week follow-up to discuss their experiences of using the app during the study period. During these interviews, participants reported that they did not experience any injuries or pain during or following the use of the app. Thematic analyses identified the following four themes: (1) barriers to PA, (2) receiving advice about PA from reliable sources, (3) tailoring the application to one's lifestyle, and (4) receiving social support from other cancer survivors.

### Barriers to Physical Activity

The participants discussed some of the barriers they faced towards frequent PA participation and the majority highlighted cancer-related fatigue as the main barrier:

*My fatigue is much better now since I finished treatment, but it still gets me bad sometimes. [P4]*

*The only thing that holds me back from exercising frequently, is the fatigue, it's always the fatigue. So [...] if an app somehow could consider my fatigue on those bad days. [Because] it really demotivates you...like you know when you just can't complete a workout because of it. [P6]*

Some participants suggested ways in which they felt a PA app could be adapted or developed specifically for cancer survivors

and how this could help to overcome fatigue to encourage PA participation:

*The app should ask about your fatigue levels [...]. When the fatigue is bad, [it] could give you some type of a yoga workout, where you just breathe and stretch and relax. I think that would nice because then you still move, you still do something. [P4]*

*Another said: On days that fatigue is bad you could have a lighter workout, like stretching or walking [...], so you still get that recommended 30 minutes [of exercise]. [P6]*

Particularly for those participants who had been diagnosed with breast cancer, lymphedema was also highlighted as a barrier to PA participation due to the fear and confusion surrounding what would be appropriate PA to carry out. In general, the participants felt that the app suggested suitable and safe exercises for dealing with lymphedema and the associated limitations:

*I still have problems with my arm [from lymph node dissection surgery], but I didn't experience any pain with the arm when exercising with the app. Those type of exercises [are] what the doctor tells you to do in the hospital after your surgery anyway. [P9]*

*You can't put too much pressure on your arms [after lymph node dissection surgery], but you have to train them too to avoid lymphedema. So I think in those terms the application was really good, definitely suitable. [P6]*

### **Receiving Advice About PA From Reliable Sources**

The app featured visual instructions that demonstrated how to perform the exercises correctly. Participants reported that together with the voiceover, the instructions were particularly helpful and made them feel confident about how to perform the exercises correctly:

*[The visuals] were really good because [they] showed you how to do everything and you felt confident that you are doing it right.' [P2]*

*Another said: "The visuals were set to be really slow, so I had time to get into position and knew what to do, so I wasn't worried about any injuries. [P9]*

*I personally am scared of getting lymphedema, and still don't know sometimes what exercises are good to prevent it, so I think that maybe educating people about [...] consequences of not exercising from a really good NHS source would be helpful. [P10]*

### **Tailoring the App to One's Lifestyle**

The participants reported that the app was suitable for use by cancer survivors and did not cause any injuries or specific problems. However, they believed it could be tailored to better suit the individual's lifestyle and fitness needs of those who have had cancer:

*Anyone with any condition could use this program, which is beneficial, but it could be more beneficial [...] more tailored to the type of cancer or disease you had, to your lifestyle and fitness goals. I think it*

*could be more fine-tuned to your circumstances, lifestyle, then that would be really helpful. [P1]*

*I think it should be more of a life context rather than just a general program, so there should be a little bit about what you should do post-treatment, and also in a longer term. At first it should be more about trying to get you more active, [...], but once your cancer improves, what are you going to do for the rest of your life? Because you need that fitness to prevent it from coming back. [P1]*

Several participants highlighted that differentiating between the types of treatment they'd undergone, the types of cancer they'd been diagnosed with, and the associated side effects should be considered when adapting a PA mobile app to cancer survivors' needs:

*The issues I might have as a colorectal cancer survivor are very different from the ones than someone who had breast cancer or prostate cancer. [P8]*

*It is important to think about treatment someone had – I think that different treatments for different cancers have different side effects, and that's important to consider, because it's the side effects that stop you from exercising. [P3]*

*It could be fine-tuned better to some of the challenges that I've got, like muscle wastage [prostate cancer] and so on, and give me something slightly different to do. [P1]*

The participants also highlighted the importance of a PA app fitting in with the context of the rest of their life, and in relation to cancer survivorship and health promotion:

*It could be even linked through NHS so you could have access to your entire medical stuff and give you a nice history of your progress. If you see that your blood pressure lowered because of exercise, [then] that would motivate you to be more active. [P11]*

*You are told to do 30 minutes of exercise a day, so [getting] something like a reminder telling you that you have completed your half an hour, or how much you have got left [of it] would be really good. [P7]*

*I think the app should maybe have like some health tips you know, like facts about cancer and best ways to be active after treatment. [P4]*

Several participants also discussed the possibility of an overall cancer survivorship app, rather than just focusing on PA:

*I think that the app should help with other things than just exercise; it should be more a lifestyle advice too. [Such as] giving you advice on counselling or tips on how to get better sleep or [listing] foods to eat that could give you more energy. [P3]*

*I think that if an app would ask you about your levels of fatigue and about how you sleep, [it] will be nice, because it will be like some sort of a diary where you can look back at your progress not only in terms of exercise but also your well-being and mood.*

*Something to look back at that documents your recovery, because it will motivate you to keep getting better. [P8]*

### **Social Support From Other Cancer Survivors**

Participants reported that having a social component (eg, forum, social network or ability to add friends) within the app was important to them and this was highlighted as something which was lacking in the current app:

*It is so important to get in touch with people who went through the same thing as you have. [...] I think that if an app for cancer survivors had a forum on it as a part of the application to motivate each other, that would be amazing. [P11]*

*If you are looking at the issues of cancer survivorship, I think personally that for cancer survivors it would be quite nice to link up with other people and build that community. [P8]*

Another said:

*Also social support of course, that's good, I use those forums and they are very helpful, even with general stuff, not just exercise. Having support from other cancer survivors is very important. [P5]*

*You do need that bit of motivation from other people. It's all about motivation when it comes to exercise [...]. When you feel low and can't be bothered to go for a walk, maybe someone else saying 'go on, get up and do it, you can do it' would motivate you. [P2]*

It was also highlighted that a social support group within the app would be very convenient and a desired component if an app were to be developed and adapted:

*We have those support groups in the hospital, but me myself I can't always make it, because we live far from the hospital. I just got an invitation for one of those and I won't be attending because I am just too*

*busy. And having that support within an app, without having to leave the house would be really nice, to kind of make some contacts and chat to other people about your experiences. [P9]*

### **Engagement With the Mobile App**

Only one participant needed additional help to install the application. All participants kept a record of their app usage throughout the 6 weeks, however, 9 participants used the log sheets provided and 2 chose to use their own means of logging their usage (eg, personal diaries). All 11 participants provided this data during weekly telephone calls with a researcher. Participants used the app a mean (SD) of 2.07 (0.68) times per week, with a mean session duration of 25.08 (8.22) minutes. App use duration ranged from 24.50 to 91.00 minutes per week with a mean (SD) of 44.00 (20.50) minutes. In the qualitative telephone interviews at T1, five participants (45%, 5/11) reported that they would continue using the application, and 100% (11/11) of participants said that they would continue using the app if it was adapted to better suit the needs of cancer survivors.

### **Physical Activity and Psychosocial Outcomes**

The results from quantitative analyses are shown in [Table 2](#). All 11 participants completed all items in each questionnaire at T0 and T1 so there were no missing data. Ten participants completed the questionnaires on a computer, and 1 participant used a tablet. Wilcoxon signed rank tests showed a significant reduction in reported sleep problems (PSQI) between T0 (median=8, IQR=15) and T1 (Median=6, IQR=10), ( $z=-2.53$ ,  $P=.008$ ). There was a significant increase in participants' strenuous PA between T0 (median=40, IQR=105) and T1 (median=120, IQR=150), ( $z=-2.80$ ,  $P=.002$ ). There was a significant reduction in participants' mild PA between T0 (median=150, IQR=90) and T1 (median=80, IQR=120), ( $z=-2.21$ ,  $P=.031$ ). There were no significant changes in other psychosocial outcomes or BMI ([Table 2](#)).

**Table 2.** Comparisons of baseline (T0) and the 6-week follow-up (T1) physical activity and psychosocial outcome measures using Wilcoxon signed rank tests.

Outcome	T0, median (IQR)	T1, median (IQR)	<i>z</i>	<i>P</i> <sup>a</sup>
Sleep quality <sup>b</sup> (PSQI)	8.0 (15.0)	6.0 (10.0)	-2.53	.008
Strenuous physical activity, min/week	40.0 (105.0)	120.0 (150.0)	-2.80	.002
Moderate physical activity, min/week	180.0 (150.0)	180.0 (330.0)	-0.76	.563
Mild physical activity, min/week	150.0 (90.0)	80.0 (120.0)	-2.21	.031
Fatigue (FACIT-Fatigue scale)	34.0 (18)	39.0 (14.0)	-1.27	.242
Quality of Life (EQ5D)				
Mobility	1.0 (1.0)	1.0 (0.0)	-1.41	.500
Self-care	1.0 (0.0)	1.0 (0.0)	0.00	1.000
Activity	1.0 (1.0)	1.0 (1.0)	0.00	1.000
Pain	2.0 (1.0)	2.0 (1.0)	-1.00	1.000
Anxiety	1.0 (1.0)	1.0 (1.0)	-1.00	1.000
Well-being (FACT-G)	40.0 (7.0)	47.0 (10.0)	-1.85	.064
Anxiety (HADS-anxiety scale)	4.0 (8.0)	3.0 (7.0)	-1.61	.137
Depression (HADS-depression scale)	2.0 (5.0)	2.0 (6.0)	-0.32	.844
BMI	23.9 (5.2)	23.4 (5.0)	-0.25	.828

<sup>a</sup>Exact significance.<sup>b</sup>Higher PSQI scores indicate increased reported sleeping problems.

## Discussion

### Principal Findings

The present study utilized a one-arm, pre-post, mixed-methods design to examine experiences of using a publicly available PA mobile application (GAINFitness) in breast, prostate, and colorectal cancer survivors. All participants (N=11) engaged with the app and qualitative interviews highlighted that the app was well-received. Recommendations were identified on how a PA app may be adapted or developed to increase the relevance and suitability for cancer survivors. Willingness and ability to complete the quantitative PA and psychosocial measures was established as all participants completed survey measures at both time points, with no missing data or reports of dissatisfaction with measurements or study procedures. Significant increases in strenuous PA participation, improvements in sleep quality, and reductions in mild PA participation were observed. There were no significant changes for any other PA or psychosocial outcomes.

Qualitative telephone interviews investigated cancer survivors' attitudes towards GAINFitness in order to understand the appropriateness of the app for use in this population. Findings from this study suggest that the app and this approach to intervention delivery were well received. Given the rising use of mobile phones and mobile technology [48], and the popularity of mHealth [49], this approach to intervention delivery is timely.

However, important barriers relating to PA in the context of cancer were highlighted. GAINFitness did not address these barriers and PA apps should be adapted to overcome such barriers and thus improve suitability for cancer survivors.

Interviews showed that video demonstrations twinned with voiceover instructions explaining how to do exercises were valued by participants. The videos provided participants with reassurance that they were performing the exercises correctly and safely. This, in combination with their desire to receive PA recommendations and advice following a cancer diagnosis from reliable (eg, NHS) sources highlights a lack of knowledge of PA and a lack of confidence to perform PA among cancer survivors. Similar findings have been previously reported. For example, one study showed that cancer survivors feel they are given insufficient information regarding PA, diet, and weight [70]. Other studies have shown that health professionals demonstrated inadequate awareness and low information provision of PA and lifestyle guidelines specifically for cancer survivors [71,72]. Lack of time during consultations has been found to be a barrier to discussing PA with cancer survivors by health professionals [71]. Further, a Macmillan Cancer Support report highlighted that over half of health professionals know little or nothing about the benefits of PA in prevention or management of the side-effects and long-term outcomes of cancer [73]. The same report found that only 6% of health professionals discuss PA with patients with cancer. In the



present study, breast cancer survivors highlighted their concerns about PA in relation to lymphedema which may be experienced after breast surgery and treatment. They discussed confusion surrounding prevention and risk of developing lymphedema in relation to PA participation and were unaware of appropriate exercises to reduce risk. Similar findings are reported by Sander and colleagues [74]. Taken together, this research illustrates the need for better awareness and understanding of the evidence for the benefits of PA for cancer survivors among health professionals and better information provision for patients. An evidence-based PA app developed specifically for cancer survivors could be recommended by health professionals. Such an app may provide PA guidance and reassurance surrounding exercises that are safe and appropriate for cancer survivors. Moreover, simply recommending an app would have minimal impact on the time constraints of consultations. Participants in the current study suggested that a PA app for cancer survivors should incorporate a feature to recommend appropriate exercises for specific cancer types.

In interviews, cancer-related fatigue was consistently discussed as an important barrier to PA participation. This supports previous literature that has found similar findings [4,41,42]. It is plausible to assume that fatigue is an important factor in the low proportion of cancer survivors meeting PA guidelines [38,39] and the observed fall in PA participation following a cancer diagnosis [40]. It is likely that cancer survivors and health professionals are unaware of the benefits of PA participation in relation to cancer-related fatigue. Given this evidence and the feedback from participants in the current study, it is necessary for a PA intervention for cancer survivors to include gradual increases in PA participation, with the option to begin with lower intensity PA and greater education surrounding the benefits of PA in combating cancer-related fatigue. The participants in the current study also suggested that a PA app tailored specifically for cancer survivors could ask users to report their level of fatigue and recommend a lower intensity program when fatigue is particularly high to encourage them to participate in some PA, rather than avoid it altogether.

The participants' feedback pertaining to the desire for a feature within the app for social support was also highlighted. The participants felt that it was important to build a sense of community among cancer survivors and an environment in which they could share their experiences and support each other to increase PA participation. This supports findings from a similar Web-based PA intervention for older cancer survivors in which the social community within the program was particularly well-received [54,55]. It is therefore recommended that a PA app specifically aimed towards cancer survivors should incorporate this as an intervention component.

The quantitative outcome measures and online approach to data collection was intended to model the process and outcome of intervention evaluation in line with MRC guidance [56]. It was intended that this could provide an indication of the potential for change in PA and psychosocial outcomes, rather than as a reliable evaluation of the efficacy of the app, which could be tested in a future RCT. It is encouraging that significant increases in strenuous PA participation and improvements in sleep quality were observed during the 6-week period. There

were significant decreases in mild PA participation. One plausible explanation is that participants displaced mild PA with vigorous. There were no other significant changes in moderate PA participation or other psychosocial outcome measures. It is possible that a more targeted PA app may demonstrate greater improvement, which could be more reliably investigated using an RCT.

The current study should be viewed in light of a number of limitations. The majority of participants were white, female, breast cancer survivors. Therefore, the results may not be generalized to other cancer survivor populations. Participants in the present study had high baseline levels of PA. Owing to limited awareness of the benefits of PA and guidelines for cancer survivors among health professionals [71,73], it is plausible that many patients are equally unaware and so only those who are motivated to be physically active volunteered to take part. The recruitment method utilized for the present study meant that calculation of a response rate of the number of participants who agreed to take part as a proportion of the number of eligible people who viewed the advertisements was not possible. It would be necessary to use more targeted recruitment strategies in future studies such as in-clinic approaches, referrals from health professionals or via face-to-face cancer support services and charities. These approaches would also allow for a calculation of the response rate which could help to determine acceptability of the intervention. However, it is reassuring that 86% (19/22) of eligible participants who contacted the study team in response to advertisements were willing to take part in the study, and all 11 participants who started the study completed it. While the GLTEQ has been frequently used among cancer survivors, future studies should aim to use objective measurements of PA (eg, accelerometers) and this would certainly be recommended in a formal evaluation of a PA app. The app selected is also currently only available on the iOS operating system and four participants had to be excluded as their mobile phone did not support the application. Finally, this study was a one-arm pre-post design study, without a control group and so we cannot be sure that the significant changes are as a result of the app. However, for the quantitative part to this study, the aims focused on modeling the data collection process and outcomes and assessing the likelihood for behavior change. The qualitative feedback surrounding the usability and content of the app can now be taken forward for intervention development, which can then be evaluated in a formal RCT.

## Conclusion

The current study demonstrates that cancer survivors engaged with a PA app and this approach to intervention delivery was well-received. However, important factors which are not included in GAINFitness were highlighted. This included not accounting for the effects of cancer-related fatigue, the lack of information provision surrounding PA participation in the context of cancer from reliable sources, the need to consider limitations associated with specific cancer types in relation to PA, and the desire for a way to receive social support from other cancer survivors within the app. There is potential for change in PA and psychosocial outcomes among cancer survivors through the use of this publicly available PA app, however, we recommend that a more targeted PA app aimed towards cancer

survivors may increase the relevance and suitability of the intervention for this population and may prove more effective. The findings of this study can be taken forward for intervention

development to adapt or develop a PA app for cancer survivors, which should be tested in a larger RCT with objective measures of PA.

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## Conflicts of Interest

None declared.

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## Abbreviations

**BCT:** behavior change technique

**BMI:** body mass index

**EQ5D:** Health and Quality of Life Outcomes Questionnaire

**FACIT-Fatigue:** Functional Assessment of Chronic Illness Therapy -Fatigue Scale Questionnaire

**FACT-G:** Functional Assessment of Cancer Therapy-General,

**GLTEQ:** Godin Leisure Time Exercise Questionnaire

**HADS:** Hospital Anxiety and Depression Scale

**ID:** identification

**LWBC:** Living With and Beyond Cancer

**mHealth:** mobile health

**MRC:** Medical Research Council

**NHS:** National Health Service



**PA:** physical activity  
**PSQI:** Pittsburgh Sleep Quality Index  
**QOL:** quality of life  
**RCT:** randomized controlled trial  
**TO:** time at baseline  
**T1:** time at the 6-week follow-up

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Original Paper

# “Googling” for Cancer: An Infodemiological Assessment of Online Search Interests in Australia, Canada, New Zealand, the United Kingdom, and the United States

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## Abstract

**Background:** The infodemiological analysis of queries from search engines to shed light on the status of various noncommunicable diseases has gained increasing popularity in recent years.

**Objective:** The aim of the study was to determine the international perspective on the distribution of information seeking in Google regarding “cancer” in major English-speaking countries.

**Methods:** We used Google Trends service to assess people’s interest in searching about “Cancer” classified as “Disease,” from January 2004 to December 2015 in Australia, Canada, New Zealand, the United Kingdom, and the United States. Then, we evaluated top cities and their relative search volumes (SVs) and country-specific “Top searches” and “Rising searches.” We also evaluated the cross-country correlations of SVs for cancer, as well as rank correlations of SVs from 2010 to 2014 with the incidence of cancer in 2012 in the abovementioned countries.

**Results:** From 2004 to 2015, the United States (relative SV [from 100]: 63), Canada (62), and Australia (61) were the top countries searching for cancer in Google, followed by New Zealand (54) and the United Kingdom (48). There was a consistent seasonality pattern in searching for cancer in the United States, Canada, Australia, and New Zealand. Baltimore (United States), St John’s (Canada), Sydney (Australia), Otaika (New Zealand), and Saint Albans (United Kingdom) had the highest search interest in their corresponding countries. “Breast cancer” was the cancer entity that consistently appeared high in the list of top searches in all 5 countries. The “Rising searches” were “pancreatic cancer” in Canada and “ovarian cancer” in New Zealand. Cross-correlation of SVs was strong between the United States, Canada, and Australia ( $>.70$ ,  $P<.01$ ).

**Conclusions:** Cancer maintained its popularity as a search term for people in the United States, Canada, and Australia, comparably higher than New Zealand and the United Kingdom. The increased interest in searching for keywords related to cancer shows the possible effectiveness of awareness campaigns in increasing societal demand for health information on the Web, to be met in community-wide communication or awareness interventions.

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**KEYWORDS**

cancer; neoplasms; infodemiology; epidemiology; geographic mapping; Google Trends; Internet; consumer health information

## Introduction

The Internet is being used globally by millions of people on a daily basis for finding health information [1]. The analysis of collective trends and patterns in seeking information about health and medical conditions has helped in giving insights into information needs at the population level [2]. It is now more than a decade since the interdisciplinary area of “infodemiology” has emerged [3] and developed to scientifically assess the distribution and determinants of information in electronic media, with main focus on the Internet. Informing public health and public policy has been considered the eventual goal in infodemiological studies [4]. From the demand side of infodemiological approaches, the analysis of queries from search engines to shed light on the status of various diseases and the analysis of people’s health information-seeking behaviors have gained increasing popularity, especially during the last 4-5 years [4]. Many researchers have provided important insights into health-related behavior of populations, specifically for various communicable and noncommunicable diseases [5]. Predicting the future burden of health issues and diseases, improving public health practice, and expanding the potentials of research in health care have shown not only development, but also standardization in recent years [6].

Google Trends (GT) Web service is a unique and popular service available to assess data on people’s interest in Internet search using Google. As a free tool, it has widely been used for infodemiological studies on a variety of communicable and noncommunicable diseases and conditions [7-18]. Nevertheless, published studies in the recent years on infodemiology of chronic diseases, especially cancer, are limited [19] and they are outnumbered by the studies on infectious diseases, mainly influenza [20].

As cancers are among the most common causes of morbidity and mortality [21], it is anticipated that many people search the Web for information regarding various cancers. One of the first infodemiological studies on cancer using Google Insights for Search (former name of GT) was done by Glynn et al who assessed the relationship between breast cancer awareness campaign and Internet search activity from 2004 to 2009. Moreover, they determined the overall levels of online activity regarding breast cancer along with prostate and lung cancers [22]. In addition, Zhang et al assessed Internet search query data, specifically on tobacco and lung cancer, in the United States, Canada, the United Kingdom, Australia, and China from January 2004 to January 2014 using GT. They aimed to conduct seasonality analyses to detect the pattern in seeking information regarding tobacco and lung cancer at the international level [23]. Recently, Bloom et al [24], Murray et al [25], Schootman et al [26], and Rosenkrantz and Prabhu [27] have shown the usage of GT data for studying skin cancer, mouth cancer, cancer screening, and imaging-based cancer screening, respectively.

However, these recent studies have shortcomings in terms of giving a bigger picture on the global health information-seeking patterns of people regarding cancer as a major noncommunicable disease entity. Almost all of them are done in the context of one country (ie, the United States; except for the work by Zhang et

al [23]), so they fall behind in terms of supporting public health practice or policy changes in other countries. Additionally, not only have they characteristically focused on one cancer type, but also they have partially assessed “parts” of the cancer diagnosis and care continuum (eg, screening, risk factors, or awareness).

Therefore, infodemiological assessment of one cancer type, in one country, from a noncomprehensive point of view, brings the opportunity for the development of studies with more comprehensive approaches. The objectives of our infodemiological study are based on the possibilities provided by GT for comparing the “Cancer” keyword classified as “Disease,” and its related keywords, simultaneously across 5 geographic locations, from January 2004 onward. For bridging the gaps in previous studies, we aimed to do the following:

1. Provide an international picture on health information-seeking behavior of people on “cancer” in the past 12 years, using search query data;
2. Assess the most popular types of cancers that have shown search interest by people in various countries;
3. Uncover the various keywords and subjects searched by people in relation to cancer;
4. Determine the degree of correlation between the main indexes of cancer burden and interest in searching for cancer;
5. Reveal whether there is any correlation between people’s search interests in various countries.

## Methods

For this infodemiological study, we used GT (Google Inc, Mountain View, CA, USA; Last Accessed on February 6, 2016) to assess demand-side data on people’s interest in Internet search using Google for “Cancer,” classified by the search engine as “Disease.”

### Google Trends Methodology

Google Trends analyzes a fraction of the total Google Web searches over a period of time on a daily basis, extrapolates the data to estimate the search volume (SV), and displays SV index graphs. Comparisons between search terms or geographical areas are possible over time since January 2004. Such terms must reach a threshold of traffic to appear in the results. To control for artificial effects of repeated queries over a short period of time from a single user, this kind of repeated queries are removed automatically [26].

Google Trends analyzes number of searches over time in Google.com for a specified term relative to the total number of searches. This proportion known as “Search Volume Index” shows “the likelihood of a random user to search for a particular term from a certain location at a certain time” [28]. Because of the relativity (search for a specific keyword divided by the total number of searches), SV has the display scale of 0 to 100. Differences in the population of Internet searchers in various regions should be accounted for. Therefore, GT has a normalization process to justify the total SV in a region in a given time period, to not automatically give the highest rankings

to those regions with the most SVs, and to make datasets from different regions or cities comparable with each other. For this to happen, GT divides a set of search data from a region by the total traffic from the same region to cancel out the effects of differences in the population of searchers and the number of search hits. After the completion of normalization, each SV point is divided by the highest SV and multiplied by 100 to be shown as percentages on the graphs. Thus, regions that have gained higher or lower normalized values during the time frame will be correspondingly close to 100 or 0, respectively. The same process is used for determining top cities. A downward SV trend in graphs does not correspond necessarily to a decrease in absolute traffic for a search term; it just shows that its popularity is decreasing [26].

Google Trends classifies important search terms as meaningful entities; for example, in this case, on typing “cancer” in GT search bar, it shows the classification of this search term as “Disease.” Google Trends also automatically categorizes the terms under prespecified categories (in this case, “Health”) and represents ranks of the search categorized under particular categories. Categories with higher ranks are shown first. Significant growth of searching for a term in a given time period in comparison with the preceding time period will highlight that term as “Rising searches” and show its increasing popularity. The term “Breakout” instead of actual percentages in “Rising searches” means a change in popularity of a search term of more than 5000% [26]. This term is specific to Google and the 5000% percentage is not affected by market share of Google in the search engine market.

Google Trends has been active since 2004 using the abovementioned methodology in background. Google introduced another complimentary service named “Google Insights for Search” in 2008 with advanced visualizations for businesses. This service was merged into GT in 2012, and therefore GT has improved in terms of visualization since then [29].

### Preliminary Keyword Searching and Adjusting Google Trends Parameters

The default time span was from January 2004 (as baseline) to the end of December 2015. Preliminary searching was initiated using the term *cancer*. Then, GT created a graph showing global trends in interest over time for this keyword in more than 50 countries during our defined period. It had a vertical scale range from 0 to 100 in which the number 100 represented the peak SV. The term *cancer* is used mainly as a keyword in the English language; although, the term is similar in French, Swedish, and Romanian languages. However, for adding cross-country comparisons and international perspective as well as assessing related keywords, we decided to focus on English-speaking countries to be able to evaluate keywords of interest related to cancer.

It was shown that “Cancer” had been automatically classified by GT under these 3 categories: Health, People & Society, and Arts & Entertainment. Because GT recommends the most relevant and popular category in the first rank (ie, “Health”), we limited all of our next searches to Health category by selecting “Health” in the “Category” drop-down menu.

### Assessing the Geographical Distribution of Search Interests and Rising Keywords

In the next step, for the international perspective of our study and cross-country comparisons, we extracted top regions (ie, countries) and cities in the “Regional interest” section. Therefore, based on the results from regional interests, we selected top English-speaking countries in descending order of corresponding averages of their weekly SVs (ie, the United States, Canada, Australia, New Zealand, and the United Kingdom). Google Trends adjusts for different population sizes in various countries and cities in calculating SVs. We extracted the “Top” Queries in each country and documented their SVs. This provided us with quantitative index for popularity of a search term from the user’s perspective. Then, we selected “Rising” Queries related to cancer in all 5 countries separately. This showed the quantity of progression in popularity of search from 2004 to 2015 for cancer-related terms.

### Data Handling and Statistical Analysis

At every stage, we exported data from GT as a comma-separated values (CSV) file into Microsoft Office Excel 2010 (Microsoft, Redmond, WA, USA) for cross-checking, description, and refinement for graphing. Graphs and maps were extracted using real-time screen snapshots from the GT website.

Moreover, to examine consistency of trend data between countries and analyze linear and temporal patterns of seasonal components among countries and their possible associations, we calculated the pairwise cross-correlations of these SVs to show the direction and degree of changes in SVs in one country in accordance with changes in SVs in another. Logically, the correlation analysis quantifies the degree of correlation between these seasonal components and shows us the time-shifts among different countries regarding seasonality of the searches about cancer. High cross-correlations between countries mean common temporal patterns in information-seeking behavior that can be used in selecting the appropriate timing of international campaigns [23].

We also assessed correlations between the rank of these 5 countries in terms of the incidence of cancer in 2012 and their corresponding ranks in the average SV for each country between 2010 and 2014. This was done separately for each year using Spearman rank correlation. Data for the incidence of cancer were based on Ferlay et al [30]; for men and women combined, age-standardized incidence rates for all cancers (excluding nonmelanoma skin cancer) per 100,000 were as follows: Australia (323.0, world rank: 3), the United States (318.0, world rank: 6), Canada (295.7, world rank: 12), New Zealand (295.0, world rank: 13), and the United Kingdom (272.9, world rank 23).

The SPSS version 22.0 (IBM Incorporated, New York, USA) was used for all statistical analyses.

## Results

Google Trends recorded 626 SV-weeks for each of the 5 countries from January 2004 to December 2015.

The average SV was highest in the United States, 63 (SD 8), and lowest in the United Kingdom, 48 (SD 7). The overall pattern showed a slight decrease in searching for cancer from 2004 to 2011 and then a small increase in the later years. There were also patterns of spikes in SVs, in nearly all countries, more noticeable in the United States, mostly during and around October each year. Apart from these regular spikes, there were two noticeable spikes in SVs in Australia in May 2005 and in the United Kingdom in March 2014, for which GT could not identify possible reasons (Figure 1). Thus, based on further information provided in the Guinness World Records, we found that Cancer Council Australia held the largest tea party in May 2005 for charity fundraising involving 280,246 participants at 6062 locations across the country [31]. Moreover, the United

Kingdom's National Health Service conducted a very large "Be Clear on Cancer" symptom awareness campaign between February and March 2014 [32].

Figure 2 shows the specific geographic distribution of searching for cancer by city, independently in each country. Baltimore (United States), St. John's (Canada), Sydney (Australia), Otaika (New Zealand), and Saint Albans (United Kingdom) were the top cities searching for cancer in their corresponding countries (SV=100). Patterns of geographic clustering were more noticeable in the United States and Canada.

Tables 1 and 2 summarize the "Top searches" and "Rising searches" in Google and their corresponding SVs and growth percentages, respectively.

**Table 1.** "Top searches" in Google related to *cancer* and their corresponding search volumes in the United States, Canada, Australia, New Zealand, and the United Kingdom; January 2004 to December 2014.

Top queries	Search volume
United States	
Breast cancer	100
Breast	100
Cancer symptoms	75
Lung cancer	40
Colon cancer	30
Canada	
Cancer symptoms	100
Breast cancer	90
Lung cancer	45
Prostate cancer	40
Prostate	40
Australia	
Cancer symptoms	100
Breast cancer	90
Skin cancer	70
Cancer council	45
Lung cancer	40
New Zealand	
Breast cancer	100
Cancer symptoms	100
Symptoms	100
Bowel cancer	50
Prostate	45
United Kingdom	
Cancer symptoms	100
Breast cancer	75
Symptoms of cancer	40
Bowel cancer	35
Lung cancer	35



**Table 2.** “Rising searches” in Google related to *cancer* and their corresponding growth percentages in the United States, Canada, Australia, New Zealand, and the United Kingdom; January 2004 to December 2014.

Rising queries	Growth percentage <sup>a</sup>
United States	
Stage 4 cancer	250%
Signs of cancer	170%
What is cancer	140%
Symptoms of cancer	90%
Cancer symptoms	80%
Canada	
Stage 4 cancer	350%
Signs of cancer	100%
Cancer cure	90%
Pancreatic cancer	90%
Ovarian cancer symptoms	80%
Australia	
Skin cancer clinic	450%
Symptoms ovarian cancer	400%
Bowel cancer symptoms	200%
Symptoms of cancer	200%
Cancer symptoms	180%
New Zealand	
Breast cancer NZ <sup>b</sup>	>5000%
Ovarian cancer	>5000%
Stomach cancer	>5000%
Symptoms bowel cancer	>5000%
Symptoms of cancer	>5000%
United Kingdom	
Cervical cancer symptoms	400%
Ovarian cancer symptoms	300%
Signs of cancer	300%
Pancreatic cancer	190%
Symptoms of cancer	180%

<sup>a</sup>Google Trends classifies terms with over 5000% increase as “breakout” and does not give exact figures.

<sup>b</sup>NZ: New Zealand.

“Breast cancer” was consistently the first- or second-ranked diagnostic entity appearing in the top 5 searches related to cancer, with SVs ranging between 75 and 100. It was followed by “lung cancer” in the United States and Canada, “skin cancer” in Australia, and “bowel cancer” in New Zealand and the United Kingdom, with SVs of roughly half of that of breast cancer.

The top 5 rising search terms related to cancer in New Zealand between 2004 and 2015 showed a breakout growth percentage in their search interests, that is, over 5000% increase, whereas

the rising searches in other 4 countries experienced a fairly smooth growth over the same time period. “Pancreatic cancer” (Canada, United Kingdom) and “ovarian cancer” (New Zealand) were the types of cancer showing greatest increase in search interest between 2004 and 2015.

Table 3 demonstrates the results of testing for cross-correlation between seasonal components of searching for cancer during the time period between the 5 countries.

**Table 3.** Pairwise Pearson correlation coefficients for weekly SVs between the United States, Canada, Australia, New Zealand, and the United Kingdom; January 2004 to December 2014 (all correlation coefficients were significant at the .01 level [2-tailed]).

	Canada	Australia	New Zealand	United Kingdom
United States	.86 <sup>a</sup>	.77 <sup>a</sup>	.56 <sup>b</sup>	.42 <sup>b</sup>
Canada		.79 <sup>a</sup>	.53 <sup>b</sup>	.40 <sup>b</sup>
Australia			.58 <sup>b</sup>	.42 <sup>b</sup>
New Zealand				.22 <sup>c</sup>

<sup>a</sup>Strong correlation.

<sup>b</sup>Moderate correlation.

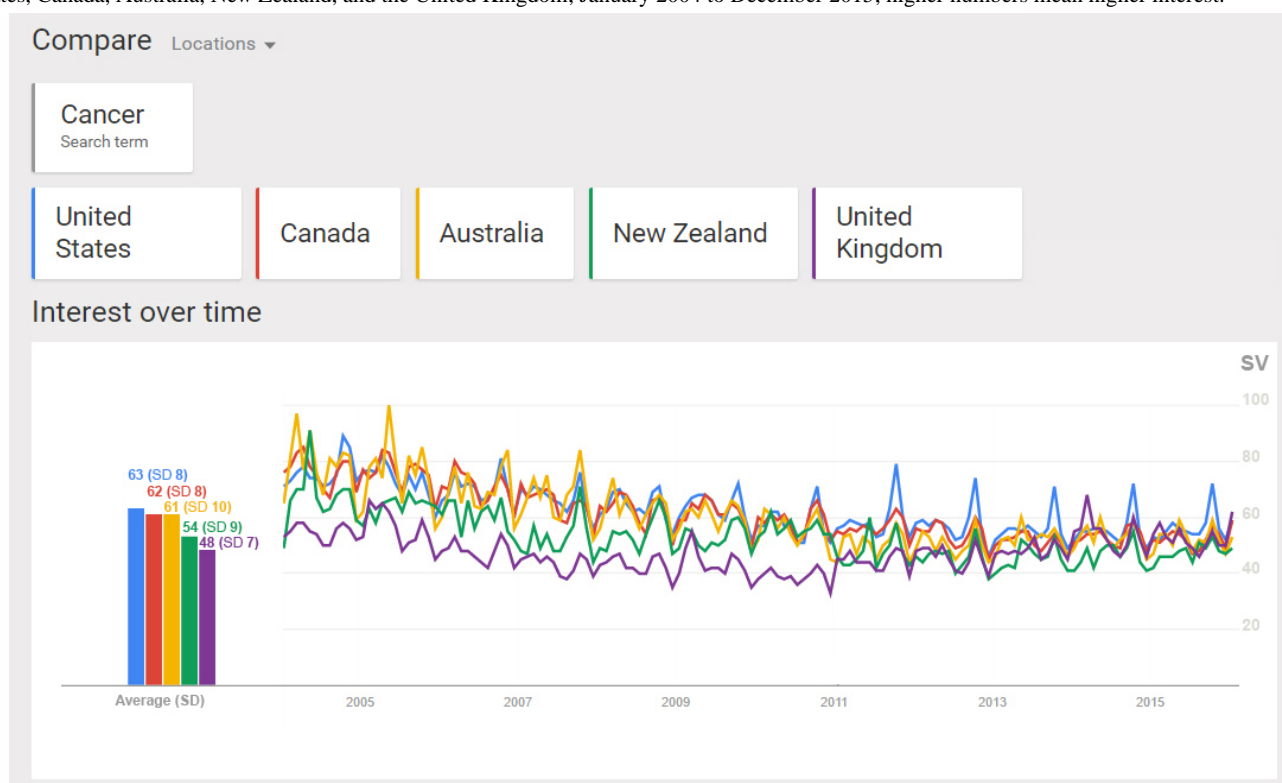
<sup>c</sup>Weak correlation.

The highest coefficient was seen between the United States and Canada, whereas the weakest was between New Zealand and the United Kingdom and the pattern was consistent in various years. Cross-correlation was strong between the United States, Canada, and Australia (>.70). Correlation was moderate between these 3 countries with New Zealand and United Kingdom.

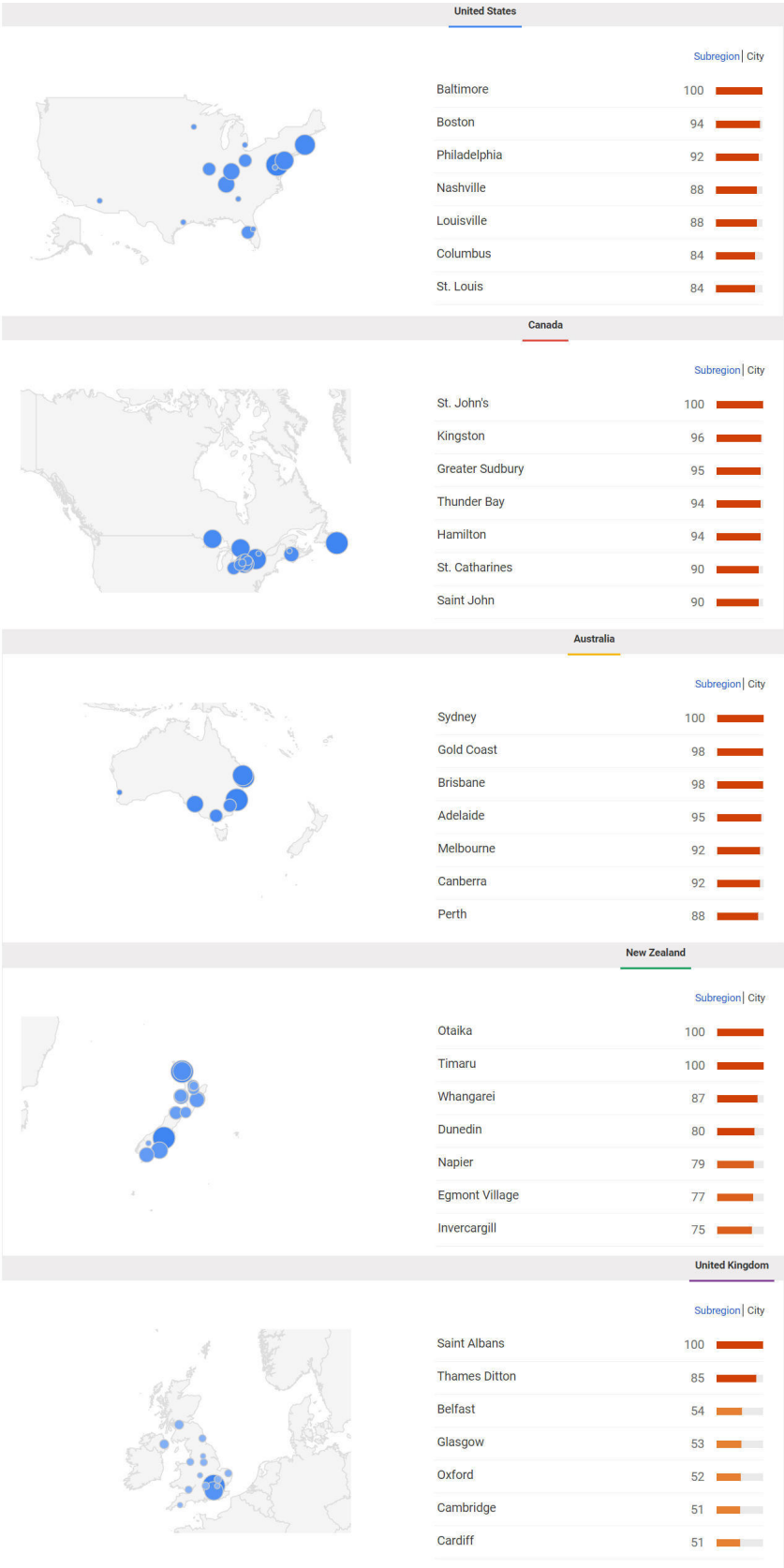
Nevertheless, all correlation coefficients were positive and statistically significant.

For these 5 countries, the highest Spearman rank correlation coefficient was between the incidence of cancer in 2012 and the average SV in the year after (ie, 2013;  $\rho=.8$ ); although, the  $P$  value was not statistically significant ( $P=.104$ ).

**Figure 1.** Average interest over time in searching for Cancer as a Disease in Google (shown as search volume [SV] on a scale of 0-100) in the United States, Canada, Australia, New Zealand, and the United Kingdom; January 2004 to December 2015; higher numbers mean higher interest.



**Figure 2.** Geographic distribution of searching for cancer in Google in the United States, Canada, Australia, New Zealand, and the United Kingdom; top cities and their corresponding search volumes; January 2004 to December 2015. The scale is up to 100; higher numbers (shown as larger circles) mean higher interest in searching, independently in each country.



## Discussion

It seems that people's interest in googling *cancer* in the United States, Australia, Canada, New Zealand, and the United Kingdom, as major English-speaking countries, is becoming comparably similar toward 2011-2015. Additionally, the temporal trend in searching about cancer is most strongly correlated between the United States, Canada, and Australia. Seasonal trends demonstrate that people may be in increased need for getting information—and possibly health services or care—regarding cancer, particularly during or near to October. Our findings contribute to infodemiology of cancer with an international perspective [23].

Previous research by Cooper et al has shown that searching activity related to cancer can be associated with estimates of the burden of cancer in three parameters; namely, cancer incidence, cancer mortality, and cancer news coverage. They also evaluated the periodicity of cancer search activity in Yahoo! and showed that estimated incidence and mortality of specific cancers were moderately correlated (rank correlation between .50 and .66;  $P=.015$  to  $P=.001$ ) with Yahoo! search activity. The volume of cancer news coverage was highly correlated with Yahoo! cancer search activity, especially on weekdays and during national cancer awareness months. The authors concluded that assessment of health information-seeking behavior using Internet search activity could be utilized as an innovative passive surveillance tool, mainly for assessing and predicting potential disease burden [33]. Although statistically insignificant, the rank correlation coefficient between the incidence of cancer in 2012 and SV in the next year may show an association between search and overall burden of cancer in these areas at ecological levels. This is a promising area of research on this topic that needs more sophisticated statistical techniques (such as time-series or regression analyses) and the replication of our methodology on specific types of cancer for cross-country comparisons.

In this investigation, we were able to show higher SVs in nearly each of the 5 countries in October, corresponding to breast cancer awareness month. This is a fact that has also been shown by Glynn et al. They clearly demonstrated that in each October, online activity levels relating to breast cancer consistently increase, significantly higher in comparison to lung or prostate cancer ( $P<.001$ ). They inferred that the annual breast cancer awareness campaigns, in comparison to other initiatives for cancer awareness, have been more effective as they have hugely accelerated online search activity. Therefore, the lessons learned from the experience of breast cancer awareness months would additionally be useful for other cancers [22]. Our results also correlate well with previous work that examined cancer search activity using the Yahoo! search engine between 2001 and 2003. Breast cancer ranked first of 23 cancers in terms of search activity, ahead of lung cancer in second place and prostate cancer in fifth [33].

Zhang et al [23] have recently demonstrated the moderately high cross-correlations and seasonality of searching for tobacco and lung cancer in the United States, Canada, the United Kingdom, Australia, and China. Similar findings might be

accessible by replicating our research methodology on specific types of cancer and their corresponding risk factors. High cross-correlation could also reflect that certain cancer promotion and awareness campaigns that are propagated over the Internet can impact more than one country at the same time, thus increasing the chances of being taken by diverse populations.

The progressive popularity of searching for various types of cancer in different countries—"Pancreatic cancer" (Canada, United Kingdom) and "ovarian cancer" (New Zealand)—is implicitly reflecting the societal demand for specific information on different cancer entities, apart from the burden of known major types of cancer in people's country of residence. On the basis of GLOBOCAN 2012, in Canada, pancreatic cancer is ranked 13 based on estimated age-standardized incidence in both sexes [34]. In New Zealand, ovarian cancer is the fifth most frequent cause of death from cancer in females by total number of cases. This becomes more important if we consider the fact that there has been debate on disassociation between the incidence of cancer conditions and SVs for related search terms to those conditions. The reason for latter debate has been the potentially large influence on health-related SVs by the recognition or diagnosis of conditions by celebrities and media [35], which may have an effect on public interest in searching. This fact has also been demonstrated by Noar et al [36]; as they showed that for digital surveillance to strengthen cancer control research and practice, one should be aware that in specific cases (pancreatic cancer in their study), diagnosis of or death because of cancer in public figures may stimulate online information seeking related to the disease entity. In addition, Evans et al described the "Angelina Jolie effect" showing the huge or long-lasting effects of media on a health topic hit to generate better understanding in society about diagnostic tests and management options for breast cancer. Angelina Jolie's decision to undergo risk-reducing mastectomy after being tested positive for the *BRCA1* gene mutation was one of the longest lasting news stories that affected referrals specific to assessment of breast cancer family history, request for *BRCA1/2* testing, and enquiries for risk-reducing mastectomy, especially in the United Kingdom around May 2013 and onward [37].

Moreover, we noticed infrequent peaks in the SVs in Australia (May 2005) and the United Kingdom (March 2014). Although GT itself flags important news and events related to peaks in the SV graphs, it showed nothing related to these 2 visible aberrancies. We could identify 2 events that seemed possibly related to these less-than-usual spikes in searching; Australia holds the world record for the largest national cancer charity fundraising act in May 2005 and the United Kingdom started a large cancer awareness program in February-March 2014. These findings show the important effects of campaigns on raising the demand for information via searching the Internet. Moreover, they highlight the need for additional cross-country comparisons on health-related information searches, as the differences between various countries would have not been shown if there had not been the possibility of comparing the trends together. In addition, by finding the probable explanations in any peak search activity related to health-related keywords, researchers may end up finding effective awareness activities or experiences

in a country, which can be used in informing public health promotion and policies.

Seasonal patterns in information seeking concerning cancer widely exist between these 5 countries. The high cross-correlation between the cancer search trends of Australia, Canada, and the United States reflects the fact that these countries may be able to collaborate to start awareness campaigns at the peak of information seeking, because the interest of information seekers in cancer information would be similarly high at intended times [23].

In an analysis of more than 12,000 people in 12 countries, it has been reported that more than 45% of individuals who have searched the Web for health-related information have done so to self-diagnose a condition [38]. There has also been a report showing Internet search for query data are correlated with patients' visits to physicians' offices [17]. We found that in each of these 5 countries, "cancer symptoms" was among the top searches and this finding may reflect the fact that people not only want to get more information about the disease itself, but also may become able to check whether they themselves (or anybody related to them) can provisionally be considered to be at risk for cancer.

### Limitations of Our Study

Google Trends may be suited for tracking search behavior in developed countries because it requires large populations of users in order to provide effective estimates. The main reason is that terms that reach a threshold of traffic appear in GT results. Moreover, GT is available in a limited, albeit increasing, number of languages and it does not support all countries or territories at the moment [39]. Because *cancer* and its related terms are mainly English, the usability of results might be limited to major English-speaking countries. Therefore, the generalizability of our findings might be limited because of sampling data. Our research may be reproduced in the future by including other countries in which English is a major language (eg, India, Pakistan, and South Africa) and by assessing the trends in other languages.

Searches for cancer may not be exclusively done using Google. Evidence from gray literature (eg, industry reports, market research results) has consistently shown that Google has been the largest player in the search engine market, having the market share of at least 50% in various developed countries since 2005 [40] and across the time frame of our study (range 50%-85%) [41]. However, other search engines such as Yahoo! or Bing are also being used by people to search for information. Specifically, data from gray literature shows that more than three-fourth of people in the United States start their online

health seeking at a general search engine (eg, Google, Bing, or Yahoo!), not on websites that specialize in health information [42]. However, we have not been able to assess the trends of people's interests in other search engines because of the proprietary availability of their Web services. Moreover, we cannot describe the demographic characteristics of Internet searchers in different countries because there are no data available from GT on demographics. This may limit the true comparison of information needs and the differences seen within and between regions and cities.

We should also highlight the fact that the presence of pharmaceutical companies and research centers in some locations might have affected the SVs in specific cities across these 5 countries. However, as the assessment of clustering needs extra data on covariates related to geographical locations, studying the reasons for clustering has been out of the scope of our research. This can be an important question to be answered in future studies.

Finally, it should be mentioned that although GT classifies "Cancer" as "Disease" and we had chosen "Health" as the major category of this assessment, we cannot assure that GT differentiates or accounts for false cognates or homonymous words in the search patterns or related keywords. The methodological literature on this classification or categorization is not well elaborated and is in need of further clarification by Google itself or future research.

### Conclusions

More dependence on the Internet worldwide, although challenging in some aspects, provides a wealth of information to show the collective thoughts and needs of populations, which can be assessed for their health issues. Exploring increasingly available online data including Internet search queries and social media information can provide novel insights for public health research and promotion. Google Trends, with its potentials, is a convenient and accessible tool to help researchers assess infodemiological aspects of health and medical conditions of interest in their populations [20,39,43].

Our study shows that GT is also a valuable tool to provide us estimates on the interest in high-burden disease entities such as cancer [44,45]. We propose using GT for getting insight into deeper aspects of problems and challenges related to cancer awareness in order to assess the status quo and to determine the need for detailed research projects on specific subjects in areas that have highest need. It may also be of help to policy makers in tailoring cancer awareness programs to areas that need them the most.

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## Authors' Contributions

FF, AA, and MSCL contributed to the conception and design of the study. AA acquired and analyzed the data. AA and FF drafted the article and AKYL, MSCL, and NS critically revised it for important intellectual content. AA and FF completed the data analysis. All authors approve the final version to be published.

## Conflicts of Interest

None declared.

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**Abbreviations****GT:** Google Trends**SV:** search volume

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Original Paper

# eHealth for Breast Cancer Survivors: Use, Feasibility and Impact of an Interactive Portal

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## Abstract

**Background:** MijnAVL is an interactive portal including patient education, overview of appointments, access to the electronic medical records (EMR), patient-reported outcomes, plus feedback and physical activity support.

**Objective:** With this study we aimed to evaluate the use, feasibility, and impact of MijnAVL among breast cancer survivors.

**Methods:** We included survivors currently or recently treated with curative intent, who completed questions on sociodemographics, patient activation (PAM), quality of life (SF-36), and physical activity (IPAQ). MijnAVL could be used noncommittally for four months. Log data were collected retrospectively and participants completed questions on acceptability, satisfaction, and the PAM, SF-36 and IPAQ.

**Results:** Ninety-two women (mean age 49.5 years, 59% on-treatment) participated, with a mean number of logins of 8.7. Overview of appointments (80% of participants) and access to the EMR (90%) were most frequently used and most highly valued. Average website user satisfaction was 3.8 on a 5-point scale. Although participants reported having more knowledge and experiencing more control of their situation after using MijnAVL, PAM scores did not change significantly. Three domains of the SF-36 (role functioning - emotional, mental health, and social functioning) and median vigorous physical activity improved significantly over time. The burden of MijnAVL for professionals was limited.

**Conclusions:** User experiences were positive and exposure to MijnAVL was accompanied by improvements in three quality of life domains and vigorous physical activity. Tailored features may be needed to enhance the usefulness and efficacy of MijnAVL. Research with a controlled design is needed to confirm our findings.

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**KEYWORDS**

eHealth; interactive portal; feasibility; breast cancer survivor

## Introduction

Cancer survivors are individuals who are undergoing, or have completed, the primary treatment phase [1] and they are often considered to have a chronic disease. Survivors may suffer from acute (eg, nausea, hair loss, pain), long-term (eg, fatigue, anxiety, sexual problems) and late effects (eg, second

malignancies, cardiovascular disease) caused by cancer or its treatment. These effects often have an impact on health status and quality of life, and might even require professional help [2]. Current models of health care, with a focus on detection and treatment of acute disease, seem no longer sustainable given the increasing number of people with a chronic disease like

cancer [3]. Additionally, the time of health professionals is limited and the costs involved in professional help are rising.

A transition to patient-centered models of care in which cancer survivors play a more active role in their care process is needed. This idea could be referred to as *patient empowerment*, which implies that cancer survivors' autonomy is respected by health professionals and that survivors have the knowledge and the psychosocial and behavioral skills needed to positively influence their health status [4]. Research has shown that interventions aimed at improving patient empowerment can have a positive effect on health behavior and health outcomes [5].

To support patient empowerment, it may be helpful to utilize information and communication technologies in health care (eHealth) [6,7]. An important advantage of eHealth is that tailored (sometimes also referred to as personalized) information and interventions can be more easily provided. In the Netherlands, approximately 95% of the population has access to the Internet. Although its use is highest among younger age groups, 75% of individuals aged 65-75 also regularly use the Internet [8]. Considering the mean age at breast cancer diagnosis in the Netherlands is 61 years, and many breast cancer survivors already use the Internet to find cancer-related information [9], they are an appropriate target population for eHealth services. To date, eHealth applications for breast cancer survivors have focused primarily on online (peer) support [10], patient education [11], or singular aspects of empowerment, such as psychological adjustment [12].

In the Netherlands Cancer Institute (Antoni van Leeuwenhoek hospital; AVL) we have developed an eHealth application to support cancer survivors during the whole cancer trajectory, known as MijnAVL (MyAVL in English). MijnAVL is a secured portal that provides survivors with personalized information, insight into their health status, and tailored physical activity advice. The aim of this study was to evaluate the use, feasibility, and impact of MijnAVL among breast cancer survivors.

## Methods

### Participants and Procedures

We invited women with histologically confirmed breast cancer who were currently receiving curative treatment (surgery, radiotherapy and/or chemotherapy) or had received such treatment 3-12 months ago. Survivors received a letter in which the purpose of the study was explained, followed by a phone call from the researchers to discuss participation and check further eligibility criteria (ie, having a computer and Internet,

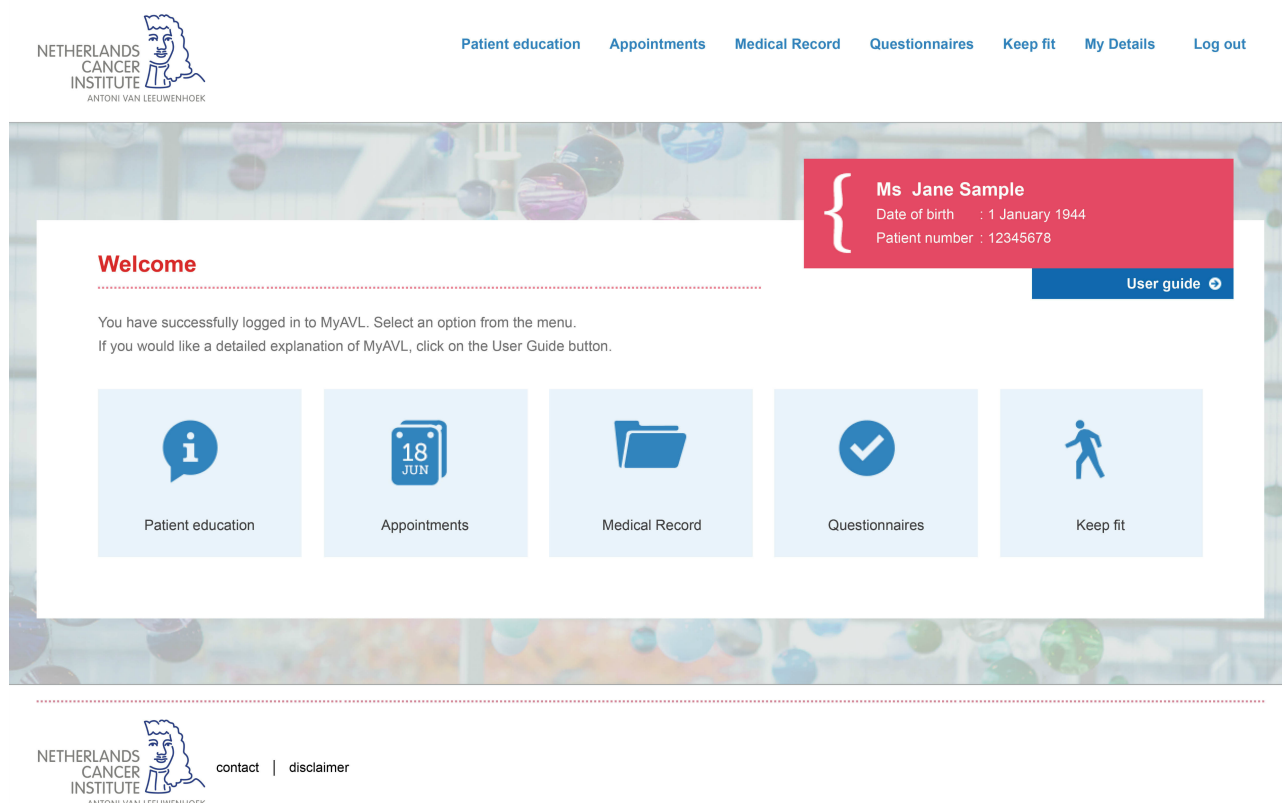
mastery of the Dutch language). Women with cognitive disorders or emotional instability were excluded. Those declining participation were asked to indicate their main reason for non-participation. The Institutional Review Board approved the study and participants provided written informed consent.

We used a pretest-posttest design. Upon completion of the baseline questionnaire, participants could access MijnAVL noncommittally for 4 months, after which they were asked to complete a post-test questionnaire. We organized a focus group with a random selection of participants to obtain more detailed feedback about MijnAVL. Health professionals (medical oncologists, surgeons, radiotherapists and nurse specialists) were asked to complete a questionnaire about the impact of MijnAVL on their work.

### Intervention

The development, content, and layout of MijnAVL have been described in detail previously [13,14]. The system includes personalized educational material (eg, about their disease, their treatment, and possible side effects) and an overview of past and upcoming appointments. Users can also access parts of their electronic medical record (EMR) including radiology, pathology and lab results, conclusions from multidisciplinary meetings, and a medication overview. This information is supported by a dictionary and placed on MijnAVL with a delay of two weeks to make sure that there is sufficient time to first discuss the results with a health professional. Additionally, users receive a request by email to complete patient-reported outcomes (PROs) about their quality of life at regular intervals. In this email, it is pointed out that these PROs can yield useful information about their health status. If participants have not completed the PROs within one week, they receive an email reminder. Both participants and health professionals are provided with a summary of the PRO scores and are encouraged to discuss these results. The physical activity support program automatically provides tailored advice based on a set of questionnaires assessing clinical characteristics, nutritional status, physical activity levels, and motivation. The advice is aimed at influencing constructs from Social Cognitive Theory - behavioral, environmental, and personal factors [15] and the Theory of Planned Behavior - attitude, subjective norm, and perceived behavioral control [16]. For example, an individual preparing to become physically active is encouraged to think of possibilities for being physically active in her home setting, whereas another individual who is already physically active and needs to maintain her level of activity is advised to (continue to) use goal setting in order to stay motivated. Figure 1 shows a screenshot of the homepage of MijnAVL.



**Figure 1.** Screenshot of the homepage of MijnAVL.

## Assessments

The use of MijnAVL (number and duration of logins, pages visited, and questionnaires completed) was automatically logged for each participant and clinical information (Union for International Cancer Control stage, type of treatment, and time since treatment) was obtained from the EMR.

### Baseline Questionnaire

First, sociodemographics such as marital status, education level, and employment status were obtained. Internet use was measured in terms of frequency and duration. The Dutch version of the eHealth Literacy Scale (eHEALS) was used to assess users' ability to find and evaluate online health information. The eHEALS score ranges between 0 and 40; 40 being the highest score [17]. We assessed expectations about MijnAVL with questions covering a range of issues derived from the Unified Theory of the Acceptance and Use of Technology (UTAUT) framework. This framework includes factors that directly or indirectly predict the behavioral intention to use a technology and/or the actual use of that technology [18]. The following factors were assessed: performance expectancy or usefulness (eg, "MijnAVL will be a valuable supplement"), effort expectancy (ease of use, eg, "MijnAVL will be easy to use"), social influence (eg, "People who are important to me will encourage me to use MijnAVL"), self-efficacy (eg, "I have the ability to use MijnAVL"), attitude (eg, "It will be a good idea to use MijnAVL"), and intention (eg, "I intend to use MijnAVL as often as needed"). Facilitating conditions were not measured, as the availability of a computer and Internet access were inclusion criteria for the study. Response options ranged from 1 (completely disagree) to 7 (completely agree).

Data on the impact of MijnAVL was examined with three validated questionnaires. The patient activation measure (PAM) was used to measure patient empowerment in terms of knowledge, skills, and confidence in self-management [19]. The PAM consists of 13 questions with response options varying from 1 (strongly disagree) to 4 (strongly agree). Responses are converted to a total score ranging from 0 to 100, with higher scores representing more activation.

Quality of life was assessed with the Short-Form 36-Item Health Survey (SF-36), which consists of eight scales (eg, physical functioning, mental health, and vitality) that are scored from 0 to 100, with higher scores being more favorable [20].

Physical activity was assessed with the International Physical Activity Questionnaire (IPAQ), which measures the frequency (days per week) and duration (minutes) of physical activity during the last seven days in the following domains: work, transportation, work at home, and leisure activities [21]. Different levels of exercise (walking, moderate, vigorous, and total) were calculated and expressed in Metabolic Equivalent of Task (MET)-minutes per week (a product of exercise intensity and duration).

### Post-Intervention Questionnaire

Participants reported on their use (eg, frequency, duration, features used) of MijnAVL. Satisfaction with MijnAVL was measured with the website user satisfaction questionnaire (WUS), assessing 11 dimensions of satisfaction such as information comprehensibility, ease of use, and web site structure [22]. Experiences were assessed with questions based on the UTAUT framework that were an adapted version of the ones that were used to measure expectations at baseline (ie,

rewritten in the past tense). We also posed specific questions on acceptability of each feature, for example, about the quality, timing, and comprehensibility of information, and about the usefulness of the feedback on PROs and IPAQ. These questions could be answered on a 5-point scale ranging from 1 (completely disagree) to 5 (completely agree). Participants rated the different features of MijnAVL and finally completed the PAM, the SF-36, and the IPAQ.

### Focus Group

We discussed experiences with MijnAVL more thoroughly and gathered information on possible improvements and facilitators of long-term use. The focus groups were audio-taped and notes were taken.

### Questionnaire for Health Professionals

Involved professionals received a short questionnaire about the impact of survivors' access to MijnAVL on their work (eg, "Did you receive questions about MijnAVL and its content?" and, "Did your workload increase?").

### Statistical Analyses

We used descriptive statistics to characterize the study sample in terms of clinical and sociodemographic variables, and to report expectations, satisfaction, experiences, use, and measures of preliminary efficacy. Given the non-normal distribution of the data, IPAQ results are reported as median MET-minutes per week. We used the Chi-square statistic and Student's t-tests to

examine possible differences between the groups on-treatment versus off-treatment in clinical and sociodemographic characteristics at baseline, as well as in expectations and experiences. We assessed changes over time on the PAM and the SF-36 with paired-samples t-tests, and on the IPAQ with the Wilcoxon Signed Rank test. These tests were also used to perform subgroup analyses (on-treatment vs off-treatment). We also checked, on an individual level, whether physical activity levels increased or decreased. We considered P-values <0.05 to be statistically significant and used the Statistical Package for the Social Sciences version 22.

Notes from the focus groups were combined with the qualitative comments from the questionnaires to highlight the most important issues. Health professionals' questionnaire responses were summarized using descriptive statistics and a qualitative analysis of answers to the open-ended questions.

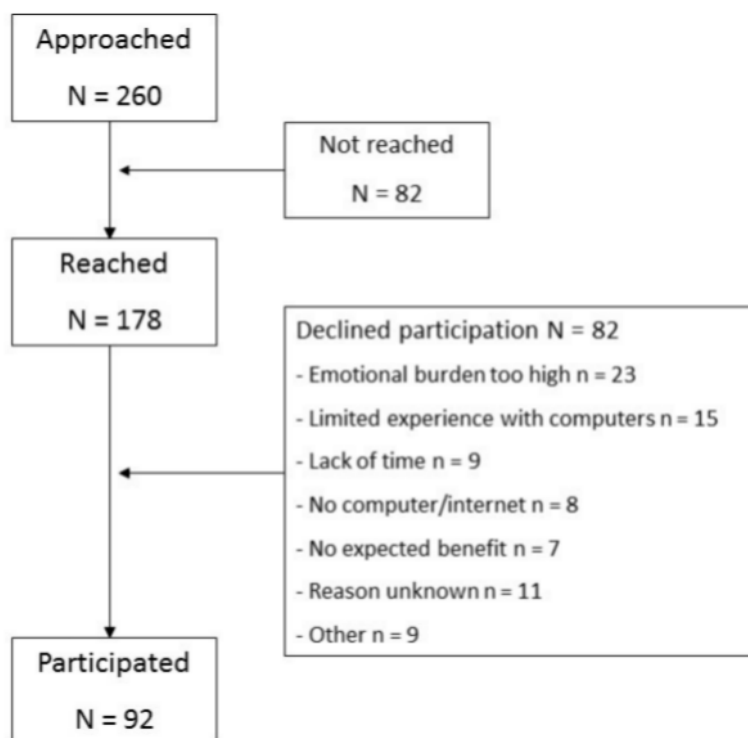
## Results

### Participants

Between January 2014 and April 2015, 260 women were invited to participate, of whom 92 agreed (response rate 35.4%). [Figure 2](#) displays the flow of patient recruitment and participation.

Fifty-nine percent of the participants were on-treatment, and those off-treatment had completed primary treatment, on average 6.2 (SD 3.0) months earlier. The sociodemographic and clinical characteristics of the sample are reported in [Table 1](#).

**Figure 2.** Participant flow chart.



**Table 1.** Baseline characteristics (N=92).

Characteristic	%
Marital status	
Relationship, living together	64.1
Relationship, not living together	8.7
Single	19.6
Divorced	5.4
Widow	2.2
Education	
Compulsory or less	6.5
Post compulsory	20.7
University or college	72.8
Employment status=	
Full-time job	28.2
Part-time job	40.0
Homemaker	4.7
Retired	10.6
Unemployed	4.7
Voluntary work	1.2
Disabled	10.6
Union for International Cancer Control stage	
Ductal Carcinoma In Situ (DCIS)	11.0
I	28.6
II	45.1
III	15.4
Type of treatment	
Surgery	19.1
Surgery + Radiotherapy	21.3
Surgery + Chemotherapy	15.7
Surgery + Chemotherapy + Radiotherapy	43.8
Hormonal therapy	56.2
Immunotherapy	7.9

Participants' mean age was 49.5 (SD 11.4) years, and the majority were highly educated and had a job. All participants had undergone surgery, and 80% (74/92) had adjuvant treatment. Ninety-six percent (88/92) had used the Internet for more than 3 years, 86% (79/92) were using it daily, and mean eHealth literacy was 30.8 (SD 4.4). Sociodemographic characteristics did not differ significantly between those on-treatment and

off-treatment. The post-intervention questionnaire was completed by 87% (80/92) of participants.

### Expectations and Experiences with MijnAVL

Participants' expectations and experiences, based on UTAUT, are shown in Table 2. Expectations were generally high, except for social norm. Experiences regarding social norm and intention were significantly lower than the expectations. For the remaining components, experiences were comparable to expectations.

**Table 2.** Expectations of and experiences with MijnAVL.

UTAUT component	Expectation	Experience	<i>P</i> -value
	Mean (SD)	Mean (SD)	
Ease of use	5.89 (0.91)	5.71 (1.17)	.228
Usefulness	5.13 (0.95)	4.86 (1.34)	.097
Attitude	6.10 (0.89)	5.89 (1.13)	.087
Social norm	4.16 (1.39)	2.82 (1.50)	.000
Self-efficacy	6.29 (0.80)	6.36 (0.81)	.524
Intention	6.43 (0.70)	5.55 (1.62)	.000

## Use

The majority of participants (69/92, 75%) indicated that it was easy or very easy to log on to MijnAVL, and 90% (83/92) used MijnAVL without any assistance. Statistics regarding use are shown in Table 3. Use varied widely across participants; the number of logins ranged from 0–62 and the duration of use from 2–38 minutes. Participants on-treatment used MijnAVL and its

features more often than those off-treatment (except for accessing quality of life scores), however the visits of those off-treatment lasted longer. PRO completion rates were high and similar for those on-treatment and off-treatment (77% and 83%, respectively). The overview of appointments and the EMR were accessed most frequently and used by the largest number of participants (80% and 90%, respectively).

**Table 3.** Use of MijnAVL

	On-treatment (N=46)	Off-treatment (N=37)	Rating (N=92)
	Mean (SD)	Mean (SD)	1–10 scale
Number of logins (in 4 months)	10.9 (12.7) <sup>a</sup>	5.6 (3.7) <sup>b,c</sup>	Not applicable
Mean duration of login (minutes)	11.3 (6.5)	15.2 (8.9) <sup>d</sup>	Not applicable
Patient education	4.0 (6.3) <sup>e</sup>	1.8 (1.3) <sup>d,e</sup>	6.9
Overview of appointments	8.8 (11.2) <sup>e</sup>	3.3 (2.1) <sup>c,e</sup>	8.7
Access to EMR	8.7 (11.3) <sup>e</sup>	3.8 (3.0) <sup>c,e</sup>	7.9
Quality of life scores	3.5 (3.9) <sup>e</sup>	2.4 (2.3) <sup>e</sup>	6.8
Physical activity support program	4.4 (3.7) <sup>e</sup>	2.4 (1.8) <sup>c,e</sup>	6.1

<sup>a</sup>N=54

<sup>b</sup>N=38

<sup>c</sup>Different from on-treatment; *P*<.001

<sup>d</sup>Different from on-treatment; *P*<.05

<sup>e</sup>These numbers reflect how many times the specific features were used during the 4-month study period.

## Satisfaction

The overall mean score for the WUS was 3.8 (SD 0.44) on a 5-point scale. The ease of use, website structure, and accuracy domains were particularly highly valued. MijnAVL as a whole was rated 7.6 on a 10-point scale, with the overview of appointments and access to the EMR being rated highest. Acceptability of MijnAVL was good in terms of perceived usefulness and comprehensibility, although the graphical presentation of PRO results was less well understood, and the information from the EMR raised questions for approximately 40% of participants. The EMR information and educational materials did not lead to anxiety for the majority of participants, and most participants indicated that access to this information increased their knowledge about, and control over, their disease. Participants reported that the patient education and physical activity advice could be improved by adapting it more to one's

personal situation and by making the advice more interesting, concise, and motivating. Participants expressed appreciation for the opportunity to complete PROs at home, but some indicated disappointment that their health professional(s) did not discuss the results with them.

## Impact

An overview of the outcome measures at baseline and post-intervention are presented for the total group (Table 4) and for participants on-treatment and off-treatment separately (Table 5). Scores on the PAM did not change significantly over time. Three domains of the SF-36 improved significantly over time: role functioning–emotional (*P*=.021) and mental health (*P*=.000) improved for those during treatment, and social functioning for those after treatment (*P*=.001). Median vigorous physical activity increased significantly from 0.0 to 360.0 MET-minutes per week for the total group (*P*=.017), although this effect was

not apparent in the subgroup analyses. However, the total amount of physical activity actually decreased over time for

about half of those on-treatment, and for about one-third of those off-treatment.

**Table 4.** Outcome measures for the total group.

	Total group (N=73)	
	Baseline Mean (SD)	Post-intervention Mean (SD)
PAM		
Score 0-100	62.7 (13.1) <sup>a</sup>	60.9 (15.4) <sup>a</sup>
SF-36		
Physical functioning	82.4 (17.8)	81.8 (16.6)
Role functioning – physical	49.0 (43.0)	51.7 (43.2)
Role functioning – emotional	65.3 (40.1) <sup>b</sup>	78.5 (37.8) <sup>b,+</sup>
Vitality	57.9 (17.9) <sup>b</sup>	60.0 (16.4) <sup>b</sup>
Mental health	69.8 (15.8) <sup>b</sup>	76.5 (14.6) <sup>b,+</sup>
Social functioning	71.2 (20.2)	80.5 (19.8) <sup>+</sup>
Bodily pain	75.0 (23.6)	74.8 (21.1)
General health	57.0 (18.5)	58.8 (17.9)
	Median (Range)	Median (Range)
IPAQ (MET-min/week)		
Walking	396 (0-19404)	594 (0-108660)
Moderate activity	1420 (0-13220)	1560 (0-11220)
Vigorous activity	0 (0-9600)	360 (0-8160) <sup>*</sup>
Total activity	2793 (0-25569)	3724.2 (0-17598)

<sup>a</sup>N=68

<sup>b</sup>N=72

<sup>\*</sup>different from baseline;  $P < .05$

<sup>+</sup>different from baseline;  $P < .01$

## Focus Group Results

Results indicated that participants (n=6) were pleased with having access to information and being able to re-read information. At the same time, focus group participants indicated that the educational materials, feedback, and advice could benefit from tailoring (ie, making the information more personal) and could be presented in a more visually attractive manner. Participants also expressed interest in being able to make and change appointments online and in obtaining access to the full EMR, and felt that providing regular updates and having their health professionals encourage them to use MijnAVL could contribute to sustained use.

## Questionnaire for Health Professionals

Twenty-four professionals, including medical oncologists, surgeons, radiotherapists, and nurse specialists (response rate 73%) completed the questionnaire. Thirty-eight percent (9/24) indicated that their patients who had access to MijnAVL asked questions about the program (eg, about the overview of

appointments, login procedures, access to the EMR). Twenty-one percent (5/24) indicated that they received questions about the content of the EMR (eg, requests for explanation of jargon, interpretation of reports). Thirty-three percent (8/24) reviewed their patients' PRO results and some discussed those results with their patients. One-quarter of the health professionals who had completed the questionnaire believed that their patients having had access to MijnAVL led to an increased workload (ranging from several to more than ten minutes).

## Discussion

The results of this study support the feasibility of MijnAVL, an interactive portal for breast cancer survivors. Use varied widely between participants, with highest levels of use being observed for those on-treatment. The scores on the UTAUT components and the WUS indicated that satisfaction with MijnAVL was relatively high, with overview of appointments and access to the EMR being most highly rated. Although both the



questionnaire and focus group results suggested that participants perceived having more knowledge and control over their disease due to exposure to MijnAVL, the PAM scores did not reflect such change over time. Participants' scores on three quality of life domains and their level of vigorous activity improved significantly from pre- to post-intervention. The focus group yielded useful feedback for improving MijnAVL (particularly the need to further tailor the information provided). Health professionals indicated that although some patients asked questions about MijnAVL, it led to only a modest increase in workload.

Ratings of experiences with MijnAVL were somewhat lower than expectations beforehand. The focus group confirmed that MijnAVL did not fully live up to the expectations, primarily because information and advice were not sufficiently tailored to individual needs. Two literature reviews have also indicated that tailored information matching user needs is an important feature of successful eHealth interventions [23,24]. Nevertheless, participants expressed high levels of satisfaction with MijnAVL and used it quite regularly, particularly individuals on-treatment. This result probably reflects the fact that during treatment, more relevant information was available, including updates of the patients' EMR, thus leading to more logins [25].

Because use of MijnAVL was on a voluntary basis, it was not possible to calculate adherence rates. However, the dropout rate was relatively low compared to other eHealth interventions [26] and the completion rate of PROs was relatively high. This result may reflect the fact that MijnAVL is directly linked to the EMR, and thus may be perceived by patients as being an integral part of the health care process; something that has been found to be an important characteristic of successful eHealth applications [24]. Another factor that might have contributed to the sustained use of MijnAVL was the use of automatic email reminders for the completion of questionnaires [27]. To further improve the use of MijnAVL it might be beneficial not only to provide more tailored information and advice, but also to facilitate social support, to have health professionals encourage their patients to use the system, and to provide feedback (eg, regarding PRO data) [23,25].

Linkage to the EMR is an important feature of MijnAVL. Importantly, clinical staff supported sharing test results and other EMR information, with the exception of their personal notes. Post-intervention, approximately 40% (10/24) of professionals indicated that participants had posed questions about MijnAVL, half of which were about medical topics. Twenty-five percent (8/24) of the health professionals indicated some increased workload due to their patients using MijnAVL. This is in contrast with an earlier study that indicated no increased workload resulting from patients' access to lab test results [28]. This difference could be due to the fact that MijnAVL provided access to a wider range of EMR data. Additional studies are needed to better understand the impact of portals such as MijnAVL on the content and processes of care. It would be particularly useful to conduct observational

studies that document the actual (versus self-reported) influence of portals on doctor-patient communication.

Despite predominantly positive experiences with MijnAVL, the impact we measured on patient empowerment, quality of life, and physical activity were relatively modest. Although participants indicated that they felt better informed because of their exposure to MijnAVL, this did not translate into increased levels of patient empowerment, at least as measured by the PAM. It is possible that the PAM is not sufficiently sensitive to changes in empowerment over time, and that more specific questions are needed to detect such changes. It may also be the case that only a relatively brief exposure to a patient portal, as was the case in the current study, may be insufficient to facilitate increased feelings of empowerment. Similarly, the modest observed improvement in quality of life and physical activity over time may be due to the relatively short exposure to MijnAVL, as well as to the absence of sufficiently tailored information. The impact of MijnAVL may be enhanced by combining its interactive features with face-to-face contacts that may increase motivation and adherence [13].

In the next version of MijnAVL we intend to incorporate more tailored information and advice based on individual information needs. Such needs may vary as a function of age, sex, educational level, ethnicity, and stage of disease [29]. We also intend to link PRO data with clinical pathways and treatment guidelines, using a stepped care approach, starting with self-management options, followed by referral to more formal forms of intervention and care, where appropriate. Finally, the physical activity support program could be improved by taking greater account of personal (eg, preferred type of exercise) and environmental (eg, support, resources) factors when providing advice. It may be particularly important to attend to the needs of those who use the portal during the period of active treatment, as we observed a decrease in the amount of physical activity in half of this group.

Our study has several limitations that need to be considered. First, all participants were experienced Internet-users and willing to use MijnAVL. This consistency may, to some degree, overestimate the feasibility and accessibility of the program, limiting generalizability to the larger population of cancer survivors. In future studies it would be helpful to also include individuals who are less experienced Internet-users or who are less prepared to use an eHealth application, and compare their needs and experiences. Second, the absence of a control group and of information about participants' use of other (educational) tools or mobile apps does not allow us to attribute the observed efficacy to the use of MijnAVL. Third, the data on physical activity were based on self-reports, which are known to be less reliable than objective measures such as accelerometers [30]. Despite these limitations, our study nevertheless is one of the first to investigate the feasibility of an interactive portal for breast cancer survivors that is fully integrated into the care trajectory and the hospital information system. In addition, the objective log data provided reliable information on the actual use of the portal.

**Table 5.** Outcome measures for participants on-treatment and off-treatment separately.

	On-treatment (N=38)		Off-treatment (N=35)	
	Baseline	Post-intervention	Baseline	Post-intervention
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
PAM				
Score 0-100	62.7 (13.2) <sup>a</sup>	61.5 (16.8) <sup>a</sup>	62.7 (13.2) <sup>b</sup>	60.1 (13.7) <sup>b</sup>
SF-36				
Physical functioning	82.2 (20.8)	80.4 (18.3)	82.5 (14.1)	83.4 (14.6)
Role functioning – physical	45.4 (42.3)	41.4 (42.4)	52.9 (46.1)	62.9 (41.7)
Role functioning – emotional	58.6 (42.6) <sup>a</sup>	77.0 (38.0) <sup>a,*</sup>	72.4 (36.6)	80.0 (38.1)
Vitality	57.4 (18.2) <sup>a</sup>	59.1 (17.0) <sup>a</sup>	58.4 (17.8)	61.0 (16.0)
Mental health	66.3 (14.9) <sup>a</sup>	77.4 (14.5) <sup>a,+</sup>	73.6 (16.1)	75.4 (14.8)
Social functioning	69.4 (21.7)	78.0 (21.7)	73.2 (18.5)	83.2 (17.4) <sup>+</sup>
Bodily pain	71.3 (27.6)	74.6 (18.2)	79.1 (17.8)	75.0 (24.1)
General health	55.0 (21.1)	55.9 (19.4)	59.1 (15.3)	62.0 (15.8)
	Median (Range)	Median (Range)	Median (Range)	Median (Range)
IPAQ (MET-min/week)				
Walking	330.0 (0-19404)	651.8 (0-9890)	627.0 (0-3762) <sup>c</sup>	462.0 (0-10866) <sup>c</sup>
Moderate activity	832.5 (0-13220)	1039.5 (0-8310)	1835.0 (0-6800) <sup>c</sup>	2430.0 (0-11220) <sup>c</sup>
Vigorous activity	0.0 (0-9600)	360.0 (0-8160)	0.0 (0-4920) <sup>c</sup>	405.0 (0-7080) <sup>c</sup>
Total activity	1921.5 (0-25569)	2542.5 (0-13374)	3326.0 (0-13106) <sup>c</sup>	4005.0 (0-17598) <sup>c</sup>

<sup>a</sup>N=37<sup>b</sup>N=31<sup>c</sup>N=33\*different from baseline;  $P<.05$ <sup>+</sup>different from baseline;  $P<.01$ 

## Conclusion

Our findings suggest that MijnAVL is a feasible eHealth application for breast cancer survivors. MijnAVL could be further improved by including more visually attractive and

tailored information, and adapted to individual information needs where possible. Research with a controlled design, a longer follow-up period, and including more specific outcome measures is needed to further document the effects of such an interactive portal.

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## Conflicts of Interest

None declared.

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## Abbreviations

**AVL:** Antoni van Leeuwenhoek hospital  
**eHEALS:** eHealth literacy scale  
**EMR:** Electronic Medical Record  
**IPAQ:** International Physical Activity Questionnaire  
**MET:** Metabolic Equivalent of Task  
**PAM:** Patient Activation Measure  
**PRO:** Patient-reported outcome  
**SF-36:** Short-Form 36-Item Health Survey  
**UTAUT:** Unified Theory of the Acceptance and Use of Technology  
**WUS:** website user satisfaction questionnaire

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