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Contents

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The Impact of Participation in Online Cancer Communities on Patient Reported Outcomes: Systematic Review

Mies C van Eenbergen[1], MA; Lonneke V van de Poll-Franse[1,2], Ph.D.; Peter Heine[3], MS; Floortje Mols[4], Ph.D.

[1]Department of Research, Netherlands Comprehensive Cancer Organisation, Utrecht, Netherlands

[2]Division of Psychosocial Research & Epidemiology, The Netherlands Cancer Institute, Amsterdam, Netherlands

[3]Stichting kanker.nl, Amsterdam, Netherlands

[4]Department of Medical and Clinical Psychology, Tilburg University, Tilburg, Netherlands

Corresponding Author:
Mies C van Eenbergen, MA
Department of Research
Netherlands Comprehensive Cancer Organisation
Postbus 19079
Utrecht, 3501 DB
Netherlands
Phone: 31 650220313
Fax: 31 882346000
Email: m.vaneenbergen@iknl.nl

Abstract

Background: In recent years, the question of how patients' participating in online communities affects various patient reported outcomes (PROs) has been investigated in several ways.

Objectives: This study aimed to systematically review all relevant literature identified using key search terms, with regard to, first, changes in PROs for cancer patients who participate in online communities and, second, the characteristics of patients who report such effects.

Methods: A computerized search of the literature via PubMed (MEDLINE), PsycINFO (5 and 4 stars), Cochrane Central Register of Controlled Trials, and ScienceDirect was performed. Last search was conducted in June 2017. Studies with the following terms were included: (cancer patient) and (support group or health communities) and (online or Internet). A total of 21 studies were included and independently assessed by 2 investigators using an 11-item quality checklist.

Results: The methodological quality of the selected studies varied: 12 were of high quality, eight were of adequate quality, and only one was of low quality. Most of the respondents were women (about 80%), most with breast cancer; their mean age was 50 years. The patients who were active in online support groups were mostly younger and more highly educated than the nonusers. The investigated PROs included general well-being (ie, mood and health), anxiety, depression, quality of life, posttraumatic growth, and cancer-related concerns. Only marginal effects—that is, PRO improvements—were found; in most cases they were insignificant, and in some cases they were contradictory.

Conclusions: The main shortcoming of this kind of study is the lack of methodological instruments for reliable measurements. Furthermore, some patients who participate in online communities or interact with peers via Internet do not expect to measure changes in their PROs. If cancer survivors want to meet other survivors and share information or get support, online communities can be a trustworthy and reliable platform to facilitate opportunities or possibilities to make this happen.

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KEYWORDS

cancer; survivors; patient reported outcomes; Internet; support groups

Introduction

Online social networks such as Facebook and LinkedIn have become seemingly indispensable aspects of modern life. A special kind of social support is online health communities. Patients meet each other online and share information and emotions related to their illness. They can share various forms of personal information online, ranging from pure data to pure

narratives, with various hybrid forms. In 1996, the Association of Cancer Online Resources (ACOR) [1] started facilitating cancer patients online by providing a platform for them to share their experiences and other information (mainly personal narratives). People write about their illness and share experiences about living with it on a day-to-day basis in a story-form; there is little to no requesting or storage of personal data. In 2004, PatientsLikeMe (PLM) [2] was established as a community in which patients can share their medical data. PLM standardizes the information to be shared, follows the course of each patient's illness process, stores that data in a structured database, and gives direct feedback in the form of figures on the course of the patient's illness, also in comparison with others on the platform.

Research by ACOR has shown that patients participate on such platforms primarily to share information on their illness with each other and not so much to share their emotions [3]. PLM studies have shown that patients seek others with similar disease characteristics [4]. Community members report benefits in decision making and symptom management, which may be related to their website use [5].

The concept of *online community* has developed in recent years as a result of improved technical possibilities. Relevant literature reviews cite various forms of online contact between patients, including bulletin boards, closed networks, mailing lists, newsgroups, communities, discussion forums (moderated or otherwise), chat rooms, Facebook groups, Twitter follow groups, email groups, and so on [6-9]. Furthermore, people have come to relate to such online platforms in novel ways, partly because of the popularity of Facebook (which was launched in 2004) and other social media networks.

The term *online communities* is not well defined in the literature, although there have been various attempts to describe the phenomenon, including the definition by Rheingold: "Virtual communities are social aggregations that emerge from the Net when enough people carry on those public discussions long enough, with sufficient human feeling, to form webs of personal relationships in cyberspace" [10]. For online communities, it should be noted that communication is electronic and independent of place and time and that such communities are usually open to new members, who can register for free. By participating, people gain insight into their illness and the opportunity to connect with others in comparable circumstances [3,11].

There are many online health communities with their own specific aims. As a potentially life-threatening illness, cancer raises a wide range of specific informational and emotional support issues, which is why we specially focus on cancer communities. In recent years, the effect of participating in online communities on different outcomes of interest has increasingly been investigated. However, as yet, there has been no summarizing overview of the most significant effects of participation.

This type of research can roughly be divided into two main variants: in the first, researchers ask community participants to complete one or more questionnaires, thereby measuring the effect on the individual; and in the second, researchers analyze content that has been produced by members—a process known as *content analysis*. This systematic review corresponds to the first variant and seeks to answer the following research questions:

1. Does the literature provide evidence of improvement in patient reported outcomes (PROs) for cancer patients who participate in online communities?
2. What are the characteristics of patients who report effects of participating in online communities?

Methods

Search Strategy and Selection Criteria

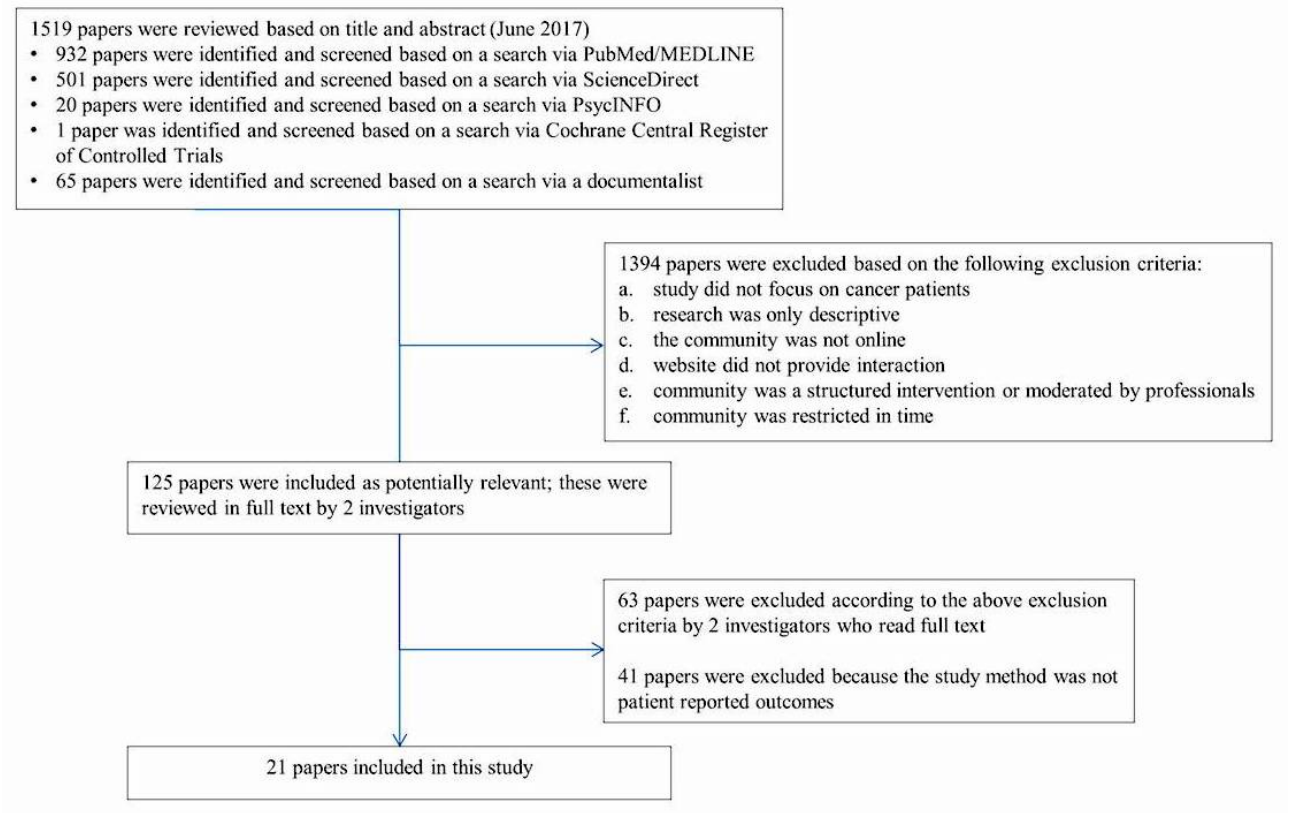
For this systematic review, we searched for publications that describe the effects of participating in online communities in terms of PROs collected from participating patients. Studies that measured effects by means of content analysis were excluded. This review focused on *asynchronous* forms of online contact, whereby participants do not need to react to one another immediately. Unlike chat sessions, they do not need to be simultaneously online. In all cases in which synchronous interaction was possible, this was always supplemental to the asynchronous form. In some cases, an online community is part of a broader service provision, so that participants can also take part in other online activities. Evaluating other forms of online contact, such as online (self-management) interventions for treatment support, is beyond the scope of this review.

PubMed (MEDLINE), PsycINFO, Cochrane Central Register of Controlled Trials, and ScienceDirect were searched (last search June 2017) using the following terms: (cancer patient) and (support group or health communities) and (online or Internet). PubMed added the Medical Subject Headings terms.

Studies were included according to the following criteria: (1) if the publication was an original peer-reviewed research study (eg, no systematic reviews, book chapters, dissertations, poster abstracts, editorials, and letters to the editor); (2) if it was written in English; and (3) if Web-based interaction between peers was possible. Studies were excluded if they (1) involved patient populations other than cancer survivors, (2) studied a structured Web-based health intervention or were moderated by professionals, and (3) studied content through content analysis of the discussions.

These inclusion and exclusion criteria were applied to our initial 1519 hits. After removal of duplicates and records not meeting the inclusion criteria, 125 records remained. Hard copies of these studies were obtained, and they were reviewed by 2 investigators (ME and FM) independently of each other. Both reviewers also used citation tracking to identify other studies potentially eligible for inclusion. This did not yield any new records. The 2 investigators agreed with each other on the final selection of studies: 21 were found to be eligible for inclusion in this review. Figure 1 is a flowchart of this selection procedure.

Figure 1. Flow chart of the literature search.



Quality Assessment

Both investigators (ME and FM) assessed the methodological quality of each of the selected studies using an 11-item standardized checklist of predefined criteria, based on established criteria for systematic review, which are presented in Textbox 1 [12,13]. Each item of a selected study that matched our criteria received 1 point. If an item did not meet our criteria, or was described insufficiently or not at all, no point was assigned. The highest possible score was thus 11. The studies were then sorted into arbitrarily defined quality categories. Studies scoring 75% or more of the maximum attainable score (≥8 points) were considered to be of *high quality*. Studies scoring between 50% and 75% (6-7 points) were rated as being of *adequate quality.* Studies scoring lower than 50% (ie, <6 points) of the maximum attainable score were considered to be of *low quality*.

Textbox 1. List of criteria for assessing the methodological quality of studies.

- A validated (quality of life [QoL] or patient reported outcome [PRO]) questionnaire is used.
- A description is included of at least two sociodemographic variables.
- A description is included of at least two clinical variables.
- Inclusion or exclusion criteria are described (patient population).
- Participation rates for patient groups are described and are more than 70%.
- Information is given about the degree of selection of sample (ratio respondents to nonrespondents).
- The study size consists of at least 50 participants (for active discussion).
- The data are prospectively gathered.
- The process of data collection is described (eg, interview or self-report).
- There is result comparison between two or more groups (eg, different chemotherapy treatments and differences in QoL for those with or without neuropathy symptoms) and/or results are compared with at least 2 time points (longitudinal vs posttreatment).
- Statistical proof for the main findings is reported.

Results

Study Characteristics

On the basis of our inclusion criteria, 21 studies remained for this review [14-34]. All those studies were published between 2005 and 2014, and the data collection described in them occurred between 2001 and 2011. Most of the studies, that is, 13 of them, were conducted in the United States [19-21,24-31,33,34]. With two Canadian studies [16,17], there were 15 in the English-language region. Only five of the studies were European: three in the Netherlands [14,15,18] and two in Denmark [22,23]. Only one study was conducted in a non-Western country, Japan [32].

The manner in which patients were asked to participate in the studies varied widely, including a notice on various websites [29], a community website [14,15], approaching participants in a training course [16], or a broader intervention [17,19-25,28,34]. Only in a few cases was there an explicit reference to the URL of the website where respondents were recruited [16,18,22,30].

The studies focused on the effects of participation on the patients' informational satisfaction and emotional support. The study populations ranged from 27 [17] to 794 [23] respondents. In most of the studies, the respondents had a mean age of approximately 50 years. In 15 of the 21 studies, breast cancer communities were the object of study [14-16,19-21,24-28,31-34] so at least 80% of the study population was women.

As far as could be ascertained, validated questionnaires specifically designed for Web-based patient-to-patient contact were not available. Instead, researchers relied on existing questionnaires developed for care providers' offline interventions toward patients or other customized questionnaires that were designed according to requirements. The studies used 29 different questionnaires (see Table 1). The most frequently used questionnaires were the Breast Cancer–Related Concerns [14,15,19,21,24,33], Functional Assessment of Cancer Therapy (FACT-B; quality of life measure for breast cancer)) [14,15,20,24,26,27], and Center for Epidemiologic Studies Depression Scale (CES-D; depression measure) [14,15,26,27,31]. The Hospitality Anxiety and Depression Scale (HADS; anxiety and depression measure) [17,25,32] and Mini-Mental Adjustment to Cancer Scale (MiniMac; mental adjustment to cancer) [14,22,23] were used fairly frequently. In many cases, a questionnaire was used only in a single study, including several custom-designed questionnaires.

Methodological Quality of the Studies

Our assessment of the methodological quality of the 21 studies according to the list of quality criteria showed that the quality scores ranged from 4 to 11 points (Table 1), the mean quality score being 7.7. A total of 12 studies were found to be of high quality [15,17,19-25,28,33,34], though only one study received the maximum attainable score of 11 points [25]. Of the remaining nine studies, eight were of adequate quality [14,16,18,26,27,29,31,32] and one [30] was found to be of low quality according to our criteria. The studies had two general shortcomings: first, either participation rates for patient groups were not described or they were described but were less than 70% (criterion 5); second, information was not provided about the degree of sample selection (criterion 6).

Reasons for and Impact of Participation in Online Communities

Patients participated mainly to share emotions [14-17,19-21,23,25-28,32-35] and to exchange information [16-18,20,22,24,25,28-30,32-34]. Sharing coping strategies played a limited role [14-17,31]. None of the studies referred to organizing practical help.

The research questions used in the studies varied strongly in terms of phrasing, which makes it difficult to compare the results. Some examples are as follows: *are people prepared to discuss sexuality online* [17]; *how does the behavior of posters compare with that of lurkers* [19]; *how does behavior change with time* [27]; *how do two patient groups or communities differ in behavior* [31]; and *what is the influence of family relations on participation in online groups* [34]. The study results often showed only minor differences between two groups, which in some cases were significant but in many cases contradicted each other.

Used Instruments for Measuring PROs

The research questions—and therefore also the results—differed greatly. To present the effects that were found, we have placed the studies into two main categories, making similarities and differences more apparent. The common subject of the first category is the extent to which participating in online groups contributed to the personal well-being of the participants in question, whereas the common subject of the second category is the extent to which personal characteristics influenced online participation. Changes in personal well-being may be attributable to patients' being able to share information [16-18,28,30] or emotions [21,23-27,31,32] with one another. Most of the studies found differences in well-being by comparing responses at two points in time, whereas some compared well-being between two different groups simultaneously. The investigated PROs ranged from screening for general well-being (ie, mood or health) through depression, anxiety, quality of life, and posttraumatic growth to cancer-related concerns. The effects found—that is, well-being improvements—were overall marginal, in most cases insignificant and sometimes contradictory. Posters were more positive than lurkers [17] and lurkers' perceived functional well-being was significantly greater than that of posters [19]. Hoybye et al [22] found no significant difference between users and nonusers in overall quality of life or psychological well-being. Namkoong et al [28] found an effect of treatment expression and reception on emotional well-being. Those with high self-efficacy benefited more. Online mailing lists appear to be an important information source for cancer patients and also for support [30]. Patients reported that they still use online groups for informational or symptom-management needs [16]. We found no convincing evidence of improvement in PROs for cancer patients who participate in online communities.

Table 1. Characteristics publications and quality score.

First author, year, country	Cancer	Data collected	Study type	n	Age, in years, mean	Women, %	Questionnaires	Conclusions	Q score
Batenburg [14] 2014, Netherlands	Breast	2010	Observational	175	48	99	Breast Cancer–Related Concerns (BCRC), Center for Epidemiologic Studies Depression Scale Revised (CES-D), Emotional Approach Coping Scale (EACS), Functional Assessment of Cancer Therapy, Breast (FACT-B), Mini-Mental Adjustment to Cancer (Mini-MAC) Scale (MIMA)	Individual differences in coping influence the relationship between online support group participation and psychological well-being.	6
Batenburg [15] 2014, Netherlands	Breast	2011	Observational	125	48	100	BCRC, CES-D, EACS, FACT-B	No negative effect of online participation; more positive effect when patients approach their emotions less actively.	10
Bender [16] 2013, Canada	Breast	2008	Observational	73	56	100	Self-made	Online communities have the potential to fill gaps in supportive care.	7
Classen [17] 2013, Canada	Gynecological	2009	Observational	27	40	100	Female Sexual Distress Scale—revised (FSDS), Illness Intrusiveness Ratings Scale (IIRS), Hospitality Anxiety and Depression Scale (HADS), Self-made	Women find the intervention acceptable. Posters tend to be more positive than lurkers.	9
Frost [18] 2014, Netherlands	Unspecified	2013	Observational	115	52	55	Self-made	Patients share medical details more willingly online than daily life or identity information.	6
Han [21] 2011, USA	Breast	2001	Observational	177		100	BCRC	A combination of empathy expression and reception is crucial to obtaining optimal benefits.	10
Han [20] 2012, USA	Breast	2001	Observational	231	51	100	FACT-B	Patterns of engagement differed according to patients' characteristics.	9
Han [19] 2014, USA	Breast	2005	Observational	325	51	100	BCRC, Partners in Health (PIH), Social support, Self-made	Patterns of engagement differed according to patients' sociodemographic characteristics and psychosocial factors. Lurkers had a higher level of perceived functional well-being than posters at 3 months post baseline.	8
Hoybye [22] 2010, Denmark	Unspecified	2003	Observational	211	50-57	85-90	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC C300), MIMA, Profile of Mood States (POMS),	Patients not inclined to use Internet-based interventions are characterized by social position and employ more passive coping strategies.	8

First author, year, country	Cancer	Data collected	Study type	n	Age, in years, mean	Women, %	Questionnaires	Conclusions	Q score
Hoybye [23] 2010, Denmark	Unspecified	2004	Randomized clinical trial (RCT)	794	53-55	84-90	MIMA, POMS	Long-lasting psychological effects of participating in Internet-based support groups still need to be confirmed.	9
Kim [24] 2012, USA	Breast		Observational	177	51	100	BCRC, FACT-B	Supportive exchanges play positive, but different, roles in predicting psychosocial health outcomes. Emotional support giving and receiving tend to reinforce each other.	9
Lepore [25] 2014, USA	Breast	2011	RCT-Control group	184		100	IIRS, Self-made	The prosocial Internet support group (ISG) did not produce better mental health outcomes in distressed survivors relative to standard ISG.	11
Lieberman [27] 2005, USA	Breast		Observational	114	46	100	CES-D, FACT-B	Validation of bulletin boards as a source of support and help for breast cancer patients.	7
Lieberman [26] 2006, USA	Breast		Observational	52	46	100	CES-D, FACT-B, Posttraumatic Growth Inventory (PTGI)	Expressing certain negative emotions online is beneficial; expressing others is not.	7
Nam Koong [28] 2010, USA	Breast	2001	Observational	231	51	100	Self-made	Treatment information exchanges had a positive impact on emotional well-being for those with higher health self-efficacy but a negative influence for those with lower health self-efficacy.	10
Osei [29] 2013, USA	Prostate	2010	RCT-Control group	40	67	0	26-item Expanded Prostate Cancer Index Composite (EPIC-260), Program Satisfaction (PRSA), Relationship Satisfaction (RS), Satisfaction with Life Scale (SWL), 12-item Short-Form patient-reported survey of patient health (SF12), 36-item Short-Form Health Survey (SF36)	Providing support using Web-based methods is effective.	7
Rimer [30] 2005, USA	Unspecified	2004	Observational	362	>50	49	Information seeking items from the National Cancer Institute's Health Information National Trends Study (HINTS), Self-made	Mailing lists appear to be an important resource for patients. Data suggest that they are perhaps underused by minority survivors.	4
Setoyama [32] 2011, Japan	Breast	2007	Observational	253		100	HADS	The results demonstrate that participating in online communities, even as a lurker, may be beneficial to patients' mental health.	7

First author, year, country	Cancer	Data collected	Study type	n	Age, in years, mean	Women, %	Questionnaires	Conclusions	Q score
Seckin [31] 2011 USA	75% Breast, 25% other cancers		Observational	255		80	CES-D, Functional Assessment of Cancer Therapy (FACT), Medical Outcomes Study (MOS) Short-Form General Health Survey (SF20), Multidimensional Index of Life Quality (MILQ)	The Internet may be particularly beneficial to older adults who feel helpless to cope with cancer in old age.	7
Shaw [33] 2006, USA	Breast		Observational	144	44,5	100	BCRC, Emotional Well-being (EWB), Positive Affect Negative Affect Scale, (PANAS), Psychological General Well-Being Index (PGWBI)	Active users were more likely at pretest to consider themselves active participants in their health care.	10
Yoo [34] 2014, USA	Breast	2005-2007	Observational	111	50,9	100	60-item index of coping (COPE), Family Environment Scale (FES)	Family environment plays a crucial role in predicting participation and moderating the effects of use of online groups on coping strategies such as problem- and emotion-focused coping.	8

Patient Characteristics Related to Effects

The studies on the influence of the various personal characteristics showed that coping strategies [14,15] and sociodemographic characteristics [19,20,22,28,33,34] influence how patients were active in an online group. On comparing active participants (posters/providers) with passive participants (lurkers/readers) and any nonusers, the age, race, socioeconomic status, and social embeddedness are revealed to influence online participation. Of the total number of respondents, 65% to 80% were younger than 60 years [30,32] or had a mean age ranging between 40 and 55 years [14,17,18,25,33,36]. Han et al [20] found a difference in mean age of 5 years between lurkers and posters and Hoybye et al [22] of 7 years between users and nonusers. However, 2 years later, the age differences between lurkers and posters had disappeared [19]. The result of Shaw's Comprehensive Health Enhancement Support System (CHESS) study [33], in which respondents were given a computer and Internet access, is that for women with an Internet connection, the demographic differences in online participation became insignificant.

According to Han, patients with good social embeddedness are less inclined to post [20], whereas Hoybye et al [22] concluded that using the Internet does not appear to be a solution for those who experience little support in their daily lives. Users (posters and lurkers) were more likely to live alone [20], and lurkers seem to have a higher perceived well-being than posters. However, the findings suggest that lurkers and posters do not differ in their short-term health outcomes and that lurkers perform better than posters in certain outcomes because of their long-term engagement in online groups [19].

Discussion

This systematic review showed that participation by cancer patients in online communities does not have a large effect in PROs. This review also indicated that most of the respondents in the reviewed studies were women (80%), as 15 out of the 21 studies were related to breast cancer communities. It was found that participants mainly want to share emotions and information and, in some cases, coping strategies as well. As the research questions and measurement instruments used in the studies varied strongly, it is difficult to compare their results.

Study Characteristics

As far as can be ascertained, no exclusive validated questionnaires exist for measuring the effects of Web-based patient-to-patient contact. A total of 28 different validated or customized questionnaires were used. If a community is also part of a broader (online) program for patients [17,19-24,28,29,33,34], it is probably even more difficult to measure the effects of participating in it.

Methodological Quality of the Studies

The studies included in this review provide only meager description of the context of the researched communities, possibly because there are few available definitions to facilitate description of differences between communities and/or categorization of their characteristics. Not only is social interaction on Internet a relatively new domain, but it is also continuously developing. In a relatively short time span (10-15 years), there have been great changes, partly because of technological developments. A community's launch year and its available starting and running budgets largely determine the technological possibilities of the platform. As the application

is almost never commercial, there is a limited budget for further development. ACOR is a prime example of this. Although it was once a pioneer, its impact has diminished in recent years because of technological limitations. The publications on this platform are from before 2010 [3,37].

This review reveals that researchers have not yet succeeded in developing a research method to assess the impact of participating in online cancer communities that, when repeated, produces results that can be compared. As yet, there is insufficient methodological framework to speak of a research field. Researchers do not even have or use a standard, agreed definition of an online community. They do not describe the characteristics of the researched communities and how these influence the research results. Presumably, the various possibilities of the technology, the graphic design, the marketing, the online and offline references to the community, the provider's reliability, and so on, all have an impact on the user experience and may partly determine participants' success and satisfaction, thereby influencing the research results. The impact of these factors should be measurable; otherwise it will be impossible to determine the effects of patients' participation in Internet communities. Research into patients' Internet use has clearly shown that personal and illness characteristics influence use [22,38]. However, it has yet to be clarified how patients' Internet skills and expectations regarding interactive possibilities influence their experienced degree of satisfaction with the platforms and affect their psychosocial well-being. In the reviewed studies, most of the research populations were too small to take population variation into account. Zhang's framework for organizing research of online health communities shows us how many variables can be studied [7]. Leimeister et al [39] designed a model for measuring social support in online communities, which makes it possible to compare the effects of participating in different communities for different patients.

None of the reviewed studies included an attempt to describe the software-based interactive possibilities and their influence on the results. The combination of rapid technological developments and different budgets has led to great differences between the online platforms, making comparison of results meaningless—if not impossible.

Reasons and Impact of Participation in Online Communities

Talking about the illness with others who are well acquainted or less well acquainted, on the Internet or otherwise, can contribute to (learning to) deal with the reality of being seriously ill [15,40,41]. In this context, online communities can have a function, in that people are able to meet each other virtually and share experiences. However, it is difficult to objectively and quantitatively measure the effect on personal well-being by means of PROs [16-18,21,23-28,30-32]. The most commonly cited factors that influence the extent to which patients are active on Internet are demographics, including age, gender, education level, and stage of illness. In the literature, no negative effects of patients' participating in online platforms are cited, although in some cases incorrect information has not been corrected fast enough in such environments [42]. Do online and offline forms of social contact between patients have the same advantages and disadvantages? The most important criterion of how social contact occurs should be patients' preferences, precisely because personal characteristics influence the effects of participation in online communities [21,23-27,31,32].

Patient Characteristics Related to Effects

It seems that the Internet has become one of the main social environments in which individuals act—to a greater or lesser degree. Whether people actually make use of the Internet is strongly determined by personal and illness characteristics, social background, needs, and various computer and Internet skills [8]. However, these variables were insufficiently taken into account in the different studies, even though they generally influence individuals' quality of life. Although participating in an Internet community does not appear to make a big difference in improving PROs, it can add considerable value for some patients, in that they are able to connect and converse with fellow patients at any time. If patients have major concerns, the effect of participation can reasonably be expected to be greater.

The limited diversity of respondents in the studies—in particular, the large numbers of women with breast cancer—makes it difficult to treat the results as generally applicable. Figures from the Netherlands Cancer Registry [43] indicate that only about one-third of all women with cancer in 2014 had breast cancer, whereas in the reviewed studies, approximately 90% of the women had that type of cancer. Most of the respondents in the reviewed studies had a mean age of approximately 50 years, whereas in the Netherlands, for example, generally at least 70% of cancer patients are 60 years or older when first diagnosed, and, in the case of breast cancer, 80% of the patients are 50 years or older. Therefore, it can reasonably be concluded that the age distribution of the surveyed population differs from that of the general population of cancer patients and that a younger population of patients is active on the Internet.

A tentative conclusion can be drawn regarding added value for women with breast cancer, although the respondents indicated very few illness characteristics to make reliable statements regarding the total breast cancer population.

Conclusions

Given the large number of influencing factors, in combination with the difficulty of comparison and the limited results, we conclude that there is little to be gained from further research in how participation in online community influences PROs. The conditions under which effects are obtained are difficult to reproduce. A specific model, such as described and tested by Leimeister et al [39], may be a more reliable tool for measuring the effects of participation in online communities.

Despite our conclusion, we believe that online communities are relevant for some patients who wish to communicate with their peers by writing and reading [44,45] because they think it will help them to cope with their situation. It is not unlike a *real* conversation with friends or relatives or reading a book describing a patient's journey. Patients can interact with peers in online patient communities, exactly at their preferred time, place, and pace. The evidence for negative implications is small [44,45].

To further this development, we believe that research on standardization of infrastructure for care communities, which has proven to be workable in practice, may be appropriate at this juncture. That would enable upscaling, also for other illness patterns and in other language regions. This may be a useful and interesting concept for a major socially responsible cooperative project involving Facebook, Google, and patient organizations. Facebook has a great deal of know-how when it comes to building social networks, and Google can readily search the content; patients can test that environment for functionality and interaction.

Conflicts of Interest

None declared.

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Abbreviations

ACOR: Association of Cancer Online Resources
PLM: PatientsLikeMe
PROs: patient reported outcomes

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Original Paper

Development, Feasibility, and Small-Scale Implementation of a Web-Based Prognostic Tool—Surveillance, Epidemiology, and End Results Cancer Survival Calculator

Michelle Henton[1*], MA; Bridget Gaglio[1*], MPH, PhD; Laurie Cynkin[2*], MHS; Eric J Feuer[3*], PhD; Borsika A Rabin[4*], MPH, PhD

[1]Clinical Effectiveness and Decision Science, Patient-Centered Outcomes Research Institute, Washington, DC, United States

[2]Office of Advocacy Relations, Office of the Director, National Cancer Institute, Bethesda, MD, United States

[3]Statistical Research and Applications Branch, Surveillance Research Program, Division of Cancer Control and Population Sciences, National Cancer Institute, Bethesda, MD, United States

[4]Department of Family Medicine and Public Health, School of Medicine, University of California San Diego, La Jolla, CA, United States

[*]all authors contributed equally

Corresponding Author:
Michelle Henton, MA
Clinical Effectiveness and Decision Science
Patient-Centered Outcomes Research Institute
1828 L St. NW
Ste. 900
Washington, DC, 20036
United States
Phone: 1 202 370 9410
Fax: 1 202 370 9418
Email: mhenton@pcori.org

Abstract

Background: Population datasets and the Internet are playing an ever-growing role in the way cancer information is made available to providers, patients, and their caregivers. The Surveillance, Epidemiology, and End Results Cancer Survival Calculator (SEER*CSC) is a Web-based cancer prognostic tool that uses SEER data, a large population dataset, to provide physicians with highly valid, evidence-based prognostic estimates for increasing shared decision-making and improving patient-provider communication of complex health information.

Objective: The aim of this study was to develop, test, and implement SEER*CSC.

Methods: An iterative approach was used to develop the SEER*CSC. Based on input from cancer patient advocacy groups and physicians, an initial version of the tool was developed. Next, providers from 4 health care delivery systems were recruited to do formal usability testing of SEER*CSC. A revised version of SEER*CSC was then implemented in two health care delivery sites using a real-world clinical implementation approach, and usage data were collected. Post-implementation follow-up interviews were conducted with site champions. Finally, patients from two cancer advocacy groups participated in usability testing.

Results: Overall feedback of SEER*CSC from both providers and patients was positive, with providers noting that the tool was professional and reliable, and patients finding it to be informational and helpful to use when discussing their diagnosis with their provider. However, use during the small-scale implementation was low. Reasons for low usage included time to enter data, not having treatment options in the tool, and the tool not being incorporated into the electronic health record (EHR). Patients found the language in its current version to be too complex.

Conclusions: The implementation and usability results showed that participants were enthusiastic about the use and features of SEER*CSC, but sustained implementation in a real-world clinical setting faced significant challenges. As a result of these findings, SEER*CSC is being redesigned with more accessible language for a public facing release. Meta-tools, which put different tools in context of each other, are needed to assist in understanding the strengths and limitations of various tools and their place in the clinical decision-making pathway. The continued development and eventual release of prognostic tools should include feedback from multidisciplinary health care teams, various stakeholder groups, patients, and caregivers.

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KEYWORDS

clinical decision-making; communication; neoplasms; patient care team; Internet

Introduction

It comes as no surprise that the Internet has changed the way patients diagnosed with cancer and their caregivers seek information about their diagnosis. The influx of big data and the use of electronic health records (EHR) in the health care system [1] have been instrumental in the evolution of the relationship between large datasets with both patients and providers. Even though the Health Information Technology for Economic and Clinical Health Act (HITECH), which was passed by Congress in 2009 [2,3], is increasing the adoption and use of EHRs, the health care industry as a whole has not been as quick to adopt changes into their systems [4], such as integrating decision support tools or predictive tools (known as nomograms) into physician workflow [5].

The lack of uptake of tools into EHR systems, matched with the increase in tool development as it relates to cancer prognosis, has led to a number of cancer prognostic tools being housed outside of the health care setting. These cancer prognostic tools often use clinical or population datasets (or sometimes a combination of both) to tell a story about millions of patients and their health. On their own, population datasets are overwhelming and not easily understood by the general public. However, when this information is broken down and formatted into tools, large population datasets can give an unbiased estimate about one patient based on the data of millions of others with similar traits. These tools are being developed to allow oncologists to project an individual's likelihood of cancer recurrence, likely benefit from chemotherapy, probability of mortality at different ages to both improve the accuracy of the oncologist's knowledge about cancer prognosis and provide a basis for informed decision-making [6], and also allow patients to understand complex health information [7]. This helps open the door for patients to take charge of their own health and gives providers an opportunity to have a conversation with patients and their caregivers about complex health information in a format that is accessible and understandable.

In order to create a Web-based prognostic tool that could draw on the most extensive cancer statistics databases, the National Cancer Institute's (NCI) Statistics Research and Applications Branch in 2008 developed the Surveillance, Epidemiology and End Results Cancer Survival Calculator (SEER*CSC, formerly known as the Cancer Survival Query System [CSQS]), a prototype of a Web-based prognostic tool. Unlike other tools such as Adjuvant! Online and Memorial Sloan Kettering's nomograms, which use clinical data [6], SEER*CSC was designed to access SEER and Medicare claims data. SEER*CSC provides physicians with highly valid evidence-based prognostic estimates about cancer to improve the quality of information that physicians have for shared decision-making and risk communication with their patients. The strength of SEER data is that it is population-based, thus providing estimates of survival that may be quite different than patients in clinical trials or seen at major cancer centers [8,9]. The sheer size of the database (from 18 widely different geographic areas representing about 30% of the United States population) ensures that even patients with somewhat uncommon sets of tumor, demographic, and comorbidity profiles can get reasonable estimates of their prognosis. With this, SEER*CSC is a means of making survival estimates from a population-based database more timely, relevant, actionable, understandable, and context-accurate for cancer patients.

The purposes of this study were to: (1) describe the iterative, multistep development and testing of SEER*CSC, (2) discuss lessons learned from a small-scale implementation study, and (3) provide directions for future refinement and release of SEER*CSC.

Methods

This study consisted of four phases: (1) formative period, (2) provider usability testing, (3) small-scale implementation, and (4) patient usability testing. The institutional review boards at all participating sites approved this study.

Formative Period

Formative research was conducted in two steps in 2005 and 2008 to develop the prototype of SEER*CSC through the NCI Office of Market Research and Evaluation and a private contractor, User-Centered Design. During this stage of the project, patient advocates were queried about SEER*CSC through usability testing, survey methods, and a focus group. In addition, 7 physicians (1 surgical oncologist, 1 breast surgeon, 2 medical oncologists, 1 urologist, 1 surgeon, and 1 physician of unknown specialty) were interviewed via telephone in 2008 with a structured interview guide, asking about respondents' background and experience with patients, their experience with similar prognostic tools, and their thoughts and reactions to SEER*CSC approach and intent.

Provider Usability Testing

Using the knowledge gathered from the formative phase, usability and feasibility data were collected from four health care delivery systems (Kaiser Permanente Colorado, University of Colorado Hospital, Denver Health Medical Center, and Veterans Administration Eastern Colorado Health Care System) on the general applicability, content and design, and implementation potential of SEER*CSC through one-on-one testing sessions with physicians and other members of cancer care teams.

The one-on-one sessions included: (1) semistructured discussion about general and prognosis-specific communication issues with cancer patients (ie, pre-test interview), (2) hands on formal usability testing session using think aloud approach and hypothetical case examples, and (3) semistructured discussion about the applicability and implementation potential of SEER*CSC (ie, post-test interview). The one-on-one sessions

were designed to last approximately 90 minutes and were conducted by 1 of 3 members of the research team who were extensively trained in qualitative interviewing, usability testing, and the use and underlying principles of SEER*CSC. We asked 2 medical oncologists from the Dana Farber Cancer Center specializing in prostate and colorectal cancer treatment to review SEER*CSC and develop hypothetical case studies for the usability testing sessions. The one-on-one sessions were audio recorded. The usability portion of the session was recorded using screen capturing software (Camtasia for Mac OS 2010). Interviewers prepared detailed field notes from each session.

Small-Scale Implementation

Based on the input from the provider usability testing, SEER*CSC was revised. This version was included in a small-scale implementation phase, which consisted of two parts. First, interviews were conducted with 5 physicians from 3 health care delivery systems (Kaiser Permanente Colorado, University of Colorado Hospital, and Denver Health Medical Center). Physician interviewees represented possible site champions for the small-scale implementation study and were knowledgeable on both clinical and information technology barriers and facilitators. All but 1 physician interviewee participated in the previous phase of provider usability testing of SEER*CSC and were familiar with the website. Second, a small-scale implementation of SEER*CSC into 3 specialty care departments (urology, oncology, and surgery) across 4 sites (Kaiser Permanente Colorado, Penrose Cancer Center in Colorado Springs, Colorado, and 2 urology private practices affiliated with Penrose Cancer Center) was conducted. A total of 9 champions were identified and were responsible for the following: (1) meet with study staff to discuss an implementation plan and schedule a time for a roll-out meeting with department staff, where study staff explained the study and demonstrated the tool, (2) distribute a follow-up email created by study staff to their department explaining the study, and (3) participate in a follow-up key informant interview once data collection was complete. Champions were also encouraged to contact study staff when they participated in any follow-up activity, such as discussing SEER*CSC with colleagues, providing a department demonstration, or sending an email/voicemail to colleagues reminding them of SEER*CSC. These activities were documented by study staff to compare with automated usage data.

Patient Usability Testing

Upon completion of the small-scale implementation study, the possibility of making SEER*CSC patient-facing was considered. To further explore this option, Web-based one-on-one usability testing of SEER*CSC was conducted with patients who were diagnosed with prostate or colorectal cancer. The purpose was to understand health information–seeking practices and preferences around communication of cancer prognostic information to further refine SEER*CSC. Prostate and colorectal cancers were included because they are common cancers often diagnosed at older ages when individuals have significant coexisting conditions. Eligible participants were identified from two advocacy groups: Prostate Cancer, International and Fight Colorectal Cancer. Champions were identified from each advocacy group to inform potential participants about the study and invite them to take part in it through their respective websites. Eligible participants were required to have had a prostate or colorectal cancer diagnosis within the last 5 years (as indicated by self-report from the time of contact). Individuals that responded to the champions' invitation and were contacted by study staff to set up a time to participate in usability testing.

The one-on-one sessions took place via Cisco WebEx and took approximately 75 minutes. Each session consisted of: (1) informed consent, (2) short survey consisting of demographic questions and questions on prognostic information seeking, (3) formal usability testing, and (4) questions soliciting feedback and recommendations for making SEER*CSC more patient focused. During the formal usability testing portion, participants were asked to enter information into SEER*CSC using case examples developed by the research team. The case examples were matched to patient's cancer history (eg, participants with prostate cancer history would use a prostate cancer case). Usability sessions were recorded using Cisco WebEx with the permission of the participants.

Data Analysis

Interviews conducted during the last 3 phases of the study (provider usability testing, small-scale implementation, and patient usability testing) were transcribed verbatim and reviewed against the audio files by a research assistant. Post-interview field notes were saved along with interview transcripts. The narrative data were entered into ATLAS.ti release 6.2 (ATLAS.ti, 2012) for analyses. Data analysis occurred throughout the data collection process. Three interviews were initially coded by 4 members of the research team who created an initial list of codes based on key points in the interview text. The 4 coders then met to discuss codes and create a formal codebook. This process was repeated with 4 additional interviews until the final codebook and thematic framework was created. The remaining interviews were coded with a subset of interviews selected for secondary coding. Comparisons between primary and secondary coders were conducted to assess inter-rater reliability. The findings were deemed to be acceptable using a qualitative comparison of coding patterns across coders and resulted in a 75% agreement. To augment information from the provider and patient usability interview transcripts and field notes, a subset of video files from the Camtasia (for Mac OS 2010) screen recordings were analyzed. A structured abstraction form was used to assess the length of time for which the tool was used per each case study as well as which pages were visited and which features of the tool were used. During the small-scale implementation trial, data were collected electronically on tool usage. Field notes were used to capture champions' efforts to promote the use of the tool and to help interpret usage data.

Results

Overview

The development of SEER*CSC followed an iterative, multistep approach, taking information from each phase into account for the refinement of the tool for the next phase. The results are presented by each phase of the project.

Formative Period

Formative data collection efforts were conducted in the early development stage of SEER*CSC and suggested potential user perspectives on utility, as well as improvements and safeguards for this prognostic tool to minimize its possible negative consequences. Information gathered by NCI through usability testing, surveys, and a 10 person focus group with patient advocates in 2005 and then again from 9 telephone interviews in 2008 identified similar themes. Patient advocates stated access to survival data is needed, but it must be presented less technically and in such a way as to keep hope alive.

Concern about misuse of prognostic information was noted by advocates. Examples included clinicians who may deny treatment to patients with a low survival rating and insurance companies using the information to ration or deny coverage for treatment. Some advocates further expressed how patients themselves might misuse or misinterpret prognostic information. However, there was consensus among advocates that prognosis information and crude survival data should be available to the patient community and that it would be of use to them. They stated that patients should be able to access any data available to their physicians, and most would use a print-out of SEER*CSC's results as the basis for dialogue with their clinicians.

Subsequent feedback from physicians and cancer patient advocates on the wireframe of SEER*CSC included: (1) many prognostic tools do not adequately account for comorbidities or account for how treatment affects prognosis, (2) SEER data are less biased than the data relied on by available prognostic tools, and (3) users are not allowed to enter clinically detailed specifications about cancer size and progression. Based on this feedback the initial version of the SEER*CSC calculator was developed.

Provider Usability Testing

A total of 57 provider interviews were conducted across four health care delivery systems. This included 36 physicians and 21 other types of providers (eg, nurse, pharmacist, and social worker). There was variability in terms of time in current position, with the majority being 1 to 5 years, followed by more than 10 years. Most providers saw cancer patients at least once per day. Demographics of provider interviewees are provided in Table 1.

In terms of usability, SEER*CSC was generally regarded as professional, intuitive, easy-to-use and navigate, and visually appealing. However, there was confusion about how to navigate to previously viewed pages, and that the user agreement and home page needed to be less information dense. Comments were very favorable for the prognostic information sections of the tool. Provider interviewees overwhelmingly felt it was important to include treatment information and the relationship with survival, as this information is key to having the prognosis conversation with their patients (see Table 2).

Based on this feedback, changes were made to SEER*CSC (see Figures 1 and 2). The most important changes involved revising the layout of the results page. This included changing the color of the charts to be more distinguishable, adjusting the years after diagnosis to default to 1, 5, and 10 years instead of 1, 3, and 5, and adding a Compare Another Patient feature that allows the user to compare 2 diagnoses using different criteria (eg, age, gender, and comorbid conditions). Additional changes included adding more information in the form of pop-up windows when hovering over a "?" throughout the tool and making the language on the website more concise.

Small-Scale Implementation

After the physician usability testing, revisions were made to SEER*CSC in preparation for the small-scale implementation. A total of 157 providers (including physicians and nurses) from 7 practices at 4 sites were assigned logins to participate in the implementation of SEER*CSC. Overall, the tool was not widely adopted during the study. Data were tracked from mid-February to mid-May, 2013. During the 3 months of data tracking, usage was low and non-sustained. Table 3 shows that providers had a total of 23 sessions with 45 case scenarios entered, most of which were comparing 1 individual case with multiple modifications (eg, altering demographics, and comorbidities). Attempts to remind champions about contacting providers in their department to use SEER*CSC were unsuccessful. This included up to 2 email reminders that provided language for champions to send to their departments with information about SEER*CSC, the link to the SEER*CSC portal, and a reminder how to log into the portal. Overall implementation of SEER*CSC was not successful.

Exit interviews with the champions revealed that there are no incentives or infrastructure in place for providers to use Web-based prognostic tools. A majority stated they did not use tools when discussing prognosis with their patients because of time and preference/habit. Additional barriers to the implementation of SEER*CSC included not having all the information providers wanted in the tool (eg, treatment), time to enter the data, and not having the tool as part of the electronic health record or readily available on the desktop.

Table 1. Demographics of interviewees who participated in the provider usability testing sessions for Surveillance, Epidemiology and End Results Cancer Survival Calculator (SEER*CSC).

Characteristics (N=57)	n (%)
Gender	
Male	21 (37)
Female	36 (63)
Age group, years	
Under 34	10 (21)
35-44	20 (35)
45-54	12 (21)
55-64	14 (25)
65 and older	1 (2)
Type of provider	
Clinical pharmacist	1 (2)
Nurse practitioner	6 (11)
Patient navigator/social worker	3 (5)
Physician	36 (63)
Physician assistant	2 (4)
Nurse	7 (12)
Nurse care coordinator	2 (4)
Specialty	
Family medicine	6 (11)
Internal medicine	8 (14)
Oncology	17 (30)
Urology	7 (12)
Surgery	10 (18)
Radiology	3 (5)
Radiation Oncology	2 (4)
Gastroenterology	2 (4)
Pharmacy	1 (2)
Health education	1 (2)
Time in current position	
Less than one year	10 (18)
1-5 years	19 (33)
6-10 years	10 (18)
More than 10 years	18 (32)
Time in health care/medicine	
0-5 years	7 (12)
6-10 years	11 (19)
11-15 years	12 (21)
More than 15 years	27 (47)

Characteristics (N=57)	n (%)
Frequency of seeing cancer patients	
At least once per day	38 (67)
At least once per week	14 (25)
Less than once per week	5 (9)

Table 2. Summary of combined physician and patient usability testing feedback of Surveillance, Epidemiology and End Results Cancer Survival Calculator (SEER*CSC).

Section	Issue identified	Recommendation
Starting pages	Not all users (especially non-cancer specialist providers) were familiar with SEER (Surveillance, Epidemiology, and End Results).	SEER needs to be better explained (in lay terms) on the home page so users who are not familiar with SEER can also understand the term and reliability of the source. In addition, SEER should be explained on the output pages for those that skip the home page and move right to the calculators.
Prostate disease characteristics	Concerns were raised about the appropriateness of selected categories for Gleason score. Many argued that more recent clinical evidence suggests different categorization of the patients based on their Gleason score. Most suggested three categories with varying cut-off values (eg, 6 and less; 7-8, 9-10).	Categorization of cases based on Gleason score should be reconsidered or existing categorization should be justified.
Prostate disease characteristics	Non-cancer specialists were not always familiar with Gleason score and would have appreciated guidance and definition of the exact clinical meaning and origin of this value. Also, the categories of pre-treatment, pure clinical, and pathologic stage were not intuitive for all interviewees.	Provide definition in the form of pop-up window. It would be important to provide clear explanation on pre-treatment, pure clinical, and pathologic stages since these categories were not always intuitive for interviewees.
Prostate disease characteristics	A few interviewees mentioned that prostate-specific antigen (PSA) values should be added to the algorithm, although one specialist thought that PSA has less impact on prognosis than Gleason score. Several patient users asked why PSA was not included.	While inclusion of PSA values into the algorithm might not be feasible, explanation on why and how the lack of PSA might impact outcomes might increase the trust of providers in the results provided by the tool.
Comorbidity calculator	Many providers expressed general agreement with the accuracy of the health status adjusted age, although several expressed concerns and/or confusion about how adjusted age is calculated and whether interactions or simple additive models are used.	Providing link to the calculations or method used for age adjustment based on comorbidities should be provided.
Comorbidity calculator	Many users wanted to know how the list of comorbidities included in the calculator was selected.	The reason for the choices of conditions in comorbidity calculator should be made more transparently available for users.
Comorbidity calculator	Many providers and patients did not understand why comorbidity data are not available for those under 66, suggesting that an explanation is needed. While some providers knew that the comorbidity calculator is only available for those 66 and over, most did not know the reason for this, and some incorrectly speculated as to the reasons.	It should be more prominently displayed why comorbidity calculator is not available for those under 66.
Summary of results	Print, email, and link functions were regarded as useful services by many interviewees. When testing these functionalities some issues were noted by our research team.	Print, email, link functions need to be thoroughly tested for proper functioning.
Summary of results	A number of users did not note the Modify chart option and needed to be prompted to use this functionality. Furthermore, patient interviewees wanted to see survival data projections beyond 10 years, going up to at least 20 years.	Arrangement of the Summary of Results page should be considered to better differentiate the Update charts and extend survival data calculations up to 20 years.
Additional resources	One consideration might be to continually update and refine the patient and physician resources, particularly as new information becomes available. Providers and patients truly saw the value in having these resources and would appreciate them most if they knew it was the latest and greatest information.	Addition of currently available Web-based prognostic tools and guidance on when to use those (from our systematic review) could be one added resource.

Figure 1. Screenshot of Surveillance, Epidemiology and End Results Cancer Survival Calculator's (SEER*CSC) Summary of Results page before physician usability testing.

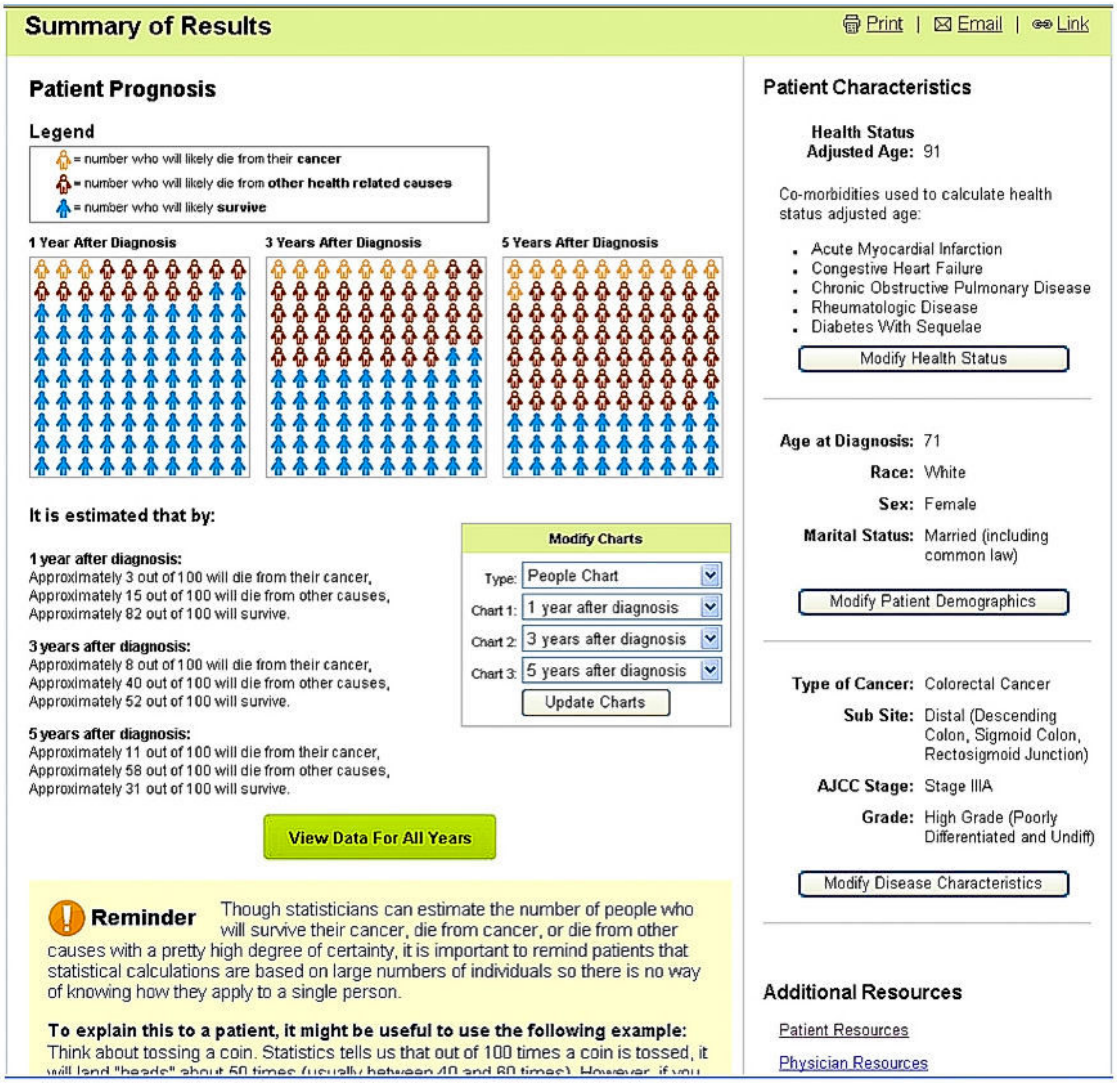

Figure 2. Screenshot of Surveillance, Epidemiology and End Results Cancer Survival Calculator's (SEER*CSC) Summary of Results page after physician usability testing.

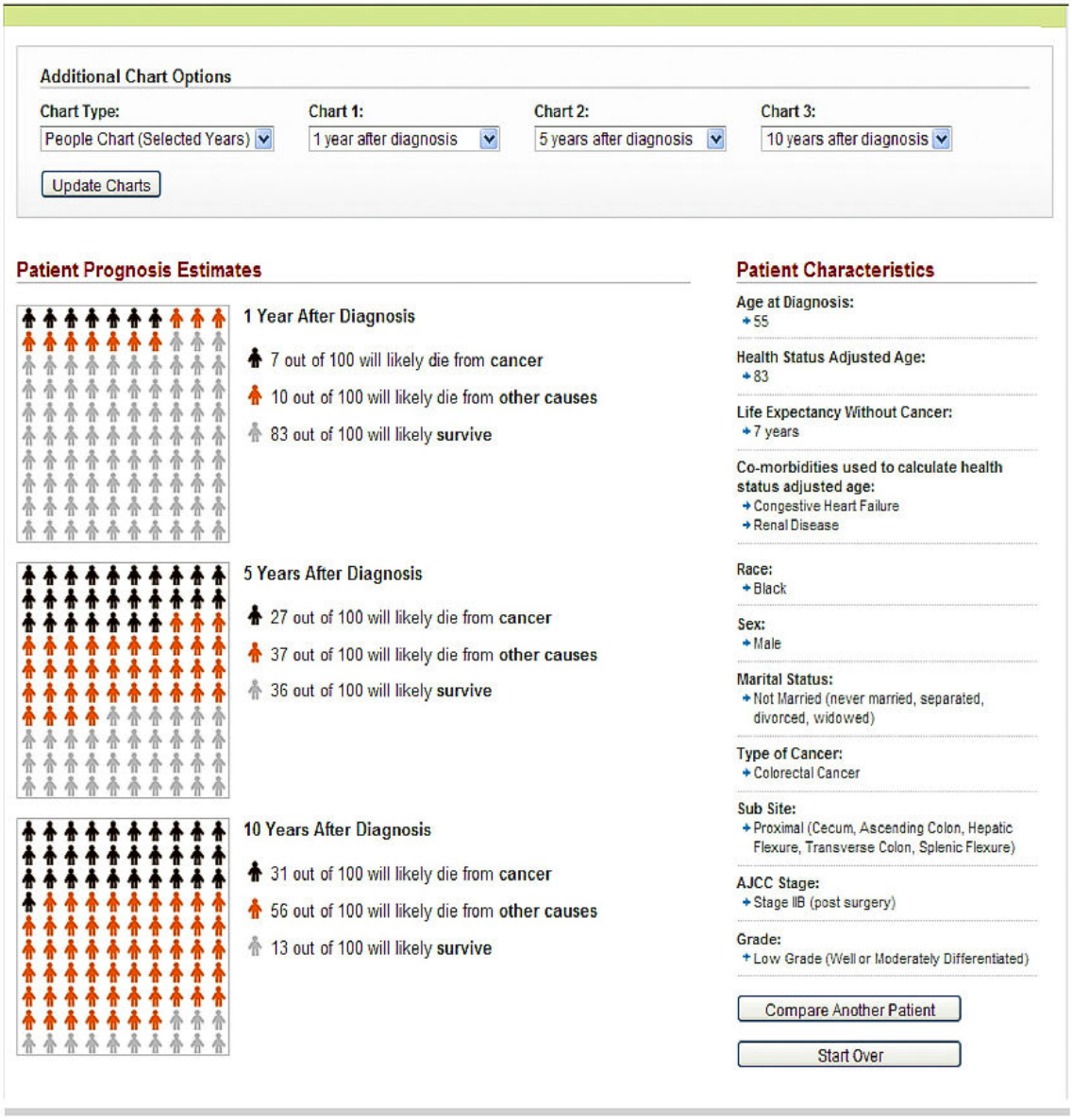

Table 3. Data tracking of Surveillance, Epidemiology and End Results Cancer Survival Calculator (SEER*CSC) usability during small-scale implementation in clinical care settings.

Data tracking in clinical care settings	Data pull 1: February 19-April 18, 2013	Data pull 2: April 18-May 17, 2013
Number of case scenarios	30	15
Type of cancer		
Prostate	22	8
Colorectal	8	7
Total number of individual providers	8[a]	4
Uses by site		
KP Urology	2	2
KP Oncology	1	0
KP Surgery	1	0
Penrose-GI	2	2
Penrose-Radiation Oncology	1	0
Private Urology Practice 1	1	0
Private Urology Practice 2	0	0
Total number of sessions	15[b]	8
Sessions by site		
KP Urology	6	5
KP Oncology	1	0
KP Surgery	1	0
Penrose-GI	4	3
Penrose-Radiation Oncology	2	0
Private Urology Practice 1	1	0
Private Urology Practice 2	0	0

[a]8 individual users signed on to the site; only 7 entered case information.

[b]15 sessions among 8 individual users; only 7 users entered case information.

Patient Usability Testing

In addition to the small-scale implementation of the SEER*CSC, usability testing and interviews were conducted with patients. A total of 14 individuals completed one-on-one sessions; 7 diagnosed with prostate cancer and 7 diagnosed with colorectal cancer. Patient participants had either completed their course of treatment or were in active surveillance or watchful waiting. Table 4 provides a summary of the patient characteristics. Overall, the reactions to SEER*CSC were positive. Patients felt the Internet was a valuable tool to inform them about their diagnosis and was necessary to help them prepare for conversations with their health care team as they moved through the disease care process.

Patients felt SEER*CSC was easy to navigate, easy to enter the data given, and provided information that would be useful to someone who was recently diagnosed with cancer. Many commented on liking the ability to choose the graphical representation of the results that best meet their needs and ability to understand. They also mentioned liking the additional resources provided. There was some concern as to whether a patient would have the information necessary to complete the disease characteristics section of the tool. The majority commented on the language and terminology used throughout the tool and that it was a limitation to using SEER*CSC. Another major weakness identified was the lack of treatment options in the calculations.

Table 4. Demographics of interviewees who participated in the patient usability testing sessions for Surveillance, Epidemiology and End Results Cancer Survival Calculator (SEER*CSC).

Characteristics	Prostate cancer diagnosis	Colorectal cancer diagnosis
Gender		
Male	7	3
Female		4
Age, years		
35-44		1
45-54	3	
55-64	3	4
65+	1	2
Race/Ethnicity		
Non-white		1
White	7	7[a]
Stage at Cancer Diagnosis		
Stage I	3	1
Stage II	1	1
Stage III	2	2
Stage IV		3
Unknown	1	
Time Since Diagnosis		
1 year	1	3
2 years	1	2
3 years	2	
4 years	3	
5 years		2

[a]Participant identified with two.

Discussion

Principal Findings

SEER*CSC is an interactive, Web-based prognostic tool using SEER and linked Medicare data that was developed, tested, and implemented over 4 phases. Overall, providers responded positively to the tool, with some recommended changes, which led to testing it in real-world, clinic settings. Providers expressed their support in patients having access to SEER*CSC. With supplemental funding, patients were given the opportunity to test the tool to gauge whether the information was understandable and whether it was something they would use.

Despite the positive feedback and enthusiasm about the tool, use during the small-scale implementation was low. Lack of utilization of tools is not new in health care settings. Studies have shown that while a number of tools, such as decision aids (DA) and other prognostic, Web-based tools, have increased in development, very few are thoroughly evaluated and/or implemented into routine practice [6,10-13]. Although current studies have shown that these types of tools help patients reduce decisional conflict, increase understanding of diagnosis, and increase patient-provider communication [14,15], there are still many factors that hinder dissemination and implementation (D&I) into real-world, clinical practice.

Based on our study, we postulate the following reasons for low uptake of SEER*CSC. First, the time required to enter necessary data. Clinicians noted that having a tool like SEER*CSC integrated into the EHR system, instead of freestanding, would decrease data entry burden. However, if it remains freestanding, non-physicians, such as nurses and navigators who initially spend time with the patient, could have an opportunity to fill in the data prior to the patient meeting with the physician, thus decreasing time that would otherwise be taken away from patient-physician interaction. Second, SEER*CSC lacks treatment options. Currently, it only provides prognostic information, which is just one part of the conversation physicians and providers have when it comes to cancer diagnosis and treatment. Physicians want to share treatment alternatives with patients. Patients not only want to know what their treatment options are, but how it will affect their prognosis, and then discuss those treatment options with their provider. However, currently no single tool provides everything. Third, providers know the prognostic information needed to

communicate with their patient, hence they do not rely on tools. Even though development of DAs are increasing, it is not yet commonplace for physicians to use them in their practice, know they have been developed and tested, or have easy access to them in their workplace.

Lessons Learned

Development of new physician or patient facing products that are designed to facilitate communication and care need to include a number of factors and follow a few basic design principles. As suggested by Kreuter and Dearing and Brownson and colleagues [16,17], using the Designing for Dissemination and Implementation (D4D&I) principles can increase the likelihood that the final product will be adopted, implemented and used in a sustained manner. Based on one of the D4D&I principles, a key lesson learned from the small-scale implementation study was engaging various stakeholders (ie, patients, physicians, caregivers, health care system leaders) early in the project (ideally in the development of the study design) and continually engaging with these groups throughout the study. Gaining support and input from those who will not only use the tool (the end user), but also those who will support the end user is essential to ensure utilization and satisfaction. Similarly, while engagement is a continual process, so is the iterative process in the development of the end product. The end product should evolve based on the needs of and testing by the end users. Patients experiencing a cancer diagnosis can have a vast health care team, including specialists, pharmacists, navigators, and nurses. As a result, the development, testing, and implementation of a decision aid needs to have input from an interdisciplinary team as well as the patients they serve.

Another important factor in designing for dissemination and implementation is to understand what barriers and facilitators exist for the implementation of these aids in the health care setting and what additional resources are needed to make their implementation successful. In our study, we collected information on barriers and facilitators of local adoption and implementation (eg, exiting channels, processes, and provider preferences). However, more work needs to be done to further explore the multilevel context in which these decision aids are implemented and used in a sustainable manner. Tools like the one developed as part of the My Own Health Report study for the pragmatic, mixed methods, and multilevel assessment of context can support such data collection [18].

Limitations

This study is not without limitations. The small-scale implementation trial was conducted in a small number of settings with little geographic diversity. Expanding to a large number of clinics across more diverse settings and patient populations may have provided different utilization patterns and better integration into practice. All of these settings had electronic health records, and thus providers would have liked the tool integrated into the system for ease of use. Testing the use of this tool in clinical settings that do not have an electronic health record or resource poor environments in terms of decision aids and decision support tools might have provided different results. Further exploration is warranted.

Future Implications

As a result of the efforts described in this paper, 2 major steps were taken. Given the major impediments to deploying a tool like this in a clinical setting, and the strong movement towards open access to health information, a decision was made to turn SEER*CSC into a public-facing application. Given the considerable use of technical medical language necessary to describe a tumor, this has required extensive revisions to the user interface to explain terms and make the overall language more understandable to a general audience. In addition, appropriate language on intended use and disclaimers must be added. Work on this is underway. Second, while no single tool can address all questions and with more tools being made available, it can be quite confusing to both physicians and patients which tools are most appropriate for which situations. The National Cancer Institute is supporting pilot work to integrate sets of high quality tools so their appropriate use case in the clinical decision pathway is clearer (eg, just after diagnosis, after initial surgery and prior to adjuvant therapy, and after a relapse).

Web-based prognostic tools face major challenges as they compete with many other priorities for the time of health care professionals. Streamlining their use (eg, by incorporation into EHRs), making sure there is institutional support, and making available information that is immediately actionable may all be necessary but not always sufficient conditions for their widespread acceptance. Making tools available to the general public faces challenges such as overcoming technical language necessary to describe the extent of disease, making sure that the tool and its limitations are properly understood, and avoiding discouraging patients with poor prognosis from having hope. The development of meta-tools for understanding the strengths and limitations of various tools and the place of each in the clinical decision making pathway are necessary. Despite these major obstacles, prognostic tools are important instruments to make sure evidence-based medicine makes its way into clinical practice and the shared decision-making conversation.

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Conflicts of Interest

None declared.

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Abbreviations

SEER*CSC: Surveillance, Epidemiology, and End Results Cancer Survival Calculator
EHR: electronic health records
NCI: National Cancer Institute

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Original Paper

Electronic-Based Patient-Reported Outcomes: Willingness, Needs, and Barriers in Adjuvant and Metastatic Breast Cancer Patients

Andreas D Hartkopf[1*]; Joachim Graf[2*]; Elisabeth Simoes[2]; Lucia Keilmann[3]; Nina Sickenberger[3]; Paul Gass[4]; Diethelm Wallwiener[1]; Lina Matthies[3]; Florin-Andrei Taran[1]; Michael P Lux[4]; Stephanie Wallwiener[3]; Eric Belleville[5]; Christof Sohn[3]; Peter A Fasching[4]; Andreas Schneeweiss[3]; Sara Y Brucker[2]; Markus Wallwiener[3]

[1]Department of Women's Health, University Hospital Tuebingen, Tübingen, Germany

[2]Research Institute for Women's Health, Department of Women's Health, University Hospital Tuebingen, Tübingen, Germany

[3]Hospital for General Obstetrics and Gynecology, National Cancer Center, University Hospital Heidelberg, Heidelberg, Germany

[4]Department of Gynecology and Obstetrics, University Hospital Erlangen, University Breast Center Franconia, Comprehensive Cancer Center Erlangen, Erlangen, Germany

[5]Clin-Sol Ltd., Würzburg, Germany

[*]these authors contributed equally

Corresponding Author:
Markus Wallwiener
Hospital for General Obstetrics and Gynecology
National Cancer Center
University Hospital Heidelberg
Im Neuenheimer Feld 440
Heidelberg, 69120
Germany
Phone: 49 6221 56 36956
Email: markus.wallwiener@gmail.com

Abstract

Background: Patient-reported outcomes (PROs) play an increasingly important role as an adjunct to clinical outcome parameters in measuring health-related quality of life (HRQoL). In fact, PROs are already the accepted gold standard for collecting data about patients' subjective perception of their own state of health. Currently, paper-based surveys of PRO still predominate; however, knowledge regarding the feasibility of and barriers to electronic-based PRO (ePRO) acceptance remains limited.

Objective: The objective of this trial was to analyze the willingness, specific needs, and barriers of adjuvant breast cancer (aBC) and metastatic breast cancer (mBC) patients in nonexposed (no exposure to electronic assessment) and exposed (after exposure to electronic assessment decision, whether a tablet-based questionnaire is favored) settings before implementing digital ePRO assessment in relation to health status. We also investigated whether providing support can increase the patients' willingness to participate in such programs.

Methods: The nonexposed patients only answered a paper-based questionnaire, whereas the exposed patients filled out both paper- and tablet-based questionnaires. The assessment comprised socioeconomic variables, HRQoL, preexisting technical skills, general attitude toward electronic-based surveys, and potential barriers in relation to health status. Furthermore, nonexposed patients were asked about the existing need for technological support structures. In the course of data evaluation, we performed a frequency analysis as well as chi-square tests and Wilcoxon signed-rank tests. Subsequently, relative risks analysis, univariate categorical regression (CATREG), and mediation analyses (Hayes' bias-corrected bootstrap) were performed.

Results: A total of 202 female breast cancer patients completed the PRO assessment (nonexposed group: n=96 patients; exposed group: n=106 patients). Self-reported technical skills were higher in exposed patients (2.79 vs 2.33, $P \leq .001$). Significant differences were found in relation to willingness to use ePRO (92.3% in the exposed group vs 59% in the nonexposed group; $P=.001$). Multiple barriers were identified, and most of them showed statistically significant differences in favor of the exposed patients (ie, data security [13% in the exposed patients vs 30% in the nonexposed patients; $P=.003$] and no prior technology usage [5% in the exposed group vs 15% in the nonexposed group; $P=.02$]), whereas the differences in disease burden (somatic dimension: 4% in the exposed group vs 9% in the nonexposed group; $P=.13$) showed no significance. In nonexposed patients, requests for support services were identified, which could increase their ePRO willingness.

Conclusions: Significant barriers in relation to HRQoL, cancer-related restrictions, and especially the setting of the survey were identified in this trial. Thus, it is necessary to address and eliminate these barriers to ensure data accuracy and reliability for future ePRO assessments. Exposure seems to be a potential option to increase willingness to use ePRO and to reduce barriers.

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KEYWORDS

breast cancer; patient-reported outcome measures; electronic patient- reported outcome; technical skills; willingness to use; needs and barriers

Introduction

Patient-Reported Outcomes in Breast Cancer Patients

Current advances in immuno-oncology and various target treatment combinations provide promising results such as long-term survival in cancer patients. However, treatment environments are challenging with regard to balancing clinical outcome and monitoring of quality of life, for example, in breast cancer patients [1,2]. Hence, patient-reported outcomes (PROs) play an increasingly important role as an adjunct to clinical outcomes in clinical practice [3]. A PRO is defined as "any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else" [4]. PROs comprise various aspects of the subjectively perceived state of health from the patient's point of view, such as the health-related quality of life (HRQoL) [3-9].

Novel Assessment of HRQoL and Adverse Events in Clinical Routine

PROs are assumed to be versatile and heterogeneous because they implicate many health conditions such as HRQoL, symptom severity (eg, using a pain scale), physical mobility, degree of psychological stress, disease-related impairment in daily routine, patient satisfaction, and drug adherence [3-13]. HRQoL is an important tool in clinical routine that comprises physical, emotional, mental, social, and behavioral components in terms of the patient's well-being and functioning from the patient's subjective perspective [12-15]. Furthermore, PROs reflect treatment success in a patient-centered manner [3-5,15-18]. Thus, PROs should be used to measure the *effectiveness* of new interventions to complement the results of *efficacy studies*, which only evaluate the success of therapeutic interventions in a clinical trial [4,18]. In the case of oncology patients, the patients' subjective perception of their own state of health is considered an important indication of the efficacy and safety of a specific therapy [19-25]. For example, in patients with metastatic breast cancer, PROs are a relevant source of information indicating whether the primary treatment aim of prolonging life with a more reasonable HRQoL is achieved [24,26-29]. The relevance of validated PRO questionnaires (eg, the European Organization for Research and Treatment of Cancer Quality of Life questionnaire-Core 30 item [EORTC QLQ-C30]) has been confirmed in several studies, in which patients with chronic diseases assessed their quality of life as being significantly worse, as compared with the clinical assessment [27-31]. Due to its high practicability and validity, EORTC QLQ-C30 is one of the most commonly used questionnaires for measuring PRO in patients with breast cancer.

Electronic Monitoring of PRO on the Rise

Validated PROs for measuring cancer-specific HRQoL (eg, EORTC QLQ-C30 and Functional Assessment of Cancer Therapy-General [FACT-G]) are already the accepted gold standard for data collection for closely related variables such as HRQoL, satisfaction with care, and drug adherence [32-34]. Currently, paper-based surveys of PRO still predominate in clinical routine, especially because there is a lack of validated electronic-based PRO (ePRO) measurement instruments pertaining to various oncological conditions [35]. There is growing demand for information and communication on behalf of patients and increasing integration of information technology in health care, which is why data on patient-relevant end points has increasingly been collected electronically in recent years. Thus, the potential of electronic health (eHealth) solutions in health care research is becoming increasingly apparent [36,37]. The benefits of digital data capture include real-time data capture, screening for deterioration of adverse events (AEs), potential cost-effectiveness for health centers, and therefore, a potential for longitudinal symptom assessment [38,39]. Long-term digital AE monitoring also seems feasible. Nevertheless, knowledge regarding patient acceptance, feasibility, and barriers remains limited, especially in relation to health status and socioeconomic aspects [40-45]. Previously collected data regarding barriers showed that older metastatic breast cancer patients with a higher disease burden may be less inclined to complete ePRO questionnaires (eg, by using tablet devices) [46]. The technical experience and skills of the patient population also have a significant impact on the adoption and adherence rates. Patients who participated in Web-based symptom monitoring showed both a 16% higher improvement in HRQoL and a 6% higher 12-month overall survival, were 7% less frequently admitted to the emergency room [38], and were more willing to use ePRO [46]. To date, little research has been conducted on whether the willingness to use eHealth applications increases when patients are exposed to it. No studies could be identified which focalize on whether the use of ePRO can be increased or potential barriers alleviated by exposure. However, studies from geriatrics indicate that reservations of elderly patients can be deferred to eHealth applications when faced directly with them [47-49]. It is also unclear to what extent sociodemographic variables influence exposure. For reliable and valid measurement of ePRO, it is relevant to identify all the variables that influence patients' response behavior.

Aims

The main aim of this study was to analyze the willingness, specific needs, and barriers of adjuvant breast cancer (aBC) and metastatic breast cancer (mBC) patients before implementing

digital ePRO assessment in relation to health status (HRQoL and therapy setting [aBC vs mBC]). We also investigated whether providing support can increase their willingness to participate in such programs. We analyzed potential differences in the willingness of aBC and mBC patients in relation to the survey setting (nonexposed vs exposed survey). The main aim of the study was to analyze the influence of an ePRO tool on the patients' willingness to participate. Second, possible hurdles for ePRO that determine nonresponse rates should be identified in breast cancer patients. With the long-term goal being to use ePRO exclusively, appropriate barriers must be identified. This trial evaluated the patients' general acceptance and practicability of ePRO in aBC and mBC subgroups. The goal was to analyze whether there was coherence between the health status (aBC vs mBC) and the willingness/frequency of barriers and between the survey setting (nonexposed vs exposed survey) and the willingness/frequency of barriers. To achieve the aims, aBC and mBC patients with and without ePRO exposure were asked to fill out questionnaires about their sociodemographic indications, technical skills, HRQoL, willingness to use, and potential barriers.

Methods

Sample and Study Design

From July 2015 to May 2016, paper-based PRO questionnaires were completed by female aBC and mBC patients treated consecutively at the Department of Women's Health in Tuebingen, Germany, and the National Cancer Center in Heidelberg, Germany. To analyze the dependency of identified barriers regarding health status in aBC and mBC patients, we compared nonexposed and exposed patients. The patients were recruited from two different studies: 106 exposed patients were recruited from electronic-based Patient-Reported Outcomes and Compliance Analysis (ePROCOM) and 96 nonexposed patients from another study [46]. All female breast cancer patients aged more than 18 years who either had metastasis or were undergoing adjuvant treatment, who additionally had sufficient knowledge of German to answer the questionnaire, and who declared their consent to fill out the questionnaires during an outpatient visit to the hospital under the supervision of an attending physician were included in the study. All patients were recruited from the PRAEGNANT network [50]. Patients had no prior exposure to any electronic assessment tools in the study in which they were currently included. If patients had prior contact with ePRO in other studies, they were not asked to participate (exclusion criteria).

After filling out their paper-based PRO questionnaires, the *nonexposed patients* were asked whether they would be interested and confident in using electronic assessments prospectively and whether there were any preexisting barriers. *Exposed patients* were provided with the actual electronic assessment application (ePROCOM). They were requested to fill out both the paper- and tablet-based PRO questionnaires so that the reliability of an ePRO tool could be analyzed. After filling out both questionnaires, they were also asked about their preferences toward future usage of either paper-based assessment or ePRO. The aim of ePROCOM was to evaluate the general patient acceptance and practicability of a Web-based application for a PRO-questionnaire for patients with aBC or mBC. The ePROCOM patients were asked to participate to compare the response behavior of patients in paper-based and Web-based questionnaires (publication in preparation). Inclusion criteria of ePROCOM were female gender, full legal age, aBC or mBC diagnosis, sufficient language skills in German, and signed declaration of consent. The ePROCOM patients were also asked to complete the questionnaire during an outpatient visit to the hospital under the supervision of an attending physician. We have previously reported on the influence of age, educational status, HRQoL, and technical skills of mBC patients [46].

The patients of both arms of the study (exposed and nonexposed) were informed about the aims of the study and were asked for their consent ex ante. The ethics committee gave prior consent for the study (project number 196/2015B02 and 089/2015B02). Randomization in this setting was not feasible, as patients were recruited from different studies. However, the trial design enabled identification of the main barriers in breast cancer patients for participating in ePRO in relation to the exposed versus nonexposed setting with regard to sociodemographic factors, therapy setting (aBC vs mBC), and HRQoL.

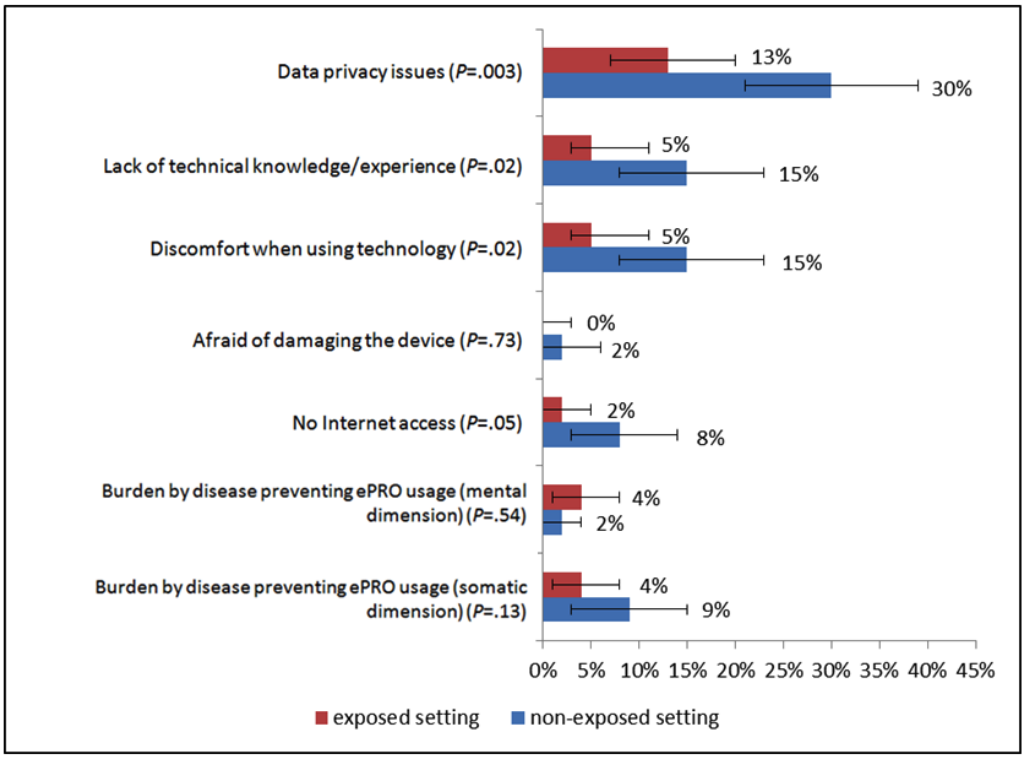
Assessments

The assessment comprised 3 parts. The first part focused on the patients socioeconomic variables. The second part focused on HRQoL according to the EORTC QLQ-C30, comprising 30 questions in 5 subscales, various symptom scales, and individual items related to the patients health status on a multidimensional level. We used only those 2 questions from the EORTC QLQ-C30 that focused on the patient's health status and HRQoL on a 7-point Likert scale (from 1=very poor to 7=excellent). The acceptance level and identification of barriers and acceptance, but not HRQoL, constituted the main focus of the analyses. Patients also completed the entire EORTC QLQ-C30 questionnaire; data on every single function and symptom scale are available upon request. Mean values were calculated in accordance with the official EORTC guidelines, which require a separate score to be calculated for each scale. The scores ranged from 0 to 100 [51,52]. In the third part of the questionnaire, the patients were asked about preexisting technical skills such as use of electronic technology at home, routine usage of digital devices such as computers, Internet use, their general attitude toward electronic-based surveys, and potential barriers in relation to their health status. Furthermore, the patients in the nonexposed survey were also asked about existing technological support structures because they only completed the paper-based questionnaire, whereas the exposed group filled out both paper- and tablet-based questionnaires. The trial design was based on the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) framework. This guidance plan was developed specifically for assessing the effectiveness of interventions and included aspects of reach, effectiveness, adoption, implementation, and maintenance [53,54].

Statistical Analysis

A frequency analysis was first performed using the Statistical Package for the Social Sciences (SPSS) version 21 (IBM) to determine the descriptive characteristics of the collected data. The goal was to demonstrate how the barriers of technology-based surveys are distributed over the entire population. The influence of the barriers on the rejection of electronic-based surveys was also identified, and the barriers among patients with preferences for paper-based questionnaires and ePRO were compared in relation to socioeconomic variables, health status, and technical skills in self-perception. Differences between nonexposed and exposed patients were identified using chi-square tests (if the variables were dichotomous and binary coded) and Wilcoxon signed-rank tests in ordinal- and metric-scaled data, because the paired samples were not normally distributed in the Shapiro-Wilks test and in quantile-quantile plots. Furthermore, a relative risks analysis was calculated to identify the influence of ePRO exposure on usability and barriers. Subsequently, we performed univariate categorical regression (CATREG) analysis to ascertain regression context between ePRO exposure and willingness to use the identified barriers [55,56]. Mediation analyses (Hayes' bias-corrected bootstrap) were then performed to expose the potential interferences of the regression model [56]. Finally, demand for technical support was measured through frequency analysis in the nonexposed group. Beforehand, we performed chi-square tests and Shapiro-Wilks test between mBC and aBC patients in both groups to identify possible statistically significant differences in relation to HRQoL and willingness to use. A bilateral *P* value of <.05 was considered statistically significant in all analyses (alpha=.05). The survey was conceived as an explorative study, in which all *P* values were to be understood purely descriptively and had no confirmatory value. Figure 1 was created in Microsoft Excel 2010.

Figure 1. Barriers for using electronic-based patient-reported outcome.



Results

Sociodemographic Variables and Technical Skills

A total of 202 female breast cancer patients completed the PRO assessment (nonexposed group: n=96 patients; exposed group: n=106 patients). We did not find significant intragroup differences between aBC and mBC patients. Table 1 shows the sociodemographic characteristics of the study group. Nonexposed patients were significantly older compared with the exposed group, and their self-rated HRQoL was reported to be worse in the EORTC QLQ-C30 survey. However, the differences in HRQoL between both groups were not statistically significant. The level of education was significantly higher in the exposed group.

The technical skills are shown in Table 2. In all dimensions and at all levels, the self-reported technical skills were higher in exposed patients, including considerable time of computer and Internet use and higher frequency of tablet usage.

Willingness to Use Technology-Based Surveys (ePRO)

The results for both treatment groups suggest that the introduction of electronic surveys will indeed improve clinical care and completion of ePRO questionnaires; however, there

were significant differences between exposed and nonexposed patients. Exposed patients more often suggested that hospital care could be improved by using ePRO questionnaires and more frequently rated ePRO assessments as being more suitable, less tiring, and less difficult (Table 2). Before exposure to the ePRO application, both groups were asked about their potential ePRO assessment usage. Overall, the disposition for potential ePRO usage was high, with 77% of all patients indicating willingness. However, there were significant differences with regard to the HRQoL (Table 2). As the percentage of adjuvant patients was obviously higher in the exposed group, adjuvant patients showed higher usage willingness, whereas the nonexposed group (with a higher percentage of metastatic patients) showed less willingness. The ePRO willingness was 92% in exposed versus 59% in the nonexposed group.

Identifying existing barriers is crucial for future implementation of ePROs in routine clinical practice. The patients were asked whether there are any existing barriers related to privacy, technology, or disease that would negatively influence their willingness to use technology-based surveys. Multiple barriers in seven dimensions were identified, and most of them showed statistically significant differences between both groups in favor of the exposed patients (Figure 1). The most evident item was concern about data security, followed by two technological barriers (lack of technical knowledge; experience and discomfort when using technology). All barriers with statistically significant differences were reported more often in nonexposed patients. In contrast, differences in the burden of the disease as a reason for nonusage were not significant between both groups.

Table 1. Sociodemographic characteristics of exposed and nonexposed treatment groups. Statistically significant values presented in italics.

Sociodemographic variables	Exposed (n=106)	95% CI	Nonexposed (n=96)	95% CI	*P* value (alpha=.05)
Age in years					
Mean (median)	51.0 (52)		56.68 (54)		*.001*
Standard deviation [range (minimum-maximum)]	11.31 [54 (30-84)]		12.38 [60 (20-85)]		
Level of education (1=lowest; 6=highest)					
Median	3.0		3.0		*.03*
Interquartile range (25%-quartile-75%-quartile)	2.0 (3.0-5.0)		2.0 (2.0-4.0)		*.03*
No qualification, n (%)	1 (.9)	(0.00-0.06)	1 (1)	(0.00-0.07)	.94
Main/secondary school leaving certificate, n (%)	43 (40.6)	(0.32-0.50)	59 (61)	(0.53-0.69)	*.003*
Advanced technical certificate, n (%)	19 (17.9)	(0.10-0.26)	15 (16)	(0.08-0.23)	.67
High school diploma (“Abitur”), n (%)	33 (31.1)	(0.22-0.40)	13 (14)	(0.07-0.22)	*.003*
Not specified, n (%)	10 (9.4)	(0.02-0.15)	8 (8)	(0.01-0.13)	.78
Therapy setting					
Metastatic, n (%)	30 (28.3)	(0.19-0.35)	65 (68)	(0.62-0.76)	*.001*
Adjuvant treatment, n (%)	76 (71.7)	(0.61-0.83)	31 (32)	(0.26-0.37)	*.001*
Health-related quality of life (EORTC QLQ C-30)[a]					
Mean (median)	60.8 (66.67)	(0.55-0.66)	58.1 (58.3)	(0.52-0.63)	.45
Standard deviation [range (minimum-maximum)]	23.75 [100 (0-100)]		21.0 [91.7 (0-91.7)]		.45

[a]EORTC QLQ-C30: European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 item.

Table 2. Self-reported technical skills for metastatic and adjuvant patients. Statistically significant values presented in italics.

Technical skills and ePRO evaluation	Exposed	95% CI	Nonexposed	95% CI	*P* value (alpha=.05)
Computer skills (self-perception by the patients, 1=lowest; 4=highest)					
Median	3.0		2.0		*<.001*
Interquartile range (25%-quartile-75%-quartile)	0.0 (3.0-3.0)		1.0 (2.0-3.0)		*<.001*
	n=99		**n=81**		
Beginner/no skills (=1), n (%)	4 (4)	(0.01-0.08)	10 (12)	(0.06-0.18)	*.04*
Basic (=2), n (%)	20 (20)	(0.12-0.28)	37 (46)	(0.37-0.58)	*<.001*
Advanced (=3), n (%)	68 (69)	(0.58-0.77)	30 (37)	(0.27-0.47)	*<.001*
Professional (=4), n (%)	7 (7)	(0.03-0.13)	4 (5)	(0.01-0.11)	.55
Computer use, in years					
Mean (standard deviation)	17.49 (7.12)		16.73 (8.25)		.52
Internet use, in years					
Mean (standard deviation)	13.57 (5.60)		11.84 (6.53)		.07
Tablet PC use (1=lowest; 4=highest)					
Median	3.0		1.5		*<.001*
Interquartile range (25%-quartile-75%-quartile)	3.0 (1.0-4.0)		2.0 (1.0-30)		*<.001*
	n=94		**n=66**		
Not at all (=1), n (%)	33 (35)	(0.26-0.45)	33 (50)	(0.35-0.63)	.06
A little (=2), n (%)	6 (6)	(0.02-0.12)	10 (15)	(0.08-0.23)	.07
Moderate (=3), n (%)	13 (14)	(0.07-0.21)	19 (29)	(0.20-0.42)	*.02*
Very much (=4), n (%)	42 (45)	(0.34-0.54)	4 (6)	(0.02-0.14)	*<.001*
	n=104		**n=86**		
Willingness to use technology-based surveys (ePRO), n (%)	96 (92.3)	(0.90-0.99)	51 (59)	(0.49-0.70)	*.001*
	n=92		**n=56**		
Do you think that the introduction of electronic surveys will improve clinical care?, n (%)	87 (95)	(0.89-0.99)	45 (80)	(0.70-0.89)	*.007*
Comparison of e-based and paper-based questionnaires					
ePRO is less suitable (=1), more suitable (=5)					
Median	4.0		3.0		*<.001*
Interquartile range (25%-quartile-75%-quartile)	2.0 (3.0-5.0)		1.25 (3.0-4.25)		*<.001*
ePRO is more tiring (=1), less tiring (=5)					
Median	4.0		3.0		*<.001*
Interquartile range (25%-quartile-75%-quartile)	2.0 (3.0-5.0)		1.0 (3.0-4.0)		*<.001*
ePRO is more difficult (=1), less difficult (=5)					
Median	4.0		3.0		*<.001*
Interquartile range (25%-quartile-75%-quartile)	2.0 (3.0-5.0)		2.0 (2.0-4.0)		*<.001*

[a]ePRO: electronic-based patient-reported outcome.

Table 3. Relative risks of willingness to use and different barriers in exposed patients in relation to the nonexposed group. Statistically significant values presented in italics.

Willingness to use and barriers	Relative risk in exposed patients (95% CI)
Willingness to use ePRO[a]	*11.834* (4.405-31.794)
Data privacy issues	*0.371* (0.179-0.769)
Lack of technical knowledge/experience	0.372 (0.138-1.006)
Discomfort when using technology	*0.243* (0.77-0.761)
I am afraid of damaging the device	-
No Internet access	0.120 (0.15-0.976)
Burden of disease preventing ePRO usage (mental dimension)	0.363 (0.093-1.411)
Burden of disease preventing ePRO usage (somatic dimension)	2.089 (0.373-11.687)

[a]ePRO: electronic-based patient-reported outcome.

Relative Risks, Regression, and Mediation Analyses

Table 3 shows the results of the probability analyses. It is apparent that the probability of willingness to use is almost 11 times higher after exposure in this collective, whereas the relative risks of existing barriers are obviously lower (especially data privacy issues and discomfort when using technology).

The CATREG analysis substantiates a statistically significant regression context between ePRO exposition and willingness, whereas the influence of the identified barriers was only low and partly not significant (Table 4) because the respective sample sizes of patients with existing barriers were too small for a valid calculation. Overall, 16.6% of the cases with expressed willingness to use can be attributed to exposure. Mediation effects of age and computer skills against the influence of exposure on willingness to use were only low (Table 5), whereas the mediation influence of education, HRQoL, and therapy setting were not statistically significant because the differences between exposed and nonexposed patients were too small. Including the variables of age and computer skills toward influence of exposure increased the explainability of the willingness to use aspect to 31.9%.

Needs and Possible Technological Support Structures

After finding strongly distinct barriers for ePRO among nonexposed patients, we asked them how they would rate the importance of 5 possible support services to help them complete a Web-based questionnaire about medical treatment, side effects, health status, and HRQoL (Table 6). On-site support services were rated as being moderately or highly important by 38%. A total of 32% patients expressed desire for a technical briefing for relatives who would support them while using the ePRO tool. Technical telephone support was rated as moderately important or very important by 52% of the nonexposed patients. The most relevant topic was data security, and 71% of the patients wanted to have full information regarding data protection measures (moderate and high importance). At least 61% would appreciate receiving direct feedback after using the ePRO application.

Table 4. Categorical regression analyses. Statistically significant values presented in italics.

Influence of exposure	*R*	R^2	Beta	*P* value (alpha=.05)
Willingness to use ePRO[a]	.407	.166	.407	*<.001*
Data privacy issues	.207	.043	−.207	*.004*
Lack of technical knowledge/experience	.129	.017	−.129	*<.001*
Discomfort when using technology	.166	.028	−.166	*.01*
I am afraid of damaging the device	.052	.003	−.052	.43
No Internet access	.138	.019	−.138	*.02*
Burden of disease preventing ePRO usage (mental dimension)	.106	.011	−.106	.12
Burden of disease preventing ePRO usage (somatic dimension)	.045	.002	−.045	.52

[a]ePRO: electronic-based patient-reported outcome.

Table 5. Willingness to use: mediation effect of sociodemographics, skills, and health-related quality of life.

Willingness to use: mediation effect of variables	R_{Mod}	R^2_{Mod}	*P* value (alpha=.05)	Indirect effect of X[a] on Y[b]	95% CI
Age	.246	.062	*<.001*	.363	(0.073-0.867)
Level of education	.152	.023	*.04*	.235	(0.017-0.608)
Computer skills	.302	.091	<.001	.536	(0.196-1.976)
Health-related quality of life	.085	.007	.28	.057	(−0.035 to 0.353)
Therapy setting	.092	.008	.18	.63	(−0.042 to 0.157)
$R^2_{ges} = R^2 + R^2_{Mod\ /\ Age} + R^2_{Mod\ /\ Skills} = .166 + .062 + .091 = .319$					

[a]X=exposure/no exposure.

[b]Y=willingness to use.

Table 6. Electronic-based patient-reported outcome preferences regarding technical support structures: How important would you rate the following support services to complete an electronic-based patient-reported outcome questionnaire during the hospital visit about your medical (after) treatment, your side effects, your health status, and your quality of life?

Support variables	Nonexposed setting	
	n (%)	95% CI
Technical briefing and onboarding completed on site, (N=69)		
Not at all	26 (38)	(0.28-0.53)
A little	16 (23)	(0.15-0.37)
Moderate	13 (19)	(0.07-0.23)
Very much	14 (20)	(0.10-0.32)
Technical briefing should include relatives, (N=64)		
Not at all	35 (55)	(0.42-0.68)
A little	9 (14)	(0.07-0.25)
Moderate	8 (13)	(0.05-0.22)
Very much	12 (19)	(0.08-0.27)
Telephone support, (N=64)		
Not at all	17 (27)	(0.18-0.40)
A little	14 (22)	(0.12-0.32)
Moderate	12 (22)	(0.12-0.32)
Very much	19 (30)	(0.18-0.42)
Transparency of data privacy, (N=70)		
Not at all	11 (16)	(0.10-0.28)
A little	9 (13)	(0.06-0.24)
Moderate	12 (17)	(0.08-0.27)
Very much	38 (54)	(0.38-0.63)
I get a direct feedback (from a doctor or the hospital), (N=68)		
Not at all	17 (25)	(0.18-0.40)
A little	10 (15)	(0.07-0.27)
Moderate	14 (21)	(0.10-0.28)
Very much	27 (40)	(0.25-0.50)

Discussion

Principal Findings

The majority of breast cancer patients expressed interest in adopting ePRO based on the impression that ePRO would positively impact hospital care and based on enhanced usability (more suitable, less tiring, and less difficult to read than paper-based PRO). Differences in relation to the setting of the survey and the patient's self-reported health status were significant because the HRQoL was higher and the number of metastatic patients was lower in the exposed group. Patients in the nonexposed group more often had reservations and were critical toward ePRO, and their willingness to use corresponding tools was because of the following barriers: Patients were often afraid of using technical devices such as tablet PCs, (especially those with metastatic diseases in the nonexposed group), and they were concerned about data privacy issues and disease-related barriers (Figure 1). Thus, the willingness to participate in ePRO assessments can be increased by offering an ePRO tool, and the influence of barriers can also be reduced in metastatic patients. Our data demonstrated that patients generally had prevalent reservations regarding electronic assessment before exposure; however, they showed willingness to use electronic assessments after exposure. Whereas 16.6% of the cases expressing willingness to use were attributed to exposure (Table 4), mediation effects of age and computer skills against exposure's influence were only low (Table 5). We found higher barriers in the nonexposed group characterized by lower HRQoL and a higher number of metastatic patients (Table 1), which suggests that health status influences the acceptance of ePRO and the emergence of barriers. The dimensions of reach and effectiveness of the RE-AIM framework could be analyzed for future improvements. The development of ideal ePRO tools has to consider the identified barriers (technical skills, HRQoL, and sociodemographic aspects) for utilization of ePRO, preferably in the general patient population and independent of their multidimensional characteristics.

Comparison With Prior Work

The results of this study contrast with those of a previous study, which identified no differences in the feasibility assessment of ePRO in relation to HRQoL [38]. The number of ePRO systems has increased in recent years, especially in oncology clinical practice, but other studies did not focus on the possible barriers to usability [57,58]. We have not found any studies in which cancer patients were asked about their barriers. Our group previously showed that older mBC patients (>62 years) with higher burden of disease may be less willing to complete ePRO questionnaires [46]. In this study, some significant barriers in relation to HRQoL, survey setting, and cancer-related restrictions were identified, whereas other reports only described the acceptance of ePRO without ascertaining barriers [40-42,57,58]. Our results agree with Basch et al [38], who reported higher self-reported computer experience (and thus potentially higher acceptance for ePRO) in patients with higher HRQoL. No other studies identified specific barriers related to technical skills, HRQoL, and sociodemographic issues as predictive factors for nonresponse in ePRO.

Limitations and Relevance

Our study was developed as a bicentric trial, and the patients were surveyed while they were receiving chemotherapy intervention. We did not enquire about the tumor stage, extent of metastasis, and the administered therapy. Furthermore, psycho-oncological information was not gathered, although psycho-oncological distress is a commonly associated burden that could potentially influence the willingness to use ePRO. There was no significant mediation effect of the therapy setting (aBC and mBC), although the number of metastatic patients was significantly higher in the nonexposed group. Also, HRQoL seemed not to be an influencing factor for willingness to use, as there were no significant differences in relation to HRQoL between exposed and nonexposed patients and no significant mediation effect. As it is known that low HRQoL and metastatic situation influence the willingness to use [46], willingness was assumed to be poor in mBC patients at the beginning, because metastasis was associated with poorer HRQoL. Probably, there were no differences in HRQoL (both in comparison of exposed and nonexposed patients as well as in the intragroup analyses), but this hypothesis could not be confirmed in this study. Hence, it can be postulated that a metastasis situation has a negative effect on usability compared with patients in adjuvant therapy especially if it results in a poorer HRQoL. An indirect effect was shown by the fact that for the exposed group significantly less metastasized patients could be recruited. The aspects of age and computer skills appeared as significant limitations, as exposed patients were significantly younger and had significantly better skills, which indicates that especially younger patients with previous experience in technology could be motivated to use ePRO.

The most important result of the study was the fact that the survey setting (nonexposed vs exposed setting) could influence the willingness to use ePRO and the probability of barriers in all mBC and aBC breast cancer patients. The willingness among exposed patients was higher, as only the patients who could envisage answering HRQoL questions with a tablet could be included in this study. In total, 130 patients declined to participate in this group, so the total impact might be negligible; however, this limitation generally occurs in other ePRO trials. Because patients with barriers were rather unwilling to take part in the study, it is unclear how exposed patients are influenced by the approach of the study personnel to participate. Therefore, the barriers in the nonexposed group must be taken seriously because they could also represent patients with potential reservations about ePRO. The comparison between nonexposed and exposed patients shows that the willingness among women with breast cancer can be increased, and barriers can be reduced by educating the patients. To prevent statistical bias in future surveys and to increase the reliability of ePRO questionnaires, the identified barriers must be eliminated. Patients with cancer, who are often limited by their disease, should be thoroughly informed about privacy security issues and the universal handling of such confidential information to address their concerns and increase their potential willingness to use ePRO applications.

Conclusions

Although general patient acceptance of ePRO was high, we identified technical and disease-related barriers. These findings underscore the need to be aware of such barriers and to eliminate them to enhance the practicability of ePRO and ensure data accuracy, reliability, and validity for future ePRO assessments to measure HRQoL. Whereas fewer preexisting barriers were found in younger breast cancer patients, older patients with poorer HRQoL and less preexisting technical skills more frequently reported barriers for ePRO. Our study showed that barriers can be overcome after exposure and the willingness to participate in ePRO assessments significantly increased. Hence, the dimensions of reach and effectiveness of the RE-AIM framework, in particular, were analyzed in this paper. The development of ideal ePRO tools has to consider the identified barriers (technical skills, HRQoL, and sociodemographic aspects) for the utilization of ePRO, preferably in the general patient population and independent of their multidimensional characteristics. Tailored educational and support services need to be implemented and evaluated in future research to relieve reservations and increase ePRO compliance. Willingness to use ePRO is dependent on sociodemographic aspects, technical skills, HRQoL, and therapy setting, but patients' acceptance of the tool can be increased when they experience it firsthand.

Conflicts of Interest

PG has received non-declared honoraria from Novartis.

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Abbreviations

aBC: adjuvant breast cancer
AEs: adverse events
CATREG: categorical regression
eHealth: electronic health
EORTC QLQ-C30: European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 item
ePRO: electronic-based patient-reported outcome
FACT-G: Functional Assessment of Cancer Therapy-General
HRQoL: health-related quality of life
mBC: metastatic breast cancer
PRO: patient-reported outcome
PROCOM: Patient-Reported Outcomes and Compliance Analysis
RE-AIM: Reach, Effectiveness, Adoption, Implementation, and Maintenance
SPSS: Statistical Package for the Social Sciences

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Original Paper

Supporting Lung Cancer Patients With an Interactive Patient Portal: Feasibility Study

Wim G Groen[1], PhD; Wilma Kuijpers[1], PhD; Hester SA Oldenburg[2], MD, PhD; Michel WJM Wouters[2], MD, PhD; Neil K Aaronson[1], PhD; Wim H van Harten[1,3,4], MD, PhD

[1]Division of Psychosocial Research and Epidemiology, The Netherlands Cancer Institute, Amsterdam, Netherlands

[2]Division of Surgical Oncology, The Netherlands Cancer Institute, Amsterdam, Netherlands

[3]Department of Health Technology and Services Research, University of Twente, Enschede, Netherlands

[4]Rijnstate Hospital, Arnhem, Netherlands

Corresponding Author:
Wim H van Harten, MD, PhD
Division of Psychosocial Research and Epidemiology
The Netherlands Cancer Institute
Plesmanlaan 121
Amsterdam,
Netherlands
Phone: 31 20 5122861
Fax: 31 20 6601449
Email: w.v.harten@nki.nl

Abstract

Background: MyAVL is an interactive portal for cancer patients that aims to support lung cancer patients.

Objective: We aimed to evaluate the feasibility and usability of the patient portal and generate preliminary evidence on its impact.

Methods: Lung cancer patients currently or recently treated with curative intent could use MyAVL noncommittally for 4 months. Feasibility, usability, and preliminary impact (ie, patient activation, quality of life, and physical activity) were studied by means of questionnaires, a focus group, and analysis of user log data.

Results: We included 37 of 123 eligible patients (mean age 59.6 years). The majority of responses (82%) were positive about using MyAVL, 69% saw it as a valuable addition to care, and 56% perceived increased control over their health. No positive effects could be substantiated on the impact measures.

Conclusions: MyAVL appears to be a feasible and user-friendly, multifunctional eHealth program for a selected group of lung cancer patients. However, it needs further improvements to positively impact patient outcomes.

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KEYWORDS

non-small cell lung cancer; patient empowerment; patient portal; supportive care; eHealth; feasibility

Introduction

Cancer and its treatment result in a wide range of physical and psychological challenges, some of which may appear years later [1], and current models of survivorship care may not be sustainable [2]. Therefore it seems imperative that cancer survivors play a more active role in their health care. One way to support this active role may be by enhancing their levels of empowerment, which encompasses being autonomous and having the knowledge and psychosocial and behavioral skills to influence one's health in a positive way [3]. eHealth programs may be helpful to support aspects of patient empowerment in individuals with chronic diseases and also cancer survivors [3,4]. eHealth programs can improve aspects of empowerment by enhancing patients' knowledge of their disease and treatments and about their own health status (eg, via patient-reported outcomes [PROs]) [3].

To date, many eHealth services in oncology have been developed for breast and prostate cancer patients [5]. Although lung cancer has a high symptom burden, very few eHealth applications have been developed recently to support this patient

population, mainly related to symptom monitoring [6-11]. To support lung cancer patients in the Netherlands Cancer Institute Antoni van Leeuwenhoek Hospital (AVL in Dutch), we developed an interactive portal (MijnAVL; MyAVL in English). MyAVL includes patient education, an overview of appointments, access to the electronic medical record (EMR), PROs with feedback of the scores, and tailored physical activity support. We developed MyAVL and selected its most relevant features following a stepwise approach: literature review [4], focus groups with patients and health professionals [12], acceptability testing based on mock-ups, and usability testing of functional prototypes [13].

The aim of this study was to evaluate MyAVL's feasibility and usability and to generate preliminary evidence on its impact when used by lung cancer patients.

Methods

Patients and Recruitment

We included patients with non-small cell lung cancer who were currently being treated or who had completed primary, curative treatment up to 12 months earlier. Treatments included surgery, radiotherapy, concurrent chemoradiotherapy, or a combination of these. Patients were approached by letter followed by a phone call from the researchers to discuss participation and check further eligibility criteria (eg, having a computer and Internet access, mastery of the Dutch language). Patients provided written informed consent, and the study procedures were approved by the local Institutional Review Board. Because the primary aim of the study was to test feasibility and usability of the portal, no a priori power calculation was performed and as many patients as possible were recruited within the project timeline.

MyAVL Intervention

The content of MyAVL, including screenshots of its features, have been described in detail previously [13,14]. In short, it includes 5 features: (1) personalized patient education material (health professionals provide the most timely and suitable patient education materials); (2) an overview of past and upcoming appointments; (3) access to the EMR, including blood tests, physiological test results (eg, lung function), pathology reports, and letters to the general practitioner and other hospitals (with medical test results made available with a 2-week delay); (4) PROs and related feedback (ie, a graphical and tabular overview of scores and access to background information on quality of life aspects such as fatigue); and (5) tailored physical activity advice based on a set of questionnaires assessing physical activity levels, motivation, and possible contraindications. MyAVL could be used noncommittally for 4 months, meaning that patients did not have to adhere to a predefined intervention schedule. Figure 1 shows a screenshot of the homepage of MyAVL.

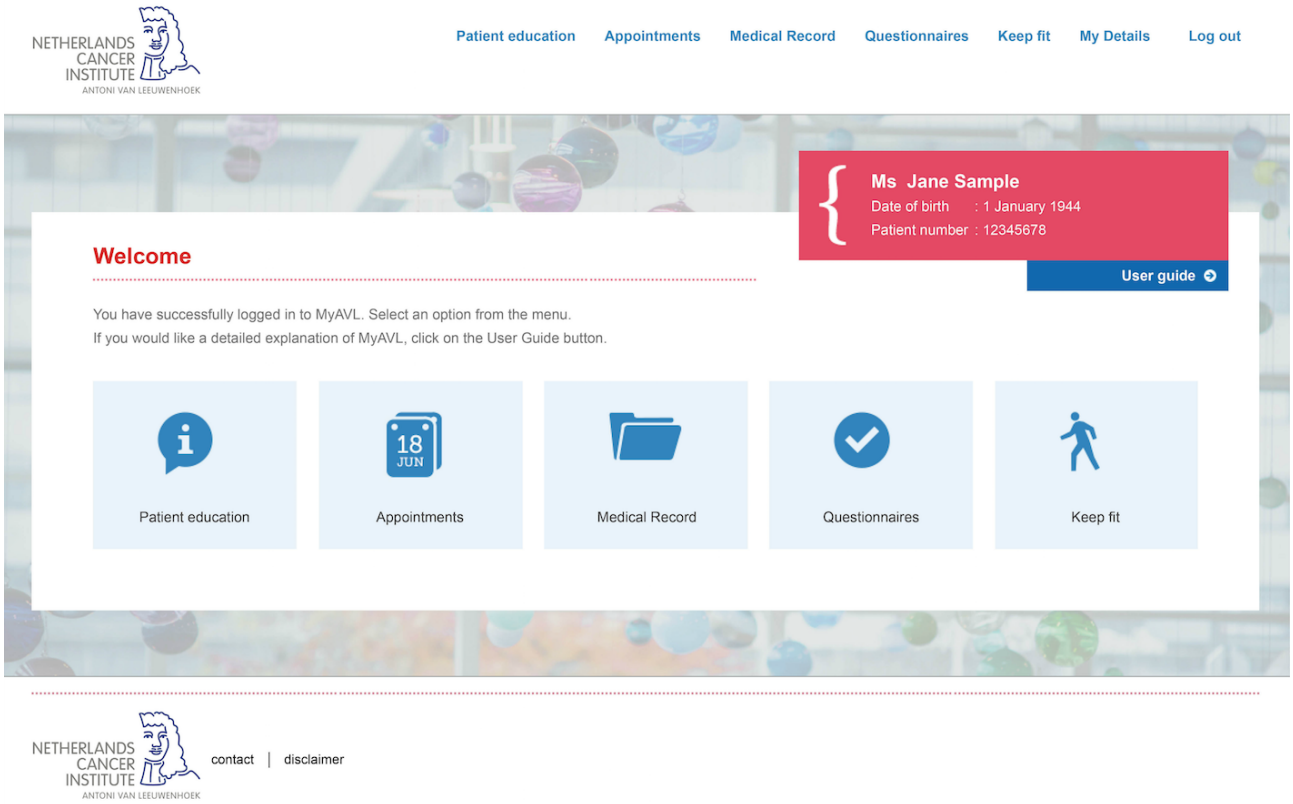
Assessments

At baseline, participants completed questionnaires on sociodemographic and effect measures: patient activation (Patient Activitation Measure [PAM]) [15-17], quality of life (Short Form Health Survey [SF-36]) [18], and physical activity (International Physical Activity Questionnaire [IPAQ]) [19]. After 4 months, log data on actual use were analyzed retrospectively, and participants completed questions on self-reported use, satisfaction (Website User Satisfaction questionnaire [WUS]), acceptability (a questionnaire based on the unified theory of acceptance and use of technology [UTAUT]) [20], and the effect measures PAM, SF-36, and IPAQ. Physical activity was expressed as metabolic equivalent of task (MET) minutes per week for moderate, vigorous, and total activity. To evaluate acceptability per component of the portal, questions were posed on aspects like level of personalization, level of comprehensibility, and level of anxiety. The response scale of these questions ranged from strongly disagree to strongly agree. Patients also rated the different components on a scale from 1 to 10 (higher scores being more positive ratings). Finally, a focus group was held with 5 participants to further discuss the pros and cons of using MyAVL and its features. The content of the focus group discussion was structured around issues that arose on the questionnaires. The session was audiorecorded, and notes were taken.

Analyses

Data on feasibility (eg, use) and acceptability were analyzed with descriptive statistics. Data on the PAM and SF-36 were presented as means and standard deviations, the IPAQ as median and interquartile range. The PAM, SF-36, and IPAQ questionnaires were scored according to standard scoring procedures. Pre- and posttest scores were compared by a paired samples *t* test except for the IPAQ, which was tested with the related samples Wilcoxon signed rank test. Focus group data were analyzed by the first author reviewing the notes and integrating these findings with the open-ended evaluative questions of the postintervention questionnaire. Topics were included if they were raised by at least 2 patients. The second author validated the formation of topics from the data. Patients needed to log in at least once to be included in the analyses. Statistical analyses were performed with SPSS version 22 (IBM Corp).

Figure 1. Homepage of MyAVL.



Results

Feasibility

Between January 2014 and August 2015, 123 patients were eligible for the study, 89 of these could be reached and were asked to participate, and 37 agreed to do so. The most common reasons for declining were having little computer or Internet experience (n=14), emotionally too burdensome (n=12), and not having a computer or Internet access (n=9).

All patients were white, and 16/34 were women (47%). Mean age of the subjects was 59.6 (SD 8.4, range 40-76) years. The majority of patients were in a relationship with someone whom they lived with and had completed postcompulsory education, and 27/34 patients (79%) were in treatment. Sociodemographic and clinical characteristics are presented in Table 1. Nearly all patients (33/34, 97%) had used the Internet more than 3 years, and 31/34 (91%) used it (almost) daily.

The mean number of log-ins during the 4 month study period was 11.2 (SD 9.1, range 0-30) with a mean duration of 12.9 (SD 13.9, range 1-77) minutes. A total of 3 patients did not log in at all and were not included in further analyses. Overview of appointments, access to EMR, and questionnaires were used most frequently, with an average of 7.5 (SD 7.0), 6.7 (SD 4.7), and 6.7 (SD 5.0) log-ins, respectively. The remaining components, patient education, quality of life scores, and Keep Fit, were accessed less often, with an average of 1.9 (SD 2.4), 3.7 (SD 3.1), and 3.1 (SD 2.5) views, respectively. On average, 2.3 (SD 2.5) PROs were completed, which is 82% of total number of PROs provided (SD 36%). The mean number of Keep Fit questionnaires filled out was 2.0 (SD 1.3). Males more frequently than females accessed overview of appointments (9.6 [SD 6.6] vs 4.6 [SD 6.6], P=.04) and the questionnaires section (8.4 [SD 5.3] vs 3.9 [SD 3.0], P<.01). No significant differences between male and female participants were noted for the other components of the portal or for the total number of log-ins. No significant differences in these variables were noted between patients in and out of treatment.

Usability

Acceptability data, as measured with the UTAUT-based questionnaire, indicated that 93% (25/27) of patients found MyAVL easy to use, 56% (15/27) reported that it contributed to a sense of control over their health, and 69% (18/26) indicated that it was a valuable addition to their health care experience. Most (22/27, 81%) were satisfied with MyAVL, and 77% (20/26) intended to continue using it. A total of 61% (17/28) reported being better informed about their disease via access to the EMR, and 43% (12/28) reported an enhanced sense of control over their disease. Average satisfaction rating (WUS score) across domains was 3.9 (maximum score is 5). Key issues that emerged from the acceptability questions and focus group are presented in Table 2.

Preliminary Data on Impact

PAM scores actually decreased slightly over time from 64.8 (SD 14.2) to 59.4 (SD 11.6) (P=.042). For the SF-36, we found no significant changes over time. Levels of physical activity did not change significantly, but vigorous physical activity tended to increase over time from a median of 0 (interquartile range, [IQR] 0-840) to 240 (IQR 0-1140) MET minutes per week (P=.053).

Table 1. Patient characteristics.

Characteristic	Total
Sex (female), n (%)	16 (47)
Age, years, mean (SD)	59.6 (8.4)
Marital status, n (%)	
Relationship, married, living together	26 (76)
Divorced	4 (12)
Widowed	3 (9)
Missing	1 (3)
Education, n (%)	
Compulsory or less	2 (6)
Postcompulsory	21 (62)
University or college	9 (26)
Other	2 (6)
Employment status, n (%)	
Full-time job	11 (32)
Part-time job	3(9)
Homemaker	1(3)
Retired	11(32)
Volunteer worker	1 (3)
Disabled	5 (15)
Missing	2 (6)
Cancer stage, n (%)	
I	13 (38)
II	5 (15)
III	16 (47)
Type of treatment, n (%)	
Surgery only	12 (35)
Surgery and chemotherapy	3 (9)
Concurrent chemoradiotherapy only	10 (29)
Concurrent chemoradiotherapy and surgery	2 (6)
Radiotherapy only	7 (21)
Currently in treatment, n (%)	27 (79)
Comordity present, n (%)	22 (65)

Table 2. Acceptability of MyAVL as a whole and its components.

MyAVL component	Used this feature (self-report) N=28 n (%)	Rating (1-10) mean (SD)	Key remarks, issues, and suggestions for improvement based on questionnaire and focus group data
MyAVL as a whole	—	7.8 (0.9)	• The 2-step authorization procedure (with username, password, and text message authentication) was found to be burdensome • Issues with non-Windows operating system (ie, iOS) • Some patients indicated that they logged in to the program less frequently because they had noted that the content of the portal did not change much during the course of the study
Patient education	11 (37)	7.1 (1.5)	• Patients indicated that too few documents were available • Some indicated that content could be more tailored to specific complaints of patients
Appointments	25 (83)	8.2 (1.2)	• No major issues; very comprehensible and useful • Past appointments were found to be useful for reimbursement purposes
Access to the EMR[a]	24 (80)	7.1 (1.1)	• Although many patients found the information useful and comprehensible, it also raised questions or anxiety in some cases • Not all data of the EMR could be accessed. Some wanted to see more (eg, imaging results, doctors' personal notes). The delay of 2 weeks before showing test results was perceived as too long by some patients. The delay should be indicated more clearly in the portal. • Data from other hospitals could not be seen via MyAVL
PROs[b]and feedback	21 (70)	7.4 (1.0)	• Graphs and tables with scores were comprehensible and valued by patients as these gave insight into their quality of life over time • Some indicated that PROs were somewhat unpleasant to complete or took too much time to complete • PROs were not often discussed during medical consultations, which disappointed some patients
Keep Fit	8 (27)	7.2 (0.8)	• Reminded several patients of the importance of physical activity • Advice was sometimes perceived as too general and could be more tailored • Recalling the amount of physical activity during the past week (needed for the questionnaire) was not always easy • Some expressed desire for a free text option to express their concerns or needs in this respect • Some expressed the need for information on services (eg, physiotherapy) that are specialized for cancer patients

[a]EMR: electronic medical record.

[b]PROs: patient-reported outcomes.

Discussion

MyAVL, an eHealth program developed in an oncology setting, was found to be feasible, easy to use, and useful by the majority of the lung cancer patients who participated in the study. Access to the EMR and the overview of appointments were evaluated very positively and used quite frequently. We expected positive effects of access to the EMR in terms of improved knowledge, autonomy, self-efficacy, and patient-clinician communication [21]. Our results supported this in part: 61% (17/28) reported that this information enhanced knowledge of their disease and 43% (12/28) indicated that it enhanced their sense of control over their disease. In general, patients indicated that they would prefer access to their full medical record and access to medical test results as soon as they have been reviewed by a professional. Reassuringly and similar to other studies [22,23], very few patients reported that having access to the EMR led to feelings of (mild) anxiety. At the same time, our measures of impact (ie, PAM, SF-36, and IPAQ) indicated no improvement over time. In fact, there was a significant, albeit small, decrease in PAM scores. One explanation may be that these outcome measures are not responsive enough to the possible effects of the portal or that the "dose" was not strong enough. For future trials on these types of interventions, more tailored or specific outcome measures may be needed. The supporting effects of MyAVL (and patient portals in general) may be further increased by

adding features focused specifically on coping and symptom control [3].

eHealth in lung cancer patients is a relatively new occurence, and few studies have been published. Most of these studies are related to symptom monitoring [7,8,10,11], which is very different from our multicomponent intervention. One study by Gustafson et al [9] reported the results of a trial in which they compared the use of a comprehensive online intervention (Comprehensive Health Enhancement Support System [CHESS]) with standard Internet access in palliative lung cancer patients and especially their caregivers. CHESS included information, communication with and support from peers, coaching feedback based on user input, and tools to organize support from family and friends. The researchers found that caregivers in the CHESS arm consistently reported lower patient physical symptom distress than caregivers in the Internet arm. Unfortunately, we did not measure symptom distress in our study so we cannot compare our findings on this aspect. The actual use they reported was quite low, with only 73.4% of caregivers and 50% of patients accessing CHESS at least once. In contrast, in our study, 34/37 patients (92%) used the application more than once. This higher use may be related to our patient sample as we only included patients who were treated with curative intent. These patients may be more capable or willing to use supporting eHealth programs than patients who receive palliative treatment. Median length of use in the Gustafson study was 103 minutes for caregivers and 146 minutes for patients, compared to a mean log-in time of 12.9 minutes in our study. This large difference might be related to the broader range of supporting tools included in CHESS.

Difficulty with patient accrual appears to be a common theme among eHealth studies in lung cancer patients [9,11]. We are not aware of any direct comparative data on interest in or use of eHealth by different cancer patient populations. However, in our study, the participation rate of patients who could be contacted was 42%, whereas in a previous study of breast cancer patients the participation rate was higher (52%) [14]. One could thus argue that lung cancer patients may be less willing to participate in such interventions. Several previous studies, including Gustafson et al [9] and Cleeland et al [11], recruited fewer patients than planned. On a positive note, those patients who did participate in our study were, in general, very satisfied with the portal. Thus for interested and motivated patients, such eHealth approaches may be very suitable.

Despite the large potential benefits of exercise [24], the physical activity support program was used by only one-third of participants. Those who received intensive treatment (eg, chemoradiotherapy) were particularly unlikely to use the program. This may be an indicator of limited feasibility of this part of the portal for these patients.

We observed relatively good compliance with completing PROs during the study period, which may be due to the fact that the PROs are perceived as part of their integrated care [25]. The accessibility of MyAVL may be further enhanced by simplifying the authorization/access procedure (Table 2).

A clear limitation of this study is the low participation rate and resulting small sample size. This small and select sample of patients may limit the generalizability of our findings, as participating patients may differ from the majority of lung cancer patients. Additionally, several components of the portal (eg, the Keep Fit component) were not used by every patient, which led to evaluations of these components by a relatively small number of patients. This might indicate that these components are less feasible for lung cancer patients. The limited number of patients in the focus group may not fully represent the views of the total group of patients. A final limitation is that patient knowledge of their disease was measured by self-report and not measured objectively, which may be subject to bias.

In conclusion, MyAVL appears to be a feasible and user-friendly multifunctional eHealth program for patients with lung cancer, although participation rate was quite low. Additional efforts are needed to increase the reach and effect of the program in terms of patient empowerment and to increase the attractiveness, perceived value, and use of the patient education and physical exercise elements of the program.

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Conflicts of Interest

None declared.

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Abbreviations

AVL: Antoni van Leeuwenhoek
CHESS: Comprehensive Health Enhancement Support System
EMR: electronic medical record
IPAQ: international Physical Activity Questionnaire
IQR: interquartile range
PAM: Patient Activation Measure
MET: metabolic equivalent of task
SF-36: Short Form Health Survey
PRO: patient-reported outcome
UTAUT: unified theory of acceptance and use of technology
WUS: Website User Satisfaction questionnaire

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Original Paper

Demands and Needs for Psycho-Oncological eHealth Interventions in Women With Cancer: Cross-Sectional Study

Johanna Ringwald[1,2], Dipl Psych; Lennart Marwedel[1], MSc; Florian Junne[1], MD; Katrin Ziser[1], MSc; Norbert Schäffeler[1], Dr; Lena Gerstner[1]; Markus Wallwiener[3], Prof Dr; Sara Yvonne Brucker[4], Prof Dr; Martin Hautzinger[5], Prof Dr; Stephan Zipfel[1,2], Prof Dr; Martin Teufel[6], Prof Dr

[1]Department of Psychosomatic Medicine and Psychotherapy, University Hospital Tuebingen, Tuebingen, Germany

[2]Comprehensive Cancer Center Tuebingen-Stuttgart, University Hospital Tuebingen, Tuebingen, Germany

[3]Department of Obstetrics and Gynecology, University Hospital Heidelberg, Heidelberg, Germany

[4]Department of Obstetrics and Gynecology, University Hospital Tuebingen, Tuebingen, Germany

[5]Department of Psychology, Clinical Psychology and Psychotherapy, University of Tuebingen, Tuebingen, Germany

[6]Department of Psychosomatic Medicine and Psychotherapy, LVR-Clinic Essen, University of Duisburg-Essen, Essen, Germany

Corresponding Author:
Johanna Ringwald, Dipl Psych
Department of Psychosomatic Medicine and Psychotherapy
University Hospital Tuebingen
Osianderstrasse 5
Tuebingen,
Germany
Phone: 49 707 1298 6701
Email: johanna.ringwald@med.uni-tuebingen.de

Abstract

Background: Over the last decade, a growing body of studies regarding the application of eHealth and various digital interventions has been published and are widely used in the psycho-oncological care. However, the effectiveness of eHealth applications in psycho-oncological care is still questioned due to missing considerations regarding evidence-based studies on the demands and needs in cancer-affected patients.

Objective: This cross-sectional study aimed to explore the cancer-affected women's needs and wishes for psycho-oncological content topics in eHealth applications and whether women with cancer differ in their content topics and eHealth preferences regarding their experienced psychological burden.

Methods: Patients were recruited via an electronic online survey through social media, special patient Internet platforms, and patient networks (both inpatients and outpatients, University Hospital Tuebingen, Germany). Participant demographics, preferences for eHealth and psycho-oncological content topics, and their experienced psychological burden of distress, quality of life, and need for psychosocial support were evaluated.

Results: Of the 1172 patients who responded, 716 were included in the study. The highest preference for psycho-oncological content topics reached anxiety, ability to cope, quality of life, depressive feelings, and adjustment toward a new life situation. eHealth applications such as Web-based applications, websites, blogs, info email, and consultation hotline were considered to be suitable to convey these content topics. Psychological burden did not influence the preference rates according to psycho-oncological content and eHealth applications.

Conclusions: Psycho-oncological eHealth applications may be very beneficial for women with cancer, especially when they address psycho-oncological content topics like anxiety, ability to cope, depressive feelings, self-esteem, or adjustment to a new life situation. The findings of this study indicate that psycho-oncological eHealth applications are a promising medium to improve the psychosocial care and enhance individual disease management and engagement among women with cancer.

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KEYWORDS

cancer, oncology, eHealth; Internet; needs; Web-based interventions

Introduction

Breast and gynecological cancer and the treatment of these diseases are psychologically challenging for affected women. A variety of physical and psychosocial impairments and lifestyle changes can occur and result in a lower health-related quality of life (QoL) and higher unmet supportive care needs [1-3]. As a consequence, about one-third of women affected by cancer develop high cancer-related distress [4] or clinically relevant syndromes (eg, adjustment disorder, anxiety disorder, and depression) [5]. Up to half of all patients express a need for psycho-oncological care to cope with the disease [6,7]. Previous studies reported that cancer patients with unmet supportive care needs are those who are younger, female, manifest high anxious or depressive scores, live alone [3,8,9], have a lower income [10], or have a lower QoL [11]. Patients with breast, colorectal, blood, lung, and prostate cancer reported higher unmet supportive care needs than patients with melanoma [12]. However, one study showed that colorectal cancer patients expressed lower unmet supportive care needs as compared to breast cancer, lymphoma, and lung cancer patients [11], and a second study demonstrated that breast cancer patients express lower needs than patients with multiple cancer sites, lung cancer, colorectal cancer, brain cancer, and other types of cancer patients [13].

Due to the high cancer-related psychological burden, current international and national cancer guidelines recommend early assessment of and support for psychosocial problems, distress, unmet supportive care needs, problems with daily activities, and lifestyle risks [14,15]. Therefore, screening tools are used to measure the level of distress [16,17].

A variety of psycho-oncology interventions have been developed to support cancer-affected patients during and after treatment to reduce unmet supportive care needs [18-20]. However systematic reviews show that a majority do not benefit from those interventions [21], especially in the long-term, and high distress still persists after several years, especially among younger women (younger than 50 years) with breast cancer. This may indicate that contexts of psycho-oncological interventions do not cover content topics that are relevant enough to sustainably engage patients [8,22]. It has been discussed that psycho-oncological interventions must address specific needs and demands of cancer-affected patients to sustainably improve their well-being [21,23]. Interventions have to be tailored according to patient preferences [23]. Additionally, psycho-oncological care has to reflect living conditions (eg, rural area [24,25] or age [23]). Furthermore, it is important to integrate psycho-oncological care into daily life in order to reduce the barriers of psychosocial care [24]. Digital media has revolutionized our lives as well as the health care industry, and it continues to do so. As technology rapidly improves, many individuals with health problems turn to the Internet to seek out relevant health information [26-30] and take part in Internet-based interventions as an active coping strategy [31,32]. eHealth and digital health have the potential to revolutionize patients' lives, and eHealth applications, electronic services or systems that support processes and communication in medicine and health care, are changing health care delivery with growing compliance on the part of both patients and health care experts [20,33,34]. Cancer patients represent a growing proportion of health information seekers [30,35]. Over the last decade, a growing body of studies regarding the application of eHealth [29,36,37] and different online interventions [38] have been published and are widely used in psycho-oncological care [39]. While online searches for cancer information, eHealth applications, and online interventions in psycho-oncological care are more common, less is known about cancer patients' real demands for online and offline psycho-oncological interventions [38,40]. Current online psycho-oncological interventions used the contents of Web-based stress management and depression programs without relying on well-conducted studies in big samples of cancer-affected persons assessing the psychological demands and needs of patients. Other interventions deliver standardized health information and patient education tools to increase patient knowledge about cancer. However, the effectiveness of psycho-oncological care is still not solid due to missing consideration about the real demands and needs for psycho-oncological care, especially in eHealth applications among cancer-affected patients [19,21,38]. McAlpine and colleagues [38] concluded in their review that further psycho-oncological eHealth applications (ePOAs) would benefit from an informed approach and objective evidence to justify the creation and implementation of ePOAs for the cancer population. In Germany, the expansion of eHealth is continuously growing and the revenue is expected to show an annual growth rate of 19.1% [41].

The aims of this cross-sectional study were to describe the cancer-affected women's needs and demands for psycho-oncological content topics for eHealth applications and determine if women with cancer differ in their demands regarding their experienced psychological burden (distress, QoL, and need for psychosocial support).

Methods

Study Design and Recruitment

A total of 1172 women with either breast or gynecologic cancer (or both) were assessed in a cross-sectional approach. Patients were recruited to answer an electronic online survey (Questback) through social media, special patient Internet platforms, self-help group leaders, patient networks (eg, Breast Cancer Aid Germany or BRCA Network), and cancer counseling centers. Duplicate entries were avoided by preventing users with the same IP address further access after completion of the survey. Furthermore, consecutive inpatients and outpatients were asked whether they would like to participate in the study (paper-and-pencil questionnaire in the department of gynecology at the University Hospital Tuebingen, Germany). The self-reported paper-and-pencil or self-reported online questionnaires took participants an average of 20 minutes to complete. Eligibility criteria were defined as an adult (age 18 years and older) with breast cancer, gynecologic cancer, or both with sufficient language skills to complete a set of questionnaires. Participation was voluntary and anonymous; no personal identifying information was collected from the patients. The beginning of the questionnaire included the consenting

page. Of the 1172 participants assessed, 41 did not meet the eligibility criteria because of another cancer diagnosis. Incomplete datasets (less than 80% response rate) were excluded, resulting in a final dataset of 716 participants, with 581 surveys completed online and 135 surveys completed as paper-and-pencil questionnaires. The local ethics committee of the University Hospital Tuebingen approved the study protocol.

Measures

Demographic and Disease-Related Information

Demographic variables included age, gender, marital status, and number and age of children. Self-reported data on the type of cancer, time since primary diagnosis, and status of disease (primary disease, metastasis, and recurrence) were also collected.

Patient Preference Survey

The patient preference survey was self-generated. In total, 25 items considered the patient preference items for an ePOA. Two categories were created with 19 content topics for a psycho-oncological intervention and 6 possible eHealth applications (Web-based application/info home page, chats and blogs, info email, consultation hotline, phone, video conference). Patients ranked their answer on a 3-point Likert scale ranging from 1=not important to 3=very important to the question, “Which content topic is important for a psycho-oncological intervention?” Next, patients ranked their answer on a 3-point Likert scale ranging from 1=not suitable to 3=very suitable to the question, ”Which application is suitable for the mentioned content topics?”

Distress Thermometer

The 11-level visual analog scale of the Distress Thermometer is widely used to measure distress and has been validated in diverse oncology applications [42,43]. Patients were instructed to choose a number indicating how much distress they have been feeling over the past week, including today, between 0=no distress and 10=the worst distress imaginable. A cut-off score of ≥5 is recommended as indicative of a high distress level [42]. A score between 0 and 4 was considered as not distressed, between 5 and 7 as distressed, and between 8 and 10 as highly distressed [44].

Hornheider Screening Instrument

The Hornheider Screening Instrument (HSI) is a widely used German 7-item screening instrument to identify patients in need of psychosocial support [45]. The short version of the HSI has been shown to be valid and reliable [46]. It asks for physical condition, mental condition, level of information about illness and treatment, psychosocial distress apart from present illness, distress of relatives, the availability of people to talk to about concerns and anxiety, and the ability to relax during the day. The need for an intervention is indicated when the calculated score is >0.30.

Quality of Life

The EuroQoL 5-Dimension 3-Level Questionnaire (EQ-5D-3L) has been used in many clinical trials and methodological studies published in the peer-reviewed literature. It is a standardized instrument for describing and evaluating a patient’s general health status and can be used for clinical assessment of QoL [47]. To measure the QoL, the visual analog scale portion of the EQ-5D-3L was used where own health today is rated on a scale from 0=worst imaginable health to 100=best imaginable health. Values >66 were consider as high QoL, between 51 and 65 as middle QoL, and <50 as low Qol. These cutoffs were analyzed with median splitting within our study group.

Data Analysis

Descriptive statistics, mean and standard deviation, frequencies, percentages, and chi-square statistics for categorical variables were performed using SPSS 21 for Windows (IBM Corp). Statistical analysis was performed to search for a relationship between patient preferences for psycho-oncological eHealth care and psychological burden with distress, QoL, and need for psychosocial support. Data were normally distributed. Chi-square statistics were used to examine the data for associations between the psychological burden and the preference for psycho-oncological content topics and ePOAs. We computed for distress (highly distressed, distressed, not distressed) and QoL (low, middle, high) in a 3×2 distribution table and for HSI (needing psychosocial support vs not needing psychosocial support) in a 2×2 distribution table. For this purpose, the responses of items were dichotomized (preferences: important vs nonimportant; eHealth applications: suitable vs nonsuitable). Missing data only occurred for the patient preference surveys. The overall mean of missing values was estimated as 2.075%. Missing values were considered only if at least 80% of each of the questionnaires had been completed. Using the Little missing completely at random test, it was confirmed that the data were missing randomly. The expectation-maximization algorithm was used to input the missing data [48]. All of the statistical tests were 2-sided, and $P<.05$ was considered statistically significant.

Results

Participants

Of the 1172 patients who responded, 716 (61.09%) datasets met the inclusion criteria, showed acceptable quality, and were included in the study. The mean age of participants was 50.2 (SD 10.3) years (range 25-83 years). Nearly 80.4% (576/716) of the patients were primarily diagnosed with cancer, and 12.2% (87/716) of participants were diagnosed with metastasis; 11.0% (79/716) were experiencing a recurrence of the past cancer diagnosis. The frequencies of other disease-related and demographic variables and mean values and standard deviations of the Distress Thermometer, EQ-5D-3L, and HSI questionnaires are presented in Table 1.

Relevant Psycho-Oncological Content Topics for eHealth Applications

The 19 content topics for a psycho-oncological intervention were rated by the patients (see Figure 1). The highest rates reached anxiety (675/697, 96.8%), followed by ability to cope (674/696, 96.8%), QoL (657/696, 94.4%), depressive feelings (655/695, 94.2%), and adjustment to new life situation (654/700, 93.4%).

Table 1. Study population characteristics: sociodemographic and disease-related information and psychological burden.

Characteristics	Total
Age, years, mean (SD); range	50.2 (10.3); 25 to 83
Length of time between first diagnosis and questionnaire completion, years, mean (SD); range	4.6 (5.0); 0 to 39
Cancer diagnosis, n (%)	
Breast[a]	652 (91.06)
Gynecologic[a]	86 (12.01)
Disease status, n (%)	
First episode[a]	576 (80.44)
Metastasis[a]	87 (12.15)
Recurrence[a]	79 (11.03)
Married/with a partner, n (%)	
Yes	600 (83.8)
No	116 (16.2)
Children, n (%)	
0	159 (22.8)
1	166 (23.2)
2	241 (33.8)
3	97 (13.6)
4	18 (2.5)
≥5	8 (1.3)
Data missing	24 (3.4)
Psychological distress, mean (SD); possible range	
Distress Thermometer	5.60 (2.57); 0 to 10
Quality of life, mean (SD); possible range	
EQ-5D-3L	62.77 (19.88); 0 to 100
Need for psychosocial support, mean (SD); cutoff	
Hornheider Screening Instrument	0.66 (1.51); >0.30

[a]Self-reported; multiple answers possible.

Lower preference rates were reached by spirituality (308/692, 44.5%), sense-making (632/692, 66.0%), and sexuality (495/692, 71.5%).

Patient Preferences Regarding Psycho-Oncological eHealth Applications

Almost all of the eHealth applications for conveying the content topics were considered by more than 50% as suitable. Web-based application/info home page (540/695, 77.7%) was considered to be the most suitable compared to other eHealth applications. Blogs or chats were considered suitable or very suitable (470/694, 67.7%). More than half considered the eHealth applications info email (387/694, 55.8%) and consultation hotline (361/694, 52.0%) suitable or very suitable. Videoconference was judged by the least number of patients (285/687, 41.5%) as suitable for psycho-oncological care (see Figure 2).

Relationship Between Psycho-Oncological Burden and Perceived Relevance of Content Topics in eHealth Interventions

Preferences for all content topics were equally distributed in the subgroups distress and QoL. Preferences were not dependent on high, middle, or low distress or high, middle, or low QoL. Also, in the context of needing psychosocial support, patients preferred the same content topics for a psycho-oncological intervention. We found no differences between participants with different levels of distress or QoL concerning the preferred content of eHealth interventions. Furthermore, time since diagnosis or prognosis as well as recruitment (eg, hospital vs Facebook) had no influence on needs (data not shown).

Figure 1. Relevant psycho-oncological content topics for eHealth applications.

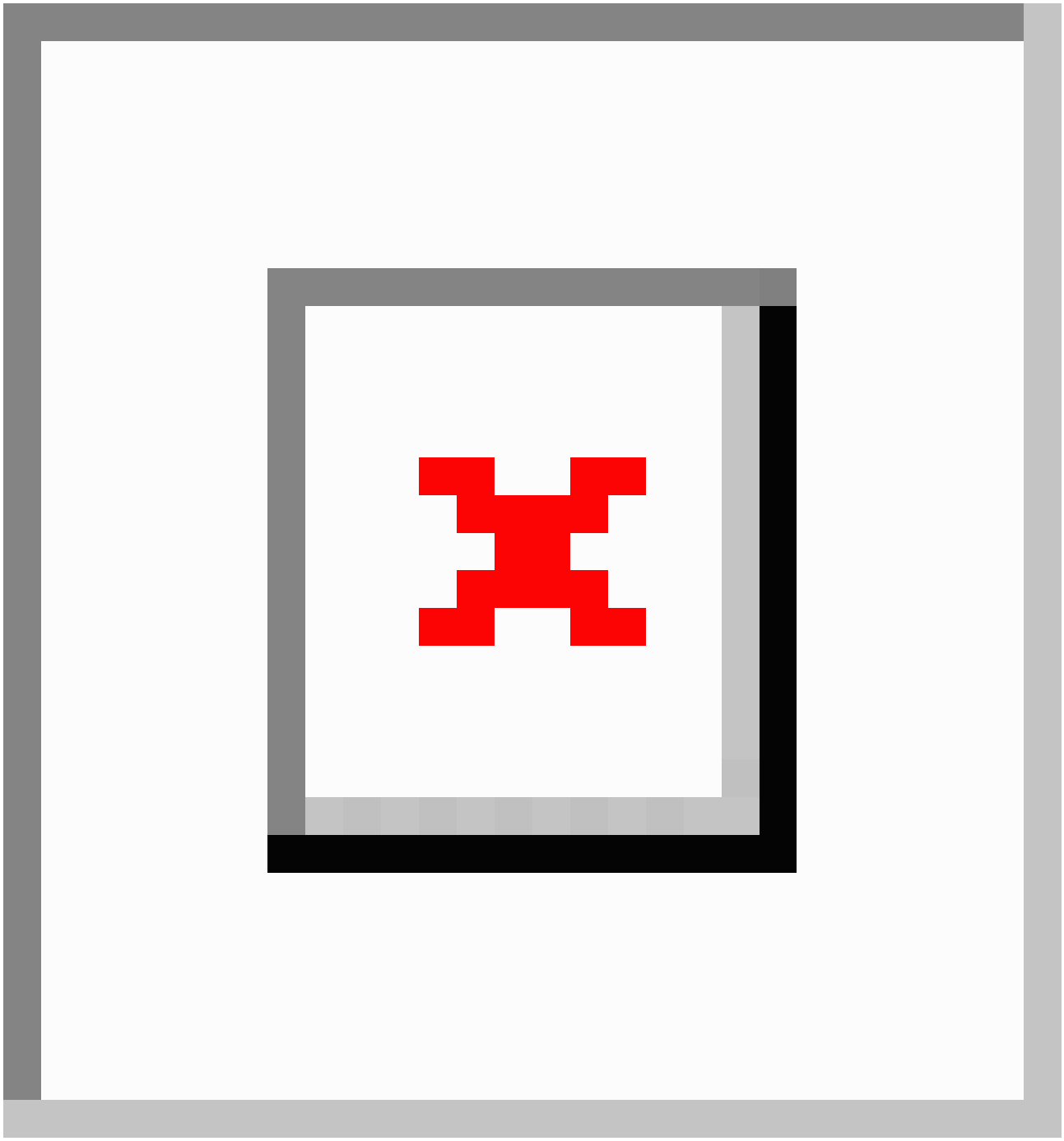
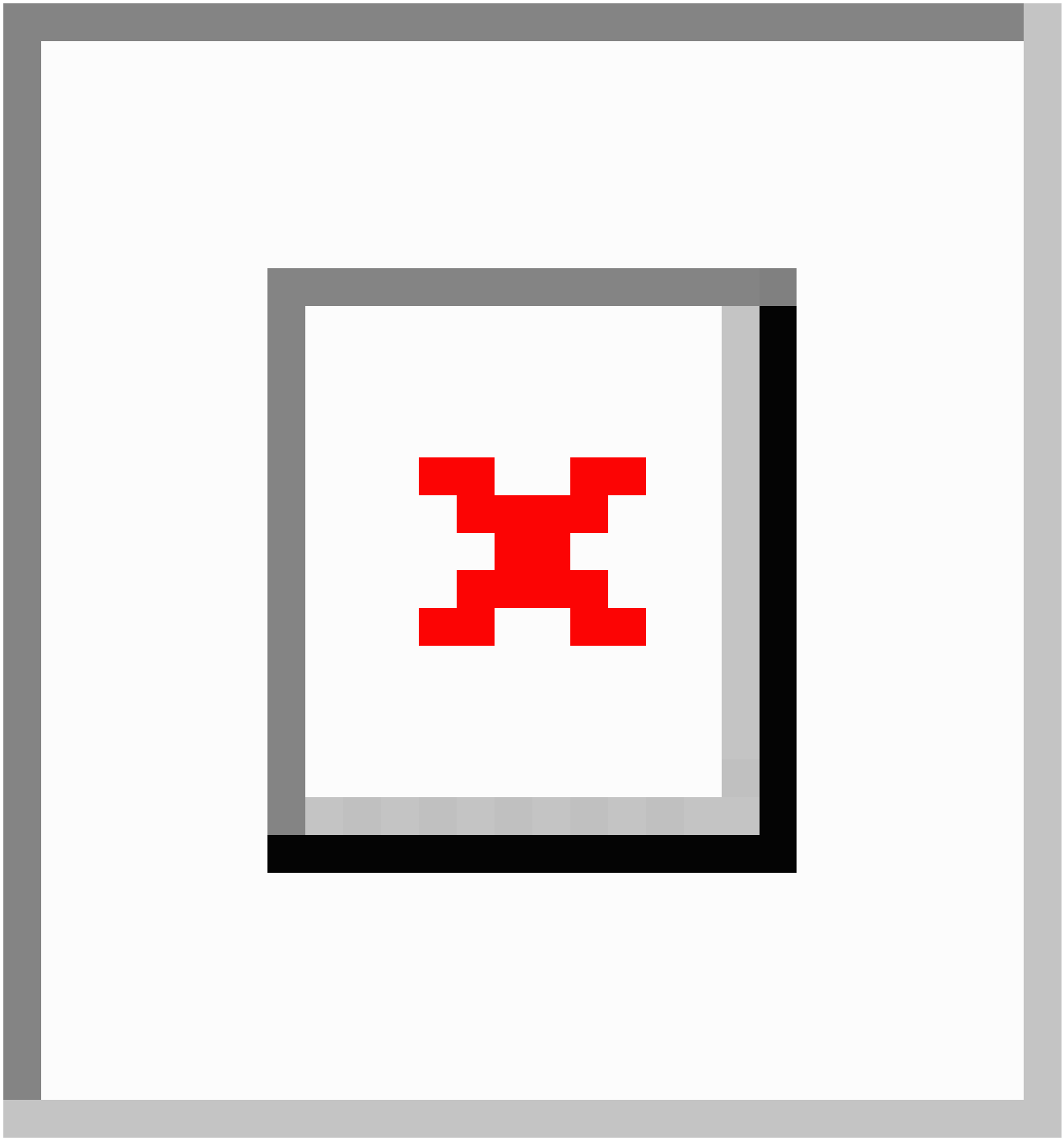


Figure 2. Patient preferences regarding eHealth application to convey psycho-oncological content topics.



Discussion

Principal Findings

Our survey explored for the first time the perceived demands and needs for a psycho-oncological eHealth intervention among women with breast and gynecological cancer. Furthermore, we investigated whether there is a relationship between psychological burden (distress, QoL, and need for psychosocial support) and content topic relevance. In this sample of 716 cancer-affected women, we found distinctively relevant content topics for eHealth interventions. The content topics of ability to cope, anxiety, depressive feelings, or adjustment to new life situations have a high impact on eHealth interventions and, in turn, reflect the needs and demands for psycho-oncological care of cancer-affected women. Spirituality, sense-making, and dealing with children had no high relevance for eHealth interventions in our sample. Furthermore, Web-based application/info home page, info email, and chats and blogs were identified as very suitable and suitable for conveying psycho-oncological content topics to the patients. We found that preferences for specific content topics and eHealth applications were equal between patients with high and low burden (experienced distress and QoL). In addition, the need for psychosocial support did not influence the demands and needs of the patients. To summarize, interestingly, women with cancer experience—independently of their psychological burden—have the same demands and needs for psycho-oncological content topics. Furthermore, they expressed

the same demands for eHealth applications in psycho-oncological care.

Interpretation of our Findings

We found in our survey that the most preferred type of psycho-oncological eHealth interventions are Web-based applications or info emails. These results are in line with previous studies that also identified high preferences for eHealth applications [10,33,34,49]. Moreover, we found that eHealth applications may have potential beneficial effects for specific psycho-oncological content topics like anxiety, coping, depressive feelings, self-esteem, or adjustment to new life situations (see Figure 1). It seems that ePOAs have the potential to support cancer-affected women in the context of delivering information, feelings of control, self-efficacy, or self-management during the time of dealing psychologically with the disease. Jansen et al [50] also found an overall positive attitude toward self-management and eHealth among different cancer survivors. Furthermore, they determined that men were more likely to report supportive care needs regarding healthy lifestyle programs, and they are in general highly interested in eHealth. Børøsund et al [51] described the use of patterns in Web-based illness management support among prostate and breast cancer patients. Regarding the use of Web-based support applications, they determined that lower levels of social support and higher depression scores were more influential among women with breast cancer, and symptom distress was more influential for men with prostate cancer. It seems that cancer-affected men are more likely to participate in eHealth applications that offer lifestyle elements, and women with cancer are more willing to participate in eHealth applications that also contain psycho-oncological elements.

The psycho-oncological content topics that were evaluated for eHealth applications (see Figure 2) are similar to the topics discovered in other studies. Different researchers discovered high unmet psychological and psychosocial needs in cancer patients and reported that it is urgently necessary to further evaluate and address these specific demands and needs in future and modern eHealth intervention [9,52,53]. In our survey, sexuality, sense-making, and spirituality were considered to be less important, a finding which diverges from other research findings [54,55]. It could be that these content topics are more suitable for face-to-face interventions and are not suitable for eHealth interventions. The content topic self-esteem was rated extremely high and considered to be very important by the patients for an eHealth intervention. In previous psycho-oncological interventions, this content topic was mostly neglected and not taken into account, especially in eHealth interventions. Furthermore, we have found that more than 50% of the patients reported a high preference for ePOAs independently of the experienced psychological burden. This is in line with the findings of Jansen et al [50] who reported that the perceived needs for supportive care, including healthy lifestyle programs, were highly accepted, and in general, cancer survivors had a positive attitude toward eHealth. Different from our findings, Jansen and colleagues [50] found that the attitude was associated with QoL [50]. An et al [30] demonstrated that cancer patients perceived more social support from the Internet when they actively posted or shared contents than when they used the Internet solely as an informational resource [30]. We also determined that chats and blogs were highly accepted by our patients. In addition, studies reported that future psycho-oncological interventions should consider daily practice and the local accessibility as ePOAs have the potential to close this gap [24,56,57]. Additionally, cancer survivors were positive toward ePOAs that enable them to enhance their own QoL and support them in finding tailored supportive care [57]. It was shown that eHealth applications are well accepted for therapy assistance in general (like patient-physician communication) and eHealth programs as a part of usual health care may be promising [29,50,57]. A promising result of our study is that a substantial group of participants in need of supportive care prefer ePOAs for the delivery of adequate psychosocial care. Furthermore, they rate eHealth as adequate for specific psycho-oncological content topics like anxiety, ability to cope, depressive feelings, self-esteem, or adjustment to new life situations.

Strengths and Limitations

Our survey study was based on a large sample (N=716) of patients diagnosed with breast cancer, gynecologic cancer, or both. Our use of various and novel recruitment strategies (Internet links, Facebook, blogs, flyers) led to a large proportion being included through the online questionnaire (n=581). This shows that eHealth is especially targeting patients with eHealth literacy, and therefore our results can be considered as representative of these patients [58]. Nevertheless, there are limitations in the sample selection and generalizability of this survey. Our survey cohort was homogenous, mostly younger, white, and highly distressed. Furthermore, it is important to note that mainly women with breast cancer (91.1%) participated in our survey. Therefore, a recruitment bias can be assumed in our study. However, this trend has been observed in similar studies, and it also reflects reality [51]. Breast cancer has the highest tumor prevalence among women, and various studies show that this patient group suffers mostly under high psychological distress [4,5] and younger patients prefer eHealth applications more than older patients. Further studies including other tumor entities and male patients are needed. Our results agree with findings of former studies [50,51]. The lack of diversity also does not allow extrapolation of study results to statements concerning other tumor entities and men. Our self-generated patient preference survey has not undergone formal reliability and validity testing. Hence, a validated questionnaire for these research questions did not exist when the study was performed.

Conclusion and Clinical Implications

Our findings show high preference rates for eHealth applications independently of experienced psychological burden among women with cancer. Furthermore, ePOAs may have a high benefit for women with cancer, especially when they address psycho-oncological content topics like anxiety, ability to cope, depressive feelings, self-esteem, or adjustment to new life situations. ePOAs have the potential to help patients overcome disease-related burden and reduce barriers in psychosocial care. However, they can encourage patients who they believe are not sufficiently burdened to participate in common

psycho-oncological interventions [24,59]. Our findings encourage the development of further innovative ePOAs that specifically focus on the evaluated psycho-oncological content topics (see Figure 1). In summary, the findings of this study indicate that ePOAs are a promising medium to improve psychosocial care and enhance individual disease management among women with cancer.

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Conflicts of Interest

None declared.

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Abbreviations

ePOA: psycho-oncological eHealth application
QoL: quality of life
HSI: Hornheider Screening Instrument

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Original Paper

Cancer-Related Fatigue in Post-Treatment Cancer Survivors: Theory-Based Development of a Web-Based Intervention

Teresa Corbett[1], BAHons, MSc, PhD; Jane C Walsh[2], BA, PhD; AnnMarie Groarke[2], BA, MA, HDipED, AFPsSI, CPsychol, PhD; Rona Moss-Morris[3], BSc, MHSc, PhD; Eimear Morrissey[2], BA, MSc; Brian E McGuire[2], BA, M Clin Psych, Dip Crim, DipHSc, PhD

[1]Centre for Clinical and Community Applications of Health Psychology (CCCAHP), School of Psychology, Faculty of Social, Human and Mathematical Sciences, Southampton, United Kingdom

[2]School of Psychology, NUI Galway, Galway, Ireland

[3]Health Psychology Section, Psychology Department, Institute of Psychiatry, King's College London, London, United Kingdom

Corresponding Author:
Teresa Corbett, BAHons, MSc, PhD
Centre for Clinical and Community Applications of Health Psychology (CCCAHP)
School of Psychology
Faculty of Social, Human and Mathematical Sciences
University of Southampton
Southampton, SO17 1BJ
United Kingdom
Phone: 44 238059 ext 7045
Email: T.K.Corbett@soton.ac.uk

Abstract

Background: Cancer-related fatigue (CrF) is the most common and disruptive symptom experienced by cancer survivors. We aimed to develop a theory-based, interactive Web-based intervention designed to facilitate self-management and enhance coping with CrF following cancer treatment.

Objective: The aim of our study was to outline the rationale, decision-making processes, methods, and findings which led to the development of a Web-based intervention to be tested in a feasibility trial. This paper outlines the process and method of development of the intervention.

Methods: An extensive review of the literature and qualitative research was conducted to establish a therapeutic approach for this intervention, based on theory. The psychological principles used in the development process are outlined, and we also clarify hypothesized causal mechanisms. We describe decision-making processes involved in the development of the content of the intervention, input from the target patient group and stakeholders, the design of the website features, and the initial user testing of the website.

Results: The cocreation of the intervention with the experts and service users allowed the design team to ensure that an acceptable intervention was developed. This evidence-based Web-based program is the first intervention of its kind based on self-regulation model theory, with the primary aim of targeting the representations of fatigue and enhancing self-management of CrF, specifically.

Conclusions: This research sought to integrate psychological theory, existing evidence of effective interventions, empirically derived principles of Web design, and the views of potential users into the systematic planning and design of the intervention of an easy-to-use website for cancer survivors.

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KEYWORDS

cancer; survivor; design; person-based approach; theory

Introduction

The number of posttreatment cancer survivors in Ireland is set to increase in coming years due to advances in screening and treatment [1,2]. This group will require ongoing supportive care as many will experience persistent negative side-effects that can impair the quality of life. Cancer-related fatigue (CrF) is the most common and disruptive symptom experienced by

cancer survivors. Fatigue is extremely complex and likely to involve the interaction of several physiologic and psychological mechanisms. Current evidence supports the use of nonpharmacological treatment strategies for reducing CrF [3]. Web-based interventions have been shown to be an effective mode of delivery and can facilitate self-management of long-term conditions [4,5], including CrF [6-9]. Chou, Liu, Post, and Hesse [10] encourage using the Internet to better serve survivors' needs as it is increasingly being used as a resource by cancer survivors. Internet delivery overcomes isolation of time, mobility, and geography [11] that are sometimes cited as barriers to seeking support for CrF [12]. Web-based interventions allow participants to engage with the content an infinite number of times, at their own pace, and in the comfort of their chosen environment [13]. Such interventions may, therefore, increase access for users by providing 24-hour access to health care interventions and having the potential to reach huge numbers of people [11]. Use of such tools may enhance empowerment and effective self-management of fatigue [6,8].

This paper describes the development of a theory-based, interactive Web-based intervention designed to facilitate self-management and enhance coping with CrF following cancer treatment [14]. There has been an increase in the development of eHealth interventions; however, these are often are not clearly described in sufficient detail to allow for replication [15,16]. Furthermore, many of these interventions are frequently not based explicitly on a particular theory or therapy [17,18]. This paper outlines the process and method of development to allow readers to gain an insight into the intervention itself but also to provide a template for developing other interventions. The content and principles used in the development process are described [19], while also clarifying hypothesized causal mechanisms [20]. The description of the design process is presented in 4 sections. The first section describes the process of establishing a therapeutic approach based on theory. The second section describes the design of the content of the intervention. The third part describes the design of the website features. The final section describes the initial usability testing of the website. The aim is to outline the rationale, decision-making processes, methods, and findings which led to the development of a Web-based intervention to be tested in a feasibility trial [21].

Methods

In this section we outline the research and planning approaches we used to develop the content of the intervention.

Part 1: Establishing a Therapeutic Approach Based on Theory and Evidence

The underlying aetiology of CrF is not well understood [22] but it is thought to be a multidimensional symptom associated with physical, mental, and emotional factors. The processes that cause persistent fatigue remain unclear [23].

Biological factors such as cancer and its treatment may lead to initial fatigue during cancer [24]. Fatigue during treatment is associated with an inflammatory response to cancer and its treatment. However, during survivorship, it is proposed that cognitive-behavioral factors may maintain fatigue [25]. These include cognitive or emotional responses to the fatigue and coping strategies employed.

Interventions for fatigue based on cognitive behavioral therapy (CBT) aim to address cognitions, emotions, behaviors, or a combination of these [26]. CBT has been found to be effective for fatigue associated with other conditions [27-29] and may be more effective than alternative psychological therapies in reducing fatigue symptoms [30].

Theoretically, the therapeutic techniques used in CBT are comparable with constructs outlined in the self-regulation model proposed by Leventhal [31,32]. Using qualitative research, we concluded that the self-regulation model to describe fatigue after cancer provides an integrated theoretical model for developing interventions for fatigue-based on cognitive-behavioral principles [33]. This theory could clarify the processes by which CBT can impact posttreatment CrF by outlining the mechanisms that are hypothesized to bring about change in symptoms [34-36].

Interventions which target these processes may improve symptom management in CrF [37]. In our intervention, the aim was to help the participant engage in a process of appraising their representation of the fatigue symptoms, and also help them to identify adaptive coping strategies hypothesized to mediate change in fatigue outcomes [14,33].

Drawing on Existing Evidence

Systematic Review

In order to identify therapies that are likely to be most effective for fatigue after cancer, a systematic review of psychological interventions was conducted. The systematic review and meta-analysis found an overall positive effect of psychological interventions on fatigue in cancer survivors [38]. However, there was considerable heterogeneity, not only in design and outcomes, but also in the quality and usability of the specific interventions. The review identified 5 primary psychological intervention types including CBT, psychoeducation, mindfulness-based strategies, motivational interviewing, and supportive therapies. Since no single intervention type emerged as superior in this review, a decision was made to base the current intervention on CBT. This decision was based on the quality and quantity of existing literature and theory [39].

Similar Interventions

Similar interventions were consulted to facilitate selection of specific behaviors that would be targeted in the intervention [34,40]. The structure and layout was compiled in line with previous CBT interventions, in particular, the Web-based "MS Invigor8" intervention [41] and the "Understanding and managing persistent cancer-related fatigue" manual [42]. MS Invigor8 was developed from a therapist-delivered, CBT-based manualized self-management intervention shown to be an effective treatment for multiple sclerosis (MS) fatigue in a randomized controlled trial [43]. The original manual was based on a cognitive behavior model of fatigue in MS [44]. A pilot trial of the Web-based version (MS Invigor8: Breaking the cycle of fatigue) suggests that a Web-based version with minimal

telephone support may be a cost-effective way of delivering the intervention for MS fatigue [41]. "Understanding and managing persistent cancer-related fatigue" is a manual structured on CBT techniques and addresses issues such as inactivity, low mood, sleep problems, worry, and reclaiming life after cancer [42]. This manual was developed for Irish individuals with fatigue after cancer but has not been tested for effectiveness. Further information and specific components of the intervention were also informed by the available evidence on symptom-focusing [45]; activity scheduling, insomnia management [46-48]; and stress management [49] in cancer patients. Relaxation techniques and descriptions on activity pacing from the "Feeling better" manual were also incorporated [50].

Practice Guidelines

Existing practice recommendations were also consulted to assess the applicability of CBT for this participant group. The National Comprehensive Cancer Network has published guidance on supporting patients with CrF following treatment. Recommendations include the use of CBT [51]. CBT is also recommended by the American Cancer Society or American Society of Clinical Oncology Breast Cancer Survivorship Care guidelines [52].

Part 2: Designing the Content of the Intervention

An intervention content manual was developed in line with previous literature and existing guidelines. The content of this intervention draws upon established cognitive-behavioral models of fatigue as well as the self-regulation model of health and illness [33]. A logic model based on the findings of the systematic review, qualitative interviews, and the feasibility study is illustrated in Figure 1. Hypothesized influences on behavior were linked to intervention sessions that were established based on previous research and CBT guidelines [22,27,41,45,53]. It is hypothesized that certain key CBT techniques are likely to influence symptom representation and coping with fatigue and that an intervention addressing these factors is likely to change an individual's appraisal of symptoms and coping responses. Changes in symptom appraisal and coping are hypothesized to lead to improvements in adjustment to, and interference of, fatigue [14].

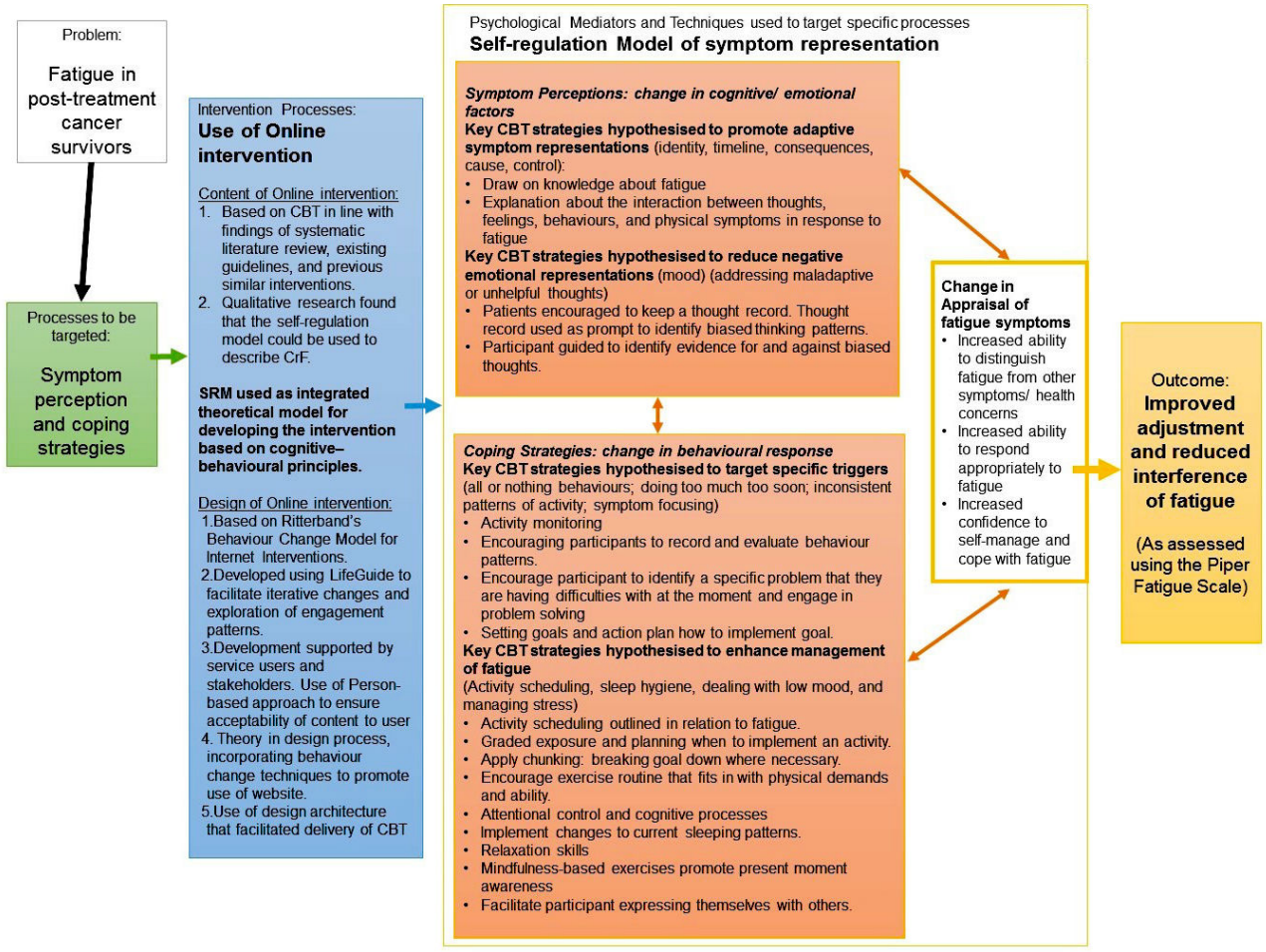
Once the content manual was developed based on traditional CBT programs, the behavior change technique (BCT) taxonomy (v1) was employed to describe components of the intervention [30]. To ensure that a comprehensive description of all aspects of the intervention was provided, content was also described with reference to the CBT competence framework for working with people with persistent physical health conditions [53]. We then summarized each of the intervention sessions and their association with the CBT [53], and the self-regulation model [54,55] constructs targeted and the BCTs used [14].

The use of the BCT taxonomy (v1) was not intended to reflect the effectiveness of particular BCTs in this intervention [35], but rather as a tool to specify techniques of the CBT intervention as a whole. The content of each of the sessions was analyzed independently by 2 coders (TC and EM). TC developed the content. EM was naïve to the content, theoretical basis, or aims of the intervention. BCTs were coded with a "0" if absent and a "1" if present. The interrater reliability was found to be moderate across each of the sessions (average κ=.67, P<.01; See Table 1). Sixty different BCTs were present across the sessions. The sessions increased in complexity, with the number of BCTs increasing as the intervention progressed. The session with most BCTs was session 5. The most commonly used BCT within the sessions was "13.2. Framing or reframing" which featured in every session.

Table 1. Interrater reliability of behavior change technique (BCT) coding for each session.

Session	Kappa
Session 1	.592
Session 2	.692
Session 3	.671
Session 4	.608
Session 5	.754
Session 6	.688
Session 7	.669
Session 8	.668
Average	.668

Figure 1. Logic model which includes theoretical model, the processes to be targeted, interventions to be used to target specific processes, and outcomes to be used in an efficacy randomized controlled trial (RCT).



Preferences of Potential Users Sought in Design: Incorporating a Person-Based Approach

Once theoretical foundations and preliminary content was mapped out, qualitative research was used to gain insight into user characteristics and identify the preferences of potential users [13,56]. The aim was to adapt the developed content for delivery via the Internet. Focus groups were carried out with survivors of cancer with fatigue (N=18), to explore their representations of fatigue in order to test the application of the theoretical model as proposed [33]. In a separate focus group session, the same participants were also asked about their perceptions of Web-based interventions and the type of features that were viewed as acceptable or unacceptable.

Participants highlighted a need for support throughout a Web-based intervention, particularly during this transitionary stage after treatment [57]. eHealth interventions can be enhanced by the use of additional methods of communicating with participants. Social support was offered through the intervention provider rather than providing a social networking facility for participants. This was considered to be better suited to this intervention where resources were limited given the inconsistency regarding the credibility and benefits of social support interventions and difficulties associated with ensuring that these tools were appropriately engaged with [58]. Messages of encouragement were used to stimulate adherence. It was decided that the research team would call participants half-way through the trial. A semistructured interview guide was developed and outlined in a manual to enable replication. These phone calls would support participants with any problems with the sessions or content, while also allowing participants to discuss their thoughts about CBT, their progress, and any of the messages provided in the intervention. The calls would be audio recorded and checked for fidelity, and any relevant content would be used to guide improvements for future iterations of the website [14]. Contact was otherwise provided via regular email reminders and updates about the intervention.

Developing a Web-based resource to support self-management after cancer treatment was endorsed by the majority of participants. Important contributions were made by participants regarding the need for some degree of personalization, credibility, and recognition of the fatigued nature of those using the website. Drawing on personal experiences, participants highlighted important domains such as an emphasis on moving forward with life after cancer rather than focusing too much on the illness.

Participants requested that the website focus on what they are able to do rather than on the limitations imposed on them by their fatigue. Therefore we aimed to increase individuals' perceptions of their capability to change behavior rather than

pointing to the implications of not changing [59]. Participants are congratulated on milestones throughout the program and emails include verbal persuasion to continue with the program [14].

Individuals emphasized the need to develop an attractive and engaging program. The name "Refresh" was chosen as suggested by participants in the qualitative research. This word was to reflect a new beginning (ie, a fresh start), and a focus on what people could do rather than the cancer experience. In order to ensure that the website was attractive to users, we sought to ensure that a simple, clear design was used [60]. Therefore, aspects such as appearance and the use of color were considered throughout the design process. The color-scheme throughout reflected the affiliation with the University.

Individuals emphasized the need to promote credibility to encourage use of the website. Participants were invited to read about the expertise of content developers. The website logo reflects the design of awareness ribbons often associated with cancer awareness. The university colors (white, purple, and green) would be used in the logo [14]. Logos of the university and the cancer charity that cofunded the research straddle the website logo.

The findings of the preparatory qualitative research, therefore, led to the development of design objectives which were consulted throughout the planning and development phases. This helped to ensure that the intervention was founded on a consistent rationale that would optimize its acceptability, feasibility, and in turn, effectiveness. With this user-oriented approach to design, the developers of the intervention were able to access information that complemented the application of psychological theory in the design of the program.

Application of Psychological Theory in Design Process

Psychological theory was also used to inform the optimal implementation of different design features and BCTs within different intervention contexts [58]. A list of intervention components resulting from the iterative process of applying principles and BCTs can be seen in Table 2.

Personalization was used throughout the website (eg, inserting a person's name) as self-referent cues are believed to be important in encouraging effortful processing [58,61]. Strategies for providing choice and flexibility were included where possible to enhance users' sense of autonomy [58]. Users were encouraged in every session to reflect on their own personal, intrinsic reasons for using the website and on how suggested changes could be incorporated into their lives [56]. The use of vignettes and quotes from the focus groups was incorporated to meet users' need for relatedness in the hope that users would feel listened to and by recognizing the challenges faced by CrF [58]. Stories from similar others, including reflections on how to cope with fatigue, aimed to develop a sense of self-efficacy through vicarious experiences. A sense of relatedness was promoted using videos and by introducing the research team via a "meet the team" page. Competence was promoted by encouragement, gradual increases in task difficulty, and available support from the team if the users had any questions [58].

A significant portion of the second session was devoted to goal-setting and learning to avoid the pursuit of inappropriate goals [62]. A "goal step-ladder" was introduced to participants to encourage the selection of sufficiently challenging and achievable goals that were linked to a longer-term distal goal [34,63]. As users progress through the sessions, the content changed from specific issues associated with fatigue management to broader issues associated with life after cancer [58,64].

As the intervention content was primarily focused on the self-regulation model theory, participants were encouraged to evaluate and reflect upon how planned or actual behavior directly affects fatigue, with framing and reframing of beliefs occurring throughout the sessions [58,65]. The use of a fatigue diary to monitor fatigue and understand its patterns was incorporated to assist participants in recognizing their symptoms. The sessions on negative mood, stress management, and relaxation provided skills-training to enhance a sense of control over the symptoms [7,66]. Participants were encouraged to actively appraise their cognitive-behavioral responses to symptoms throughout the sessions, and also in the phone calls with the intervention (for further information, see the study protocol [14]).

Table 2. Principles of website design and associated behavior change techniques (BCTs) included to promote the use of the "Refresh" program.

Principles of website design	Behavior change techniques
Social Support	3.1. Social support (unspecified)
	3.2. Social support (practical)
	3.3. Social support (emotional)
	6.3. Information about others' approval
	12.2. Restructuring the social environment
Autonomy	2.1. Monitoring of behavior by others without feedback
	10.7. Self-incentive
	10.9. Self-reward
Goal setting	1.1. Goal setting (behavior)
	1.2. Problem solving
	1.3. Goal setting (outcome)
	1.4. Action planning
	1.5. Review behavior goals
	1.7. Review outcome goals
Self-monitoring	2.3. Self-monitoring of behavior
	2.4. Self-monitoring of outcomes of behavior
	5.4. Monitoring of emotional consequences
	12.5. Adding objects to the environment
Self-efficacy	6.3. Information about others' approval
	10.4. Social reward
	14.4. Reward approximation
	15.1. Verbal persuasion about capability
Personalization	7.1. Prompts or cues
Normalizing symptoms	5.1. Information about health consequences
	5.2. Salience of consequences
	5.3. Information about social and environmental consequences
	5.6. Information about emotional consequences
	6.2. Social comparison
	4.3. Re-attribution
Focus on abilities	15.3. Focus on past success
	16.3. Vicarious consequences
	8.6. Generalization of target behavior
	8.7. Graded tasks
Skills-focused	4.1. Instruction on how to perform the behavior
	4.2. Information about Antecedents
	6.1. Demonstration of the behavior
	8.1. Behavioral practice or rehearsal
	8.2. Behavior substitution
	8.3. Habit formation
	8.4. Habit reversal
Length of the sessions	7.1. Prompts or cues
Credibility	9.1. Credible source

Results

The findings of the preparatory deductive and inductive research were collated to create a plan of what the Web-based intervention should contain [19]. The following paragraphs describe the process of developing the intervention based on the results of this preparatory work. Factors such as website structure, views of stakeholders and how to present the content were considered before a version of the website was tested for usability.

Part 3: Developing Web-Based Materials

The development process was informed by academics, clinical psychologists, and health psychologists having experience working with individuals affected by CrF, cancer, or fatigue. Specialists in the development and evaluation of Web-based behavior change interventions were also consulted. These included individuals with expertise in the design and implementation of interventions built using LifeGuide open-source software [67]. In order to ensure that an acceptable and feasible intervention was developed, the views of stakeholders, such as health care staff were also considered [13,68]. These included cancer care workers and staff at a local cancer support center. These consultations helped us to anticipate factors external to the intervention that may act as a barrier or facilitator to its implementation, or its effectiveness [20]. These included issues relating to computer literacy, the burden of fatigue, and potential preferences for offline support in this user group. We sought to design the website so that it would be easy to use and understand, with these considered as key factors in initial feasibility testing [14]. We also decided to use a variety of recruitment strategies to target individuals who were most likely to engage with a Web-based intervention (ie, through social media as well as through traditional recruitment methods) [14].

A draft content manual and plan for the structure of the Web-based intervention were designed. Due to the nature of eHealth interventions, certain aspects of the content manual could not be translated as originally planned. For example, some paragraphs were replaced with diagrams as shorter text was required to make the website more visually appealing. A storyboard was made for each session to demonstrate how the information would be presented on each Web page. Time and staffing resources were limited and so certain aspects of the content were prioritized by the research team [13]. These were based on the theoretical underpinnings of the research, as depicted in the logic model. Other aspects were altered or delivered in a different way than originally planned and some features that were not deemed essential were removed (eg, superfluous messages that did not include a BCT) [13,69]. An iterative review process then took place with the design team examining the different sessions. The original offline manual was useful as the website was extensively tunneled and tailored throughout this process, as with similar interventions (eg, Michie et al) [19].

All pages were created in Life-Guide's virtual research environment (VRE) [70]. This allowed the team to share Web-based feedback, comments, and suggested amendments on each of the pages. Employing testing methods that allow for the exploration of user experiences allows researchers to better understand the processes involved [13,19,56].

Intervention Structure

According to Danaher, McKay, and Seeley [71], the information architecture (IA)—the structure of website information—is a key factor that is often overlooked in the design of behavior change websites. The "Refresh" program utilized a hybrid IA design. The layout allowed for easy navigation to each of the main sections of the site. This design was in line with user preferences as it allowed the individual to explore content weekly sessions outside the main intervention while still maintaining the focused forward movement of the tunnel program [71].

The user would begin by accessing an initial Web page that contains a welcome and access to a sign-up page (see Multimedia Appendix 1)). Logging in enabled access to a page that provided matrix-like access to 4 content areas (see Multimedia Appendix 2). Once logged in, each user was presented with a personalized home page that provided information about the last time the user logged in. The user had free access to 5 different pages from the home page (a matrix design; see Multimedia Appendix 3). This matrix design was also used on the optional pages that facilitated autonomy by allowing interested users to seek out supplementary information about the program if they wished to do so [71].

The 8 sessions of the intervention were similar to the weekly sessions conducted in traditional in-person CBT [14]. Given the structured nature of traditional CBT, some tunneling was necessary. The pages that used a tunnel design require few navigational controls other than the "back" and "next" buttons. A linear model was better suited for multisession programs in which users were assigned tasks to do in between Web-based sessions. This model also allowed for an incremental increase in the amount of information and BCTs that a user was exposed to, increasing the likelihood that the user learned and potentially used the strategies. Further information about the procedure of the intervention is published elsewhere [14].

Ancillary pages in the hybrid design could enable the user to customize their experience, seeking out extra information if they chose and not being constrained by the tunnel design. Ancillary pages provided links to Web page resources outside of the program; however, these were programmed to open in a new tab to ensure that users did not need to leave the website to gain extra information. Participants' answers were saved to reload at the end of each page so that participants could pick up where they left off if they have to log out or take a break during a session. This design was used to facilitate user autonomy.

Hybrid designs offer the user alternative (and potentially more engaging) ways of interacting with, or revisiting content [71]. It was decided that this structure would be attractive as well as usable based on the reported preferences of participants in the qualitative study.

Presentation of Content

The sessions were short in length and a brief amount of text was displayed on each page. People do not tend to read long pages of text in Web-based interventions [72]. Participants often scan the page, picking out individual words, sentences, or images. To improve clarity, short concise sentences were presented in large, clear font styles. Text was chunked into short paragraphs to make the page feel less text-heavy. Lots of empty space (eg, between borders and text) and bullet pointed message were used to break up text. Bold font was used to highlight the main points on the page, with main points at the top of the page. Attempts were made to fit what needs to be conveyed on a page so that end users would not need to scroll down if possible. To break up text and reinforce meaning, as well as to reduce monotony, a variety of media were used to deliver the content. These included illustrations, text, animated videos with music and voiceovers, and the use of vignettes based on testimonials from qualitative research participants [73].

Part 4: Usability Testing

Usability testing was employed to further develop and improve the website by assessing preliminary functionality, acceptability, usability, and engagement [19,72]. The data was analyzed to examine beliefs of the users and information about specific content, format, and navigation-related feedback. This feedback was used to modify the relevant components of the intervention [19,72].

Users were asked to "think aloud" to enable the team to identify problems people might experience when working through the intervention (eg, navigational difficulties or potential adverse reactions). Participants (a testicular cancer survivor and a nurse) interacted with functional draft Web pages and asked to comment on their reactions to every aspect of the intervention, focusing on the helpfulness of information provided, comprehension, and ease of use [56]. They were asked to describe what they liked or disliked, or if there were any aspects of the intervention that they would change. The findings are summarized in Textbox 1.

Other participants used the intervention alone as an end user and completed a survey about their experiences after completing some or all of the intervention. These participants included a cancer care assistant, a spouse of a cancer survivor with fatigue, and 2 PhD students studying health psychology. This was to gather information about how people use the program in the absence of a researcher. Again, participants were asked to note any aspects that they found particularly beneficial or not useful, easy to use or problematic, and aspects which they particularly enjoyed or disliked [13].

The team encouraged users to provide critical feedback to guide improvements to the program [56,74]. Major changes to the intervention were not required at this stage. Some minor modifications were incorporated, and pages were redrafted (see Textbox 1). At this stage, the primary aim was to establish usability. Assessment of user satisfaction and acceptability will be conducted with a sample of posttreatment cancer survivors in the pilot trial [14].

Textbox 1. Changes to website design identified by user-testing.

Changes

Change bright purple border around buttons. Use darker shade.

- Use of bold font to emphasise key points and improve design.
- Fix formatting issues relating to content layout.
- Some videos not working, voiceover volume low.
- Include an instruction video to introduce the site.
- Change unhelpful jargon and terminology.
- Some typos identified.
- Remind people to scroll down on pages where it is necessary to do so.
- Email reminder should contain a link to the website for easy access.
- Ensure that email reminders are sent on time.
- Increase font size in some parts of the website.

Discussion

Principal Findings

This paper describes the development of "Refresh," a Web-based, CBT-based intervention for CrF after the completion of cancer treatment. The intervention was developed through the systematic application of theory, evidence, and user-testing [19]. Despite being a complex and multifaceted intervention, transparency was sought by detailing the components of the intervention, the proposed mechanisms of change. Efforts were made to reduce the "black box" criticism of interventions [15,19] by offering a clear description of the intended intervention, and how it is expected to work, before its evaluation [20].

The cocreation of the intervention with the experts and service users allowed the design team to ensure that an acceptable intervention was developed. Involving users from the target group at the design stage can significantly contribute to the

development of interventions by highlighting aspects of the design that would have otherwise been missed [75,76]. However, due to time and financial constraints, it was not always possible to involve users as much as we would have hoped. Final testing of the website was carried out by colleagues in some cases, rather than individuals with fatigue. Testing the website with the target audience could improve implementation by further considering the burden of using the website and the levels of computer literacy required. We are keen to explore this further in our feasibility and pilot trials of the website [14].

Acknowledging the limitations of our design process, we therefore suggest that our method could potentially serve as a template, with the hope that researchers would continue to develop and refine this process.

Conclusions

This evidence-based Web-based program is the first intervention of its kind based on the self-regulation model theory, with the primary aim of targeting the representations of fatigue and enhancing self-management of CrF, specifically [33]. In line with the Medical Research Council (MRC) guidelines, the use of theory in developing the content was predicted to facilitate understanding of the causal assumptions underpinning the intervention [15]. The use of theory also reflects recent research which recognizes self-management as essential components for recovery of health and well-being in cancer survivorship [7,77].

The development of the intervention was informed by the MRC guidelines on developing complex interventions [15]. There is a need for the publication of more detailed descriptions of foundations that underpin complex interventions, promoting methodological rigor, and transparency in the design process [15,78]. This research sought to integrate psychological theory, existing evidence of effective interventions, empirically derived principles of Web design, and the views of potential users into the systematic planning and design of the intervention of an easy to use website for cancer survivors [1,5,7,19,75].

Conflicts of Interest

None declared.

Multimedia Appendix 1

Welcome screen of "Refresh" intervention.

[PNG File, 395KB - cancer_v3i2e8_app1.png]

Multimedia Appendix 2

Login Sucess Screen of the "Refresh" intervention.

[PNG File, 272KB - cancer_v3i2e8_app2.png]

Multimedia Appendix 3

Homepage of the "Refresh" intervention.

[PNG File, 484KB - cancer_v3i2e8_app3.png]

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Abbreviations

BCT: behavioral chenge technique
CBT: cognitive behavioral therapy
CrF: cancer-related fatigue
MS: multiple sclerosis
VRE: virtual research environment

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Original Paper

"Thanks for Letting Us All Share Your Mammogram Experience Virtually": Developing a Web-Based Hub for Breast Cancer Screening

Adam Galpin[1*], PhD; Joanne Meredith[1*], PhD; Cathy Ure[1*], MSc; Leslie Robinson[2*], EdD

[1]Directorate of Psychology and Public Health, School of Health Sciences, University of Salford, Salford, United Kingdom

[2]Directorate of Radiography and Occupational Therapy, School of Health Sciences, University of Salford, Salford, United Kingdom

[*]all authors contributed equally

Corresponding Author:
Adam Galpin, PhD
Directorate of Psychology and Public Health
School of Health Sciences
University of Salford
The Crescent
Salford, M6 6PU
United Kingdom
Phone: 44 161 2957146 ext 57146
Email: A.J.Galpin@Salford.ac.uk

Abstract

Background: The decision around whether to attend breast cancer screening can often involve making sense of confusing and contradictory information on its risks and benefits. The Word of Mouth Mammogram e-Network (WoMMeN) project was established to create a Web-based resource to support decision making regarding breast cancer screening. This paper presents data from our user-centered approach in engaging stakeholders (both health professionals and service users) in the design of this Web-based resource. Our novel approach involved creating a user design group within Facebook to allow them access to ongoing discussion between researchers, radiographers, and existing and potential service users.

Objective: This study had two objectives. The first was to examine the utility of an online user design group for generating insight for the creation of Web-based health resources. We sought to explore the advantages and limitations of this approach. The second objective was to analyze what women want from a Web-based resource for breast cancer screening.

Methods: We recruited a user design group on Facebook and conducted a survey within the group, asking questions about design considerations for a Web-based breast cancer screening hub. Although the membership of the Facebook group varied over time, there were 71 members in the Facebook group at the end point of analysis. We next conducted a framework analysis on 70 threads from Facebook and a thematic analysis on the 23 survey responses. We focused additionally on how the themes were discussed by the different stakeholders within the context of the design group.

Results: Two major themes were found across both the Facebook discussion and the survey data: (1) the power of information and (2) the hub as a place for communication and support. Information was considered as empowering but also recognized as threatening. Communication and the sharing of experiences were deemed important, but there was also recognition of potential miscommunication within online discussion. Health professionals and service users expressed the same broad concerns, but there were subtle differences in their opinions. Importantly, the themes were triangulated between the Facebook discussions and the survey data, supporting the validity of an online user design group.

Conclusions: Online user design groups afford a useful method for understanding stakeholder needs. In contrast to focus groups, they afford access to users from diverse geographical locations and traverse time constraints, allowing more follow-ups to responses. The use of Facebook provides a familiar and naturalistic setting for discussion. Although we acknowledge the limitations in the sample, this approach has allowed us to understand the views of stakeholders in the user-centered design of the WoMMeN hub for breast cancer screening.

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KEYWORDS

decision making; eHealth; cancer screening; qualitative research; social media; mammography

Introduction

Background

Web-based tools provide significant opportunity to improve cancer-related health communication across the whole cancer spectrum, from prevention and screening to living with and beyond cancer [1]. Successful implementation requires an understanding of how the particular affordances of Web-based applications allow new opportunities for increasing health-related knowledge and decision making. It is also important to understand the particular informational needs and emotional experiences of the intended users. This paper presents the study conducted by the Word of Mouth Mammogram e-Network (WoMMeN) group to develop a Web-based resource to improve knowledge of and decision making in breast cancer screening. We focus in this paper on our analysis of an online *design group* who were brought together as a means of understanding the needs of our stakeholders.

In breast cancer screening, information on both benefits and risks needs to be balanced in order to help women make choices about whether to get a mammogram. This is a complex issue because the benefits are frequently disputed, and the risks, for example, treating a low-grade disease that was never going to develop into a cancer [2], can be devastating. These controversies are hotly debated in the medical field and the supporting evidence is contradictory. Understandably, women report being confused about whether to undergo screening for breast cancer [3] and uptake figures for breast cancer screening in the United Kingdom have steadily declined for 4 years up to 2015 [4]. Individuals using the Internet for electronic health (eHealth) must navigate a variety of information sources and weigh up the validity of the sources [5]. In the case of screening, they are required to apply this information to estimate the perceived risk, physical and emotional discomfort, inconvenience and usefulness of the screening, and the psychological and practical implications of detection [1].

Web-based tools offer the potential to facilitate decision making around screening by providing resources for communication, information, and shared experiences. In a related context, Skjøth et al [6] conducted qualitative research on the factors salient to care providers and pregnant women when considering screening for Down syndrome. Some of the women in the study reported a preference for resources on the Internet and advice from family and friends over the information booklets they received. They were keen to hear the experiences of pregnant women and placed importance on finding reliable information in a single location. These results highlight the desire to access both experiential information from women in a similar position (consistent with the rise in peer-to-peer health care) [7] and reliable information within a single resource. In this context, and other sensitive and complex health contexts such as breast cancer screening, it is important to understand how users access, consume, and respond to information before designing a Web-based resource. However, it is also necessary to seek the views of the health professionals who have a stake in ensuring that their service users are reliably informed.

The WoMMeN project was initiated through recognition of the potential for a digital resource to facilitate women in making informed decisions regarding breast cancer screening and to help them make sense of the potentially confusing data available. A project committee was established that included mammographers, psychologists, expert patients and service users, marketing and legal specialists, and a Web designer. This multidisciplinarity follows from recommendations for an integrated approach to eHealth tool development [8,9] and aligns our methods with the principles of user-centered design (UCD). The importance of UCD has been recognized in a number of approaches to eHealth decision aids that have sought to understand the needs of stakeholders and users through development [6,10]. The road map of the Center for eHealth Research and Disease Management (CeHRes) described by van Gemert-Pijnen et al [11] provides arguably the most comprehensive framework for applying UCD to eHealth product design. The CeHRes road map promotes (1) gaining an understanding of the lives of end users and other stakeholders (contextual inquiry), (2) seeking a deeper understanding of the values of key stakeholders (value specification), (3) involving users in the development of a product (design), (4) developing an operational plan for the implementation of the technology (operationalization), and (5) evaluating the product (summative evaluation).

The CeHRes framework is a useful lens through which to understand how we have involved stakeholders throughout the design of the WoMMeN hub (see Multimedia Appendix 1). We explored initial ideas through focus groups with potential service users (contextual inquiry) and from these emerged the idea that an online forum would meet women's needs in seeking resources on mammography [12]. Potential features of the hub were ranked in importance in a modified card-sort by service users and practitioners. A beta version of the hub was developed and tested for usability issues with 6 service users (design), allowing tweaks before a wider launch. In addition, workshops have been run throughout the United Kingdom to address practitioners' concerns with interacting online with clients [13] (operationalization).

Objectives

The focus of this paper is on the novel approach we have taken to understand the key requirements, motivations, and anxieties of our stakeholders (the value specification phase in the CeHRes framework). In order to address difficulties in recruiting a face-to-face user design group from such a busy population, we decided to recruit a user design group through social media. This group was recruited in January 2015 and at the peak of the survey comprised 111 women (a roughly equal split of practitioners and nonhealth professionals). Members joined this closed Facebook group, which provided a naturalistic approach to understanding how women talked about breast cancer screening. The content from these conversations was analyzed

to extract topics and values that underpinned how the hub was to be designed. To our knowledge, this is the first time that social media has been used in this way in the context of eHealth product design. Although we found this a supportive way of facilitating talk about breast cancer screening, we additionally wanted to supplement the approach by administering a more structured set of questions via an online survey posted to the Facebook group.

This paper therefore presents two complementary analyses that utilize both natural talk and survey data. The aim of this paper is to report the utility of our approach within a UCD context, so we present here a critical perspective of our data analysis using these methods.

Methods

Design

The wider project adopted a mixed-methods approach through the combination of qualitative data from the Facebook group and survey and quantitative data from the survey. The analysis presented in this paper is based on the qualitative thematic framework analysis that we conducted using data from both the Facebook group and survey.

Participants

Facebook Group Participants

We took a pragmatic approach to recruitment. Each member of the research team, including practitioners, service users, and academics, used their own social media networks to advertise the project and recruit participants. To ensure we included the voice of a number of less well-represented groups, such as women with disabilities and women from black and ethnic minority groups, we also undertook more targeted recruitment via key informants from these groups who were known to us. However, we did not aim to stratify membership according to demographic information, and in this way, anyone was welcome to join. The only exclusions were men because of the potential that their inclusion may inhibit women in their discussions about breast health. There were 71 Facebook group members at the end point of the data sampling period.

Survey Participants

All Facebook group members were invited to take part in the survey. In total, 23 women participated; 12 were health professionals and 8 worked in breast cancer screening; 7 had received a cancer diagnosis and 6 had never had a mammogram.

Survey Materials

Survey responses were collected using an 11-part anonymous survey distributed through Bristol Online Survey. The first nine sections concerned different aspects of the hub design: (1) topics of information, (2) organization of information, (3) search options, (4) communication options, (5) access to health professionals, (6) own posting preferences, (7) privacy and security, (8) regulation, and (9) additional features. Each main question was followed by a number of different options as to how a particular aspect might be designed, followed by free text boxes asking participants to "explain the decisions behind your ratings." Question 10 was an additional free-text box asking whether there was anything else we had missed. Question 11 recorded professional background and mammography experience.

Survey Procedure

An invitation to take part in the survey was posted on the Facebook group. An introductory screen informed participants of the purpose of the survey and assured them that any questions could be ignored. The survey took approximately 20 min to complete.

Analysis

Facebook Data

All Facebook threads dated from February 2015 to July 2015 that related to breast cancer screening or the hub were extracted from the Facebook group. This amounted to 70 threads, with only those threads with more than 2 responses included in the analysis.

A total of 2 researchers independently analyzed the first 10 threads to identify topics of conversation. A consensus meeting was then held to construct the framework for analysis [14]. The framework comprised a number of themes identified during initial coding, and each theme was further divided according to group members' background (service user, mammographer, WoMMeN research group member, and nonmammographer health practitioner). The remaining threads were then split between the researchers who each coded them based on the framework. Additional topic themes were noted, and a final consensus meeting was held to confirm theme saturation and to ensure new themes were embedded within the framework.

Survey Data

The qualitative data from the free-text survey responses was analyzed thematically according to the process described by Braun and Clarke [15].

Results

The results of both the qualitative analysis from the Facebook group (denoted by thread number) and the analysis of qualitative answers to the survey (denoted by participant number) are presented here. In our analysis, we have also differentiated between health professionals (mammographers and health practitioners not working in breast cancer screening) and service users (nonhealth professionals who may or may not have had screening) to examine differences in stakeholder needs. From the data, two themes emerged: (1) the power of information and (2) the hub as a place for communication and support. In analyzing these themes, we hope to show the benefits of using an online user-design group.

Theme 1: The Power of Information

In this theme, the importance of having balanced information on the hub was discussed. Women in both the survey and on Facebook suggested that it was important to have relevant, factual information that could embolden them to make clear and informed decisions.

Health professionals expressed the view that providing enough information is key to empowering service users to make decisions around breast cancer screening:

> *...knowledge Is power.* [Facebook, thread 68, mammographer]
>
> *I think it's important to give women enough information about the screening process & examination so they are aware about what will happen when they attend.* [Survey, p5, mammographer]

The first quote comes from a mammographer on Facebook and was posted in response to a story about breast cancer death rates dropping in the United States. This initial message that "knowledge Is power" suggests that if women know that breast cancer screening may reduce rates of breast cancer death, they may be more likely to go for screening. In terms of designing the hub, then, having enough information about the right things is important; that is, not just the practical information but also information about why women should go for breast cancer screening. The second extract, also from a mammographer, further emphasizes that it is important for women to have enough information about the screening process. The fact that they suggest that women will need "enough" information about the process and examination implies that perhaps women do not always have this when they attend appointments.

However, we also found that some respondents highlighted that the information could potentially be misleading and threatening. One of the mammographers commented:

> *I think there is always scope to challenge/dispute/discuss what is reported in the media. Patients are so information hungry these days that we need to keep on top of what is being spread in the non-medical public domain to ensure its accuracy.* [Facebook, thread 8, mammographer]

This extract was posted on the Facebook group, and it orients to the fact that many people want a lot of information and will go to a variety of sites to gain this. She also notes, though, that there is a lot of inaccurate information in the public domain, particularly in the media, and staying aware of this information is important for practitioners.

However, health professionals do recognize that some women may prefer to avoid receiving too much information, as it can be overwhelming:

> *I appreciate many women are ostriches—that they would rather dig their head in the sand and not know until they have to.* [Survey, p23, health practitioner]
>
> *...some woman would be better off not knowing because once you know it's there it will effect [sic] your quality of life for most woman and we are still not sure which is safe to leave and even then I'm not sure I would just leave it.* [Facebook, thread 2, mammographer]

The first example is a response to a question about what information women would like to see on the hub. The respondent suggests that some women would prefer not to have all the relevant information until they need to. The second example is slightly different, in that it comes from a Facebook discussion about women going for screening and finding precancerous cells, which might take many years to develop into cancer, if at all. Here the argument is made that for some women it would be better not to know about these precancerous cells.

Overall, the health professionals in our sample emphasized the importance of women receiving accurate information about breast cancer screening but also acknowledge that some women wish to limit the information they have access to. Health professionals plausibly have experience of, and a professional interest in, the ways in which women manage health information. Nevertheless, we found similar suggestions regarding information made by service users:

> *Knowledge of the whole process will help to allay fears.* [Survey, p21, service user]

This extract, from a woman with no experience of screening, supports the same view as the health professionals. She suggests that knowledge of the "whole process" is needed, which conceivably relates to the screening appointment, receiving results, what happens if you are recalled, and so on.

Service users also acknowledged the potential for information to be seen as a threat. The following extracts are both from women who had a cancer diagnosis:

> *Accuracy of mammograms—the statistics around breast cancer, risk factors, likelihood of its return, and the different types of breast cancer are mindblowing. In this sense I choose to limit how much information I seek out.* [Survey, p16, service user]
>
> *It would be better for them to be able to search for a particular area rather than having trawl through a lot of information and questions that may not be relevent [sic] to them at that time.* [Survey, p21, service user]

Here both the participants suggest that there is a huge amount of information available about breast cancer screening, and this can be overwhelming. Their cancer diagnoses may be relevant to this perspective as we would expect breast cancer screening information to have a particular emotional resonance. The service users' extracts imply a desire for *control* over when and which information is accessed. This contrasts with the extract from the health professional suggesting women were "ostriches" who did not want to be exposed to some information.

Service users raised the issue of having access to patient stories, which was not prominent in the responses of health professionals:

> *Patient stories...positive and negative...are always powerful. When a professional wants to put info out there, personally think they should also be obliged to include case histories "for" and "against."* [Facebook, thread 8, service user]

The poster argues that including patient stories on the hub can be helpful for users. This is, then, a different type of information, in that it is not merely information about the screening process

or managing factual inaccuracies, but rather experiential information.

Analysis of the comments around information allowed some key principles to emerge to inform the design of the hub. Both the health professionals and service users recognized that although information is empowering, it can also be misleading or emotionally distressing. Health professionals more often emphasized the importance of factual materials, whereas service users called for experiential information. This highlights the need to provide a variety of sources for women on breast cancer screening, which is clearly indicated in this quote from a member of the research team:

> *This is why an on-line hub where women can have as little or as much as they want and in whatever format they want is better [then I would say that wouldn't I!].* [Facebook, thread 56, member of the research team]

Our strategies for applying this evidence are described in the discussion.

Theme 2: The Hub as a Place for Communication and Support

The second theme that emerged from the survey and Facebook data was that the hub should also be a place for communication between women on the issue of breast cancer screening and for women to be able to support one another. However, the type of communication emphasized differed between service users and health professionals. This is reflected in the first two extracts presented here, from a potential service user with no experience of breast cancer screening:

> *I think opportunities to communicate, share and support each other.* [Survey, p4, potential service user]
>
> *It's invariably easier to deal with problems/concerns when you have someone/people in similar situations to turn and relate to.* [Survey, p4, potential service user]

This respondent suggests that an important part of the hub will be the chance for women who are invited to, and attend, breast cancer screening to support one another. A number of studies have noted the benefits of online forums in facilitating peer-to-peer support in symptomatic populations [16-18], and our results suggest this is also valued for asymptomatic populations making screening decisions.

Although lay people and service users were keen to emphasize support among peers, health professionals focused more on the potential for interaction between the screening population and practitioners:

> *I'm hoping that better quality information ad [sic] conversation going both ways from the women and the staff will help us all [...] we will at least be able to provide more support and information than we are able in the 6 short minutes available during the exam.* [Facebook, thread 50, mammographer]
>
> *I think it's vital that health professionals be able to communicate with users in a variety of ways to suit their needs.* [Survey, p3, mammographer]

The first example suggests that practitioners often do not have enough time to speak in detail to women who go for screening. Therefore, having a Web-based resource could allow practitioners to achieve this without the time constraints of offline interactions. The second quote is from a mammographer in response to a question about how they would like to communicate with service users online. They are recognizing the need for a variety of routes for interaction, but it is not clear from the quote whether they are referring to the needs of the health professionals or the service users.

Despite both health professionals and service users being enthusiastic about the need to offer communication and support, there was also recognition of the potential pitfalls of doing this online and particularly in a text-only form of interaction:

> *I'd by concerned about inappropriate comments or misinterpreted dialogue.* [Facebook, thread 6, service user]
>
> *Virtual communication in an open community, existing without facial cues & intonation, will always present danger. It's a bit like reading a novel, everyone's experience is individual to how the reader interpreted the characters.* [Survey, p3, mammographer]
>
> *Discussions can get heated.* [Survey, p11, mammographer]

Participants noted a number of concerns about online communication, including inappropriate comments and the potential for arguments. Of particular concern was the lack of facial cues, which participants suggested might lead to misinterpretation of posts and, implicitly, to arguments. From the analysis, we noted that service users were interested in supporting each other, whereas health professionals were interested in supporting service users. Therefore, the hub should provide a way for both service users and health professionals to communicate with each other.

Discussion

Principal Findings

In this research, we sought to use a novel method to inform the design of a Web-based resource to aid decision making around breast cancer screening. We drew on the CeHRes framework [11] to inform our methodology, and we have reported here how we addressed the *value specification* of stakeholders through a social media–based user design group. This approach allowed us to involve users in the design of a resource for breast cancer screening through analyzing the comments within a Facebook group, in addition to survey responses.

Our findings showed that women want both information and support around decision making in breast cancer screening. Health professionals and service users showed the same broad concerns overall. However, there were subtle differences in the way these were expressed, revealing potentially different needs

in a Web-based resource. This is highlighted, for instance, through the emphasis on the health professionals' concern over accurate information provision and the service users' focus on experiential information and control over information consumption. Therefore, the design of the hub was influenced by these different needs. As both service users and health professionals valued access to accurate information, all information posted on the site is curated for accuracy by experienced mammographers. We suggest that any health resource seeking buy-in from health professionals should acknowledge their stake in managing the misleading information that may exist in the public domain. Our findings that both health professionals and service users recognized the need for choices around what information is accessed led us to incorporate different types of information on the hub in distinct areas. For example, the breast cancer screening process was mentioned by both groups of stakeholders, and therefore, we have included a distinct area within the hub describing the mammogram. We have also included tabs for general information, frequently asked questions, and a research area for women who want to access original papers. Service users valued experiential information, and this is supported on the hub through a blog and forum so women can access and share a range of experiences. The blog and forum shared a dual purpose. They allowed women to interact regarding their experiences, which the service users in particular suggested as important. The forum also allowed practitioners to engage in discussion and provide information or to point women to sources of accurate information. Women's concerns about the potential issues regarding discussions becoming heated are managed through the forum being moderated by members of the WoMMeN research team. There is also a *pinned* ethical statement at the entry point to the forum, which reminds posters of their ethical obligation to respect other people's views and sensitivities.

One benefit of having a user group that includes people who are *naïve* participants is that they may think about aspects of an online group, such as peer-to-peer support, which health professionals and researchers might conceivably consider a lower priority relative to factual information. However, the downside of having users with no experience of, in this case, breast cancer screening is that perhaps they will not understand precisely what issues may arise from that process and so their responses may not come from experience. Our approach is evidence that stakeholders with different levels of domain expertise can be engaged in online dialogue together to produce useful insights into their particular needs.

One of the strengths of our approach was how the Facebook group data and the directed survey questions compensated for the limitations of each method. The survey allowed for direct questions to be asked of the group, but surveys are also "inherently limited by the questions they ask" [19]. By also using the Facebook group, it meant we were not constrained to just ask direct questions, but we could also draw upon naturally emerging topics of conversation. There are a number of benefits to using more naturalistic data in these contexts; they allow for novel questions and issues that are of interest to the participants to be raised, and they reduce the role of the researcher in the interaction [20]. The Facebook group also meant that the members of the user design group were not constrained by time and space, and so they could engage in the group at a time of their choosing and in the comfort of their own home [21]. It also meant that we could take a more longitudinal approach when consulting with our participants about design choices. The Facebook group, however, was not anonymous. Members of the research team posted in that group, and their presence could potentially have limited discussions. Therefore, the survey allowed us to create an anonymous space for respondents to indicate what they wanted in the hub.

A second benefit of the online design group was the ability to triangulate our findings from both types of data [22]. The naturally occurring discussion in the Facebook group often supported the comments that were made when asked directly through the survey. For instance, women in the survey expressed their apprehension about misinterpreted dialogue, and this was also raised naturalistically in the Facebook group where the issues of the lack of interpretation and facial cues were discussed. This suggests it was a *natural* concern of participants rather than just one that participants raised when questioned. It is noteworthy that such comments came from the Facebook group where individuals were interacting with relatively little heated debate, although there were, of course, disagreements. In fact, we saw participants providing each other with support when group members went for mammograms (eg, "thanks for letting us all share your mammogram experience virtually"). In general, the lack of prominent differences between the two datasets was an interesting feature of our findings.

Limitations

One important consideration is the characteristics of participants in a social media–based design group. Individuals who sign up to research are often highly motivated and knowledgeable [23,24] and as such there may be self-selection bias. The women in the Facebook group had often had experience of breast cancer or were health professionals and were particularly health literate. That they were therefore motivated by the topic and generally positive about the importance of attending breast cancer screening may mean that they were not typical of women who are invited for breast cancer screening. Therefore, when using these methods of user design, it is important to take account of the fact that many of the people involved in a user design group may actually be very motivated and knowledgeable. An implication is that they may sometimes make decisions about what they think should be on the hub based on what *women in general* wanted rather than what they, as motivated, knowledgeable women wanted. However, this issue is not exclusive to online research and also affects offline patient and public involvement groups [25]. What might be problematic for our particular approach is whether the level of Internet literacy of our group is reflective of everyone invited for breast cancer screening and, in particular, the women over 50 who may not use Facebook or other social media [26].

A further limitation involves the presence of the research team within the Facebook design group. It could be argued that this potentially impacted on how free the women in the group felt to be able to voice negative opinions about the hub. However,

each individual, including those from the research team, has multiple identities in relation to the topic. For instance, a member of the research team could also have experience of being screened, of having cancer, and of being a health professional. Therefore, within the group, they were not always acting as a member of the research team but brought their own experiences to the discussions. This, along with off-topic posts (eg, sharing recipes or cultural topics), potentially reduced the salience of the group as a research context and the research team as researchers.

Conclusions

The data have enabled us to create the WoMMeN hub with features women told us they (and other women) wanted. Our analysis allowed us to see that information and support are valued within the context of breast cancer screening by both health professionals and service users. However, by also acknowledging the orientation of the respondents, differences in the way they prioritized these emerged. Web-based decision aids provide valuable opportunities to empower service users. However, to facilitate their success, our data suggest they should embed opportunities for experts to dispel misleading information while allowing service users to exchange experiences. Therefore, our work has shown that it is essential to understand that *one size does not fit all* and designers need to be aware of the requirements of specific stakeholders through a user-centered, participatory approach. The methods we have reported here may help in this regard by providing a convenient and accessible online environment in which insight can be gained from natural dialogue and validated by direct questioning.

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Authors' Contributions

LR initiated the wider project, created and developed the user design group, and sought ethical approval for this study. AG designed, conducted, and analyzed the survey and cowrote the draft of the manuscript with JM and LR. LR and CU conducted the framework analysis. JM synthesized the thematic analysis. All authors contributed to the further drafts of the manuscript and approved the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

A PDF document containing screenshots of the Wommen Hub.

[PDF File (Adobe PDF File), 1MB - cancer_v3i2e17_app1.pdf]

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Abbreviations

CeHRes: Center for eHealth Research and Disease Management
eHealth: electronic health
UCD: user-centered design

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Original Paper

A Lifestyle Intervention via Email in Minority Breast Cancer Survivors: Randomized Parallel-Group Feasibility Study

Raheem J Paxton[1], MSc, PhD; Richard Hajek[2], PhD; Patricia Newcomb[3], PhD; Megha Dobhal[4,5], MPH; Sujana Borra[4,5], MPH; Wendell C Taylor[6], MPH, PhD; Deborah Parra-Medina[7], PhD; Shine Chang[8], PhD; Kerry S Courneya[9], PhD; Gladys Block[10,11], PhD.; Torin Block[10], BS; Lovell A Jones[12], PhD

[1]Department of Community Medicine and Population Health, The University of Alabama, Tuscaloosa, AL, United States
[2]Center for Health Equity and Evaluation Research, The University of Texas MD Anderson Cancer Center, Houston, TX, United States
[3]Texas Health Resources, Texas Health Harris Methodist Hospital, Fort Worth, TX, United States
[4]School of Public Health, University of North Texas Health Science Center, Fort Worth, TX, United States
[5]Institute of Healthy Aging, University of North Texas Health Science Center, Forth Worth, TX, United States
[6]Department of Health Promotion and Behavior Sciences, The University of Texas Health Science Center at Houston, Houston, TX, United States
[7]Department of Mexican American & Latina/o Studies, The University of Texas at Austin, Austin, TX, United States
[8]Department of Epidemiology, The University of Texas MD Anderson Cancer Center, Houston, TX, United States
[9]Faculty of Physical Education and Recreation, University of Alberta, Edmonton, AB, Canada
[10]Turnaround Health, a division of NutritionQuest, Berkeley, CA, United States
[11]School of Public Health, University of California at Berkeley, Berkeley, CA, United States
[12]School of Public Health, Texas A&M Health Science Center, Bryan, TX, United States

Corresponding Author:
Raheem J Paxton, MSc, PhD
Department of Community Medicine and Population Health
The University of Alabama
1132 Northeast Medical Bldg
Tuscaloosa, AL, 35401
United States
Phone: 1 205 348 6857
Email: rpaxton@ua.edu

Abstract

Background: Our data have indicated that minority breast cancer survivors are receptive to participating in lifestyle interventions delivered via email or the Web, yet few Web-based studies exist in this population.

Objective: The aim of this study was to examine the feasibility and preliminary results of an email-delivered diet and activity intervention program, "A Lifestyle Intervention Via Email (ALIVE)," delivered to a sample of racial and ethnic minority breast cancer survivors.

Methods: Survivors (mean age: 52 years, 83% [59/71] African American) were recruited and randomized to receive either the ALIVE program's 3-month physical activity track or its 3-month dietary track. The fully automated system provided tools for self-monitoring and goal setting, tailored content, and automated phone calls. Descriptive statistics and mixed-effects models were computed to examine the outcomes of the study.

Results: Upon completion, 44 of 71 survivors completed the study. Our "intention-to-treat" analysis revealed that participants in the physical activity track made greater improvements in moderate to vigorous activity than those in the dietary track (+97 vs. +49 min/week, $P<.001$). Similarly, reductions in total sedentary time among those in the physical activity track (−304 vs. −59 min/week, $P<.001$) was nearly 5 times greater than that for participants in the dietary track. Our completers case analysis indicated that participants in the dietary track made improvements in the intake of fiber (+4.4 g/day), fruits and vegetables (+1.0 cup equivalents/day), and reductions in saturated fat (−2.3 g/day) and trans fat (−0.3 g/day) (all $P<.05$). However, these improvements in dietary intake were not significantly different from the changes observed by participants in the physical activity track (all $P>.05$). Process evaluation data indicated that most survivors would recommend ALIVE to other cancer survivors (97%), were satisfied with ALIVE (82%), and felt that ALIVE was effective (73%). However, survivors expressed concerns about the functionality of the interactive emails.

Conclusions: ALIVE appears to be feasible for racial and ethnic minority cancer survivors and showed promising results for larger implementation. Although survivors favored the educational content, a mobile phone app and interactive emails that work on multiple email domains may help to boost adherence rates and to improve satisfaction with the Web-based platform.

Trial Registration: ClinicalTrials.gov NCT02722850; https://clinicaltrials.gov/ct2/show/NCT02722850 (Archived by WebCite at http://www.webcitation.org/6tHN9VsPh)

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KEYWORDS

breast neoplasm; African Americans; diet; feasibility study; physical activity; posture; program evaluation; Internet; computer tailoring; email

Introduction

Breast cancer survivors suffer from high rates of overweight or obesity and often do not meet current guidelines for physical activity and intake of fruits and vegetables [1-3]. Poor lifestyle habits of breast cancer survivors contribute to diminished health-related quality of life (HRQoL), increased risk of comorbid conditions, cancer recurrence, and premature mortality [2]. Unfortunately, even though minority breast cancer survivors suffer disproportionately from these circumstances, they remain underserved and underrepresented in epidemiological and intervention research [4-6]. Therefore, studies designed to improve the lifestyle behaviors of minority cancer survivors are warranted.

Comprehensive reviews and meta-analytic studies have indicated that clinic-based or in-person studies intended to improve diet, exercise, and HRQoL in cancer survivors have had promising results [2,7-10]. However, distance and time are fundamental barriers to participating in these studies [3,11]. Several researchers have advocated for home-based interventions that include telephone counseling or tailored print materials [12,13]. Whereas many home-based programs have led to significant improvements in healthy lifestyle behaviors [14-20], they are not always sustainable because telephone counseling and mass mailings require significant personnel effort. Studies that utilize the Web offer a potential to overcome the challenges (cost, time, and distance) experienced in traditional home-based interventions [21]. Given these benefits, there has been an increase in advocacy for Web-based interventions [22,23], especially those designed for cancer survivors [24-31]. Previous Web-based studies developed for cancer survivors have observed significant improvements in lifestyle behaviors [28,29,31-34].

Despite the recent surge in Web-based interventions among cancer survivors, few studies have focused on minority cancer survivors [34]. Also, the majority of the studies have focused primarily on physical activity [25-28,30,31], with only a few intervening on dietary intake [24,29,32]. Therefore, we proposed to address this limitation by testing the feasibility and preliminary effects of a previously developed fully automated system that utilizes weekly emails, self-monitoring and goal-setting tools, and automated counseling phone calls to improve physical activity and dietary intake [35]. We utilized an evidence-based program entitled "A Lifestyle Intervention Via Email" (ALIVE) [36]. In previous research, ALIVE demonstrated improvements in moderate to vigorous physical activity and fruit and vegetable consumption as well as reductions in saturated and trans fat in a sample of healthy worksite employees. In this study, participants were randomized to either a physical activity or a dietary track. We hypothesized that survivors randomized to the physical activity track would experience greater improvements in moderate and vigorous physical activity than those randomized to the dietary track. Similarly, we hypothesized that survivors randomized to the dietary track would experience greater improvements in fruit and vegetable consumption and reductions in saturated and trans fats than those randomized to the physical activity track.

Methods

Recruitment and Consent

Minority cancer survivors were recruited using nonprobability sampling techniques. Survivors were identified via word of mouth, existing relationships with community-based organizations, and cases ascertained from tumor registries in the North Texas metropolitan area. Eligibility criteria included (1) a previous diagnosis of breast cancer, (2) being at least 18 years old at study enrollment, (3) having completed treatment (except hormonal therapy) at least 6 months before study enrollment, and (4) receptivity to participating in a Web-based intervention study. Also, those who self-identified as African American, Hispanic, or of mixed ethnicity (ie, Asian and African American or African American and non-Hispanic white) were eligible for this study. We used a rolling recruitment process for screening and consenting participants. Survivors completed the screening and consent process from June 2014 to October 2015 using a multi-gated approach. All identified survivors were screened with Web-based surveys that assessed prior history of cancer, lifestyle factors (ie, diet and exercise), and physical activity readiness. The Physical Activity Readiness Questionnaire (PAR-Q) was used to identify contraindications to physical activity[37]. In the event where contraindications were identified, participants were asked to provide information indicating physician approval. Survivors with invalid data or who were not identified as cancer survivors were ineligible. Once survivors completed the screening survey, they were directed to a separate link containing a Web-based consent form. The screening and consent links were distinct from those later delivered for the ALIVE website. Ethical approval by the University of North Texas Health Science Center and participating health care institutions was established before enrolling survivors (Clinical trial registration number, NCT02722850).

Randomization and Enrollment

After participants completed the screening and consent process, a random number generator was used to randomize survivors to either a 3-month physical activity or a 3-month dietary track. Survivors were then sent track-specific enrollment links (ie, physical activity or dietary intake) to begin the ALIVE intervention. Participants in the dietary track could further choose between changing their dietary fat and added sugar intake or their fruit and vegetable intake. Data from participants working on both dietary behaviors were treated as one diet track for this analysis. A total of 71 minority survivors were randomized with equal probability to each track. Survivors received a US $20 incentive for completing each assessment. Thus, if they completed the baseline and follow-up assessment, they received a total of US $40.

Study Goals

Survivors in the physical activity track were encouraged to meet or exceed current federal recommendations for physical activity (eg, ≥150 min of moderate to vigorous physical activity per week). Survivors in the fruit and vegetable subtrack were encouraged to meet or exceed current recommendations for fruit and vegetable intake (eg, ≥3.5 cup servings of fruit and vegetable consumption). Survivors in the fats and added sugar track were encouraged to decrease intake of saturated and trans fats, decrease added sugars, and increase the intake of "good" fats and carbohydrates to meet or exceed these health recommendations (ie, ≤50 g/day of added sugars and ≤10% of calories from saturated fat) [38]. Content and messages provided to survivors were track specific and designed to promote a target behavior or behaviors.

Intervention

ALIVE was developed in collaboration between the Kaiser Permanente of Northern California Division of Research and NutritionQuest. No tailoring or modifications were made to the original program for this study. ALIVE was a theory-based coaching system derived from the principles of various theoretical models including the social cognitive theory [39,40], goal-setting theory [41], social marketing [42], and the transtheoretical model [43]. It was designed to enable participants to break up large goals into small achievable goals that could be accomplished weekly. ALIVE was delivered to survivors via an individualized website and interactive emails delivered weekly. At baseline, survivors were asked to complete a diet and activity health risk assessment. The risk assessment provided tailored feedback based on assessed levels of diet and activity and a planning tool to guide improvements in track-specific behaviors. Behavior change strategies such as goal setting, self-monitoring, rewards, cues to action, and repetition were incorporated throughout the program. Functions and features of the ALIVE program were identical across tracks, whereas content (eg, recommended goals and health education materials) differed by track. ALIVE uses participant-reported diet and activity behaviors to individualize the weekly goals it recommended to participants. A brief description of the ALIVE components are reported in Table 1.

Measures

Physical Activity and Sedentary Behavior

The Physical Activity Questionnaire (PAQ) was adapted from the Cross-Cultural Activity Participation Study (CAPS) Questionnaire [44]. It comprised 34 domain-specific activities (ie, household and caregiving, sedentary, transportation-related activities, and leisure and sport-related activities). Survivors were asked to indicate how many days per week and minutes per day they participated in each of the activities in a typical week. For the purpose of this study, minutes of moderate to vigorous physical activity per week were utilized as our physical activity outcome. In addition, estimates were derived from several forms of sedentary behavior (ie, total, discretionary, television-viewing, and other), which served as a separate outcome. Test-retest reliability of the instrument utilized in the original ALIVE study indicated adequate reliability [35]. Physical activity and sedentary behaviors were assessed at the baseline and 3-month assessment via the ALIVE system.

Dietary Intake

The dietary questionnaire queried participants on the intake of 35 commonly consumed foods identified as significant contributors to the intake of fruits and vegetables, added sugars, and saturated and trans fats in the National Health and Nutrition Examination Survey [45]. Survivors were asked to report the frequency and portion size of each of the 35 items and the subtype of select items (eg, diet soda vs non diet soda). The items included commonly consumed foods (eg, hamburgers), fruits and vegetables, nuts, grains (eg, cereals), processed meats (eg, hot dogs), sweets (eg, candy, pastries, and cookies), dairy (eg, milk, eggs, and cheese), and juices (eg, 100% fruit juice and Hi-C). The response scale ranged from items they consumed multiple times daily to items they consumed only a few times per month. Nutrient estimates were calculated based on consumption patterns and usual portion sizes consumed. The resulting nutrient estimates were derived from established databases [46,47]. The dietary items had acceptable test-retest reliability in the original ALIVE study [35]. Dietary intake was assessed at the baseline and 3-month assessment via the ALIVE system.

Process Evaluation and Feasibility

Survivors were asked to report on their satisfaction with components of the ALIVE system in a separate Web-based survey. Satisfaction was rated on a 5-point Likert-type response scale ranging from 1 (very dissatisfied) to 5 (very satisfied). We also included a separate overall satisfaction question. We used one question to assess the perceived effectiveness of ALIVE to change health behaviors and another question to assess whether they would recommend ALIVE to other cancer survivors (yes or no). Finally, we included open-ended questions that provided survivors with the opportunity to report on three likes and three dislikes about the ALIVE program. Our process evaluation facilitated our ability to assess the following components of feasibility: acceptability (ie, satisfaction), demand (ie, adherence to website usage), implementation and practicality (ie, success or failure of execution reported in the

qualitative responses), and limited efficacy (ie, change scores and effect sizes) [48].

Sociodemographic and Medical Data

These self-report data were collected during the screening survey. The data included items related to age, education, employment status, age at diagnosis, disease stage at diagnosis, and comorbid conditions. We summed the number of comorbid conditions (ie, arthritis, diabetes, high blood pressure, heart disease, and high cholesterol) to create a single continuous variable.

Table 1. Components of the ALIVE (A Lifestyle Intervention Via Email) program by study track.

Features	Physical activity	Dietary intake
Individual tailoring: Information used to tailor content was based on the baseline diet and physical activity survey.	• Preference for facility-based or home-based exercises • Stage of physical activity readiness • Social support for exercise • Physical activity barriers • Suggestions to reduce sedentary behavior • User home page	• Habits related to cooking and eating out • Stage of dietary readiness • Specific foods consumed • Social support for healthy eating • Dietary barriers • Suggestions to reduce the top three sources of problematic nutrients • User home page
Tailored goal setting: Content encouraging progress toward goal attainment. New goals were set once old ones were accomplished.	• Weekly emails suggesting four to six small-step goals tailored to characteristics mentioned above (eg, I will walk 5 min at lunch time today) • Queries about physical activity goal achievement	• Weekly emails suggesting four to six small-step goals tailored to characteristics mentioned above (eg, I will have a salad at lunch one day this week) • Queries about dietary goal achievement
Midweek reminders	• Reminded survivors of their physical activity goals	• Reminded participants of their dietary goals
Tips: Tips sent out weekly.	• Tips provided information related to achieving physical activity goals and overcoming specific physical activity barriers	• Tips provided information related to achieving dietary goals and overcoming specific dietary barriers
Goal tracker: Tracks which goals survivors achieve.	• Tracked goals related to the frequency, type, and duration of physical activity	• Tracked goals related to the frequency, type, and quantity of dietary nutrients
Simulation tool: An interactive feature of the ALIVE website for simulating effects of recommended goals	• Allowed the participant to simulate how changing the frequency, quantity, or type of specific activities impacts total physical activity levels	• Allowed the participant to simulate how changing the frequency, quantity, or type of specific foods or beverages impacts total nutrient levels
Health notes: Each week, a different topic was discussed.	• Topics included research on the relationship between physical activity and various health outcomes	• Topics included research on the relationship between a healthy diet and various health outcomes
Provisions for social support: Weekly goals and tips encouraging survivors to build a support systems with friends and family members. Chat rooms were available for participants to discuss problems and offer solutions to each other.	• Provided suggestions such as walks with colleagues at lunch time • Allowed survivors to engage and troubleshoot physical activity barriers and solutions.	• Provided suggestions to eat healthy meals with friends and family • Allowed survivors to engage and troubleshoot dietary barriers and solutions.
Automated phone calls: 3- to 5-min calls that facilitated goal setting, provided positive words of encouragement, and emphasized stage specific processes of change. Survivors also queried about personal barriers and goals.	Calls encouraged: • Scheduling physical activity • Overcoming physical activity barriers • Making public commitments to be active • Identifying a workout partner • Reporting your physical activity achievements to others • Encouraging friends to hold you accountable to activity goals	Calls encouraged: • Planning healthy meals • Overcoming dietary barriers • Making public commitments to consume a healthy diet • Identifying a friend who would go out and consume a healthy meal with you • Reporting your dietary achievements to others • Encouraging friends to hold you accountable to your dietary goals

Statistical Analysis

Descriptive statistics were computed to describe the study population. Chi-square tests for independence and Fisher exact tests were used to determine whether there were categorical differences in the sociodemographic and medical variables between study tracks. Subsequent nonparametric Wilcoxon rank-sum tests were computed to determine whether there were mean or median differences in the continuous outcomes at baseline. Generalized mixed-effects models (PROC GLIMMIX) were used to estimate within and between-group changes in study outcomes over time. Given that many of the outcomes were nonnormal, log-normal or Poisson distributions were specified. The effects in the model comprised time, track, time by track interaction, and significant covariates identified in the initial analyses. Furthermore, survivors nested within study tracks were treated as a random effect. Cohen *d* values were also computed to estimate the effect size. Separate analyses were conducted for cases with complete data and for those where an intention-to-treat (ITT) protocol was applied. To account for missing data in our intention-to-treat analysis, the last observation was carried forward. Furthermore, descriptive statistics were computed for process evaluation data, and *t* tests were used to make comparisons between the two study tracks. All data were analyzed using Statistical Analysis System (SAS) version 9.3 (SAS Institute Inc, Cary NC), and statistical significance was determined a *P* value of ≤.05 with a two-sided test.

Results

Descriptive Statistics

Recruitment and Consent

In total, 162 minority survivors expressed interest in participating in the study, but only 71 of them (43.8%, 71/162) received the allocated intervention materials (see Figure 1). Unfortunately, 86 of the 162 persons who expressed interest in the study provided incorrect email addresses (N=13) or failed to return follow-up emails and phone calls (N=73). The randomized survivors were on average 52 years old at study enrollment, which was 8 years after initial cancer diagnosis. Most were African American (83%, 59/71), college educated (65%, 46/71), and diagnosed with regional stage disease (54%, 38/71). Most failed to meet guidelines for intake of fruit and vegetables (72%, 51/71) and saturated fat (61%, 43/71). Roughly, half were obese (52%, 37/71), whereas a surprising number (63%, 45/71) were already meeting current guidelines for physical activity at baseline (these data are not shown).

Figure 1. Consolidated standards of reporting trials (CONSORT) diagram.

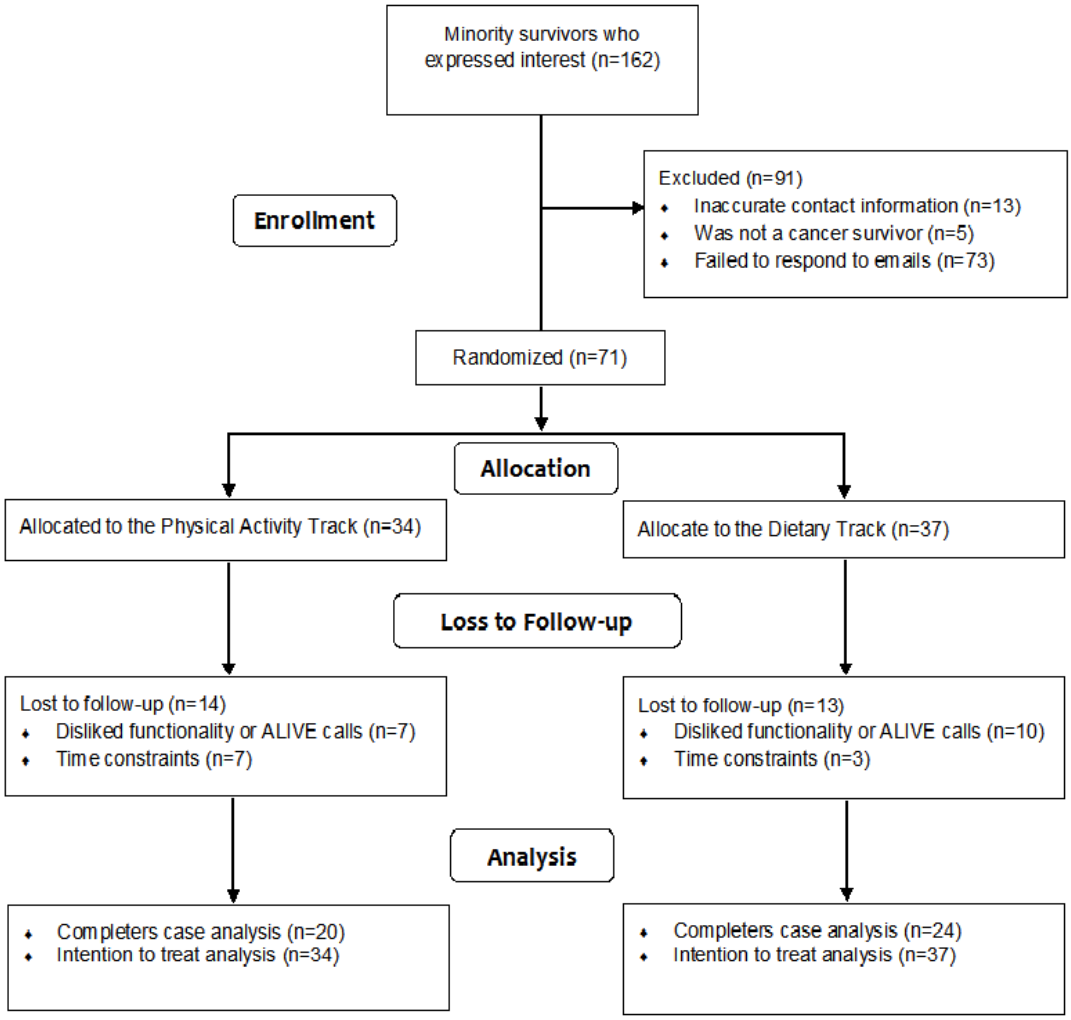

Table 2. Descriptive statistics comparing completers and noncompleters at baseline.

Variables	Total sample N=71	Completers n=44	Noncompleters n=27	*P* value[a]
Mean age (SD [b])	52.2 (8.6)	52.0 (7.8)	52.6 (9.9)	.62
Median and range of age	53 (26-72)	52 (32-69)	54 (26-72)	-
Mean age at diagnosis (SD)	43.9 (8.9)	43.3 (7.2)	44.8 (11.2)	.21
Mean years out from diagnosis (SD)	8.4 (6.5)	8.8 (6.9)	7.7 (5.8)	.57
Race or ethnicity, n (%)				.86
African American	59 (83)	36 (61)	23 (39)	
Hispanic	8 (11)	5 (63)	3 (37)	
Mixed	4 (6)	3 (75)	1 (25)	
Currently employed, n (%)	51 (72)	33 (75)	18 (67)	.45
Education, n (%)				.20
College graduate	46 (65)	31 (70)	15 (56)	
Stage, n (%)				.60
Localized	14 (20)	9 (21)	5 (19)	
Regional	38 (54)	23 (52)	15 (56)	
Distant	19 (26)	12 (27)	7 (25)	
Treatment, n (%)				
Surgery	67 (94)	41 (93)	26 (96)	.37
Radiation	49 (69)	30 (68)	19 (70)	.85
Chemotherapy	53 (75)	33 (75)	20 (74)	.93
Hormone	31 (44)	19 (43)	12 (44)	.92
Number of comorbidities, mean (SD)	0.8 (0.9)	0.8 (1.1)	0.7 (0.7)	.93
Median and range of comorbidities	1 (0-4)	1 (0-4)	1 (0-2)	-
Select lifestyle behaviors, mean (SD)				
Body mass index	30.8 (6.0)	30.5 (5.8)	31.3 (6.6)	.66
Fruit and vegetable intake in cup servings	2.8 (1.6)	2.7 (1.6)	3.0 (1.6)	.48
Fiber intake in g/day	16.4 (8.1)	16.2 (7.9)	16.7 (8.6)	.84
Saturated fat in % calories	11.8 (7.7)	11.8 (7.7)	11.7 (7.9)	.84
Minutes of moderate to vigorous physical activity/week	222 (272)	240 (233)	194 (329)	.19
Total sedentary minutes/week	1462 (886)	1412 (853)	1554 (949)	.65

[a]Categorical *P* values are based on chi-square or Fisher exact test, whereas continuous *P* values are based on nonparametric Wilcoxon rank-sum test.
[b]SD: standard deviation.

Attrition at the 3-month assessment was 38% (27/71), with no differences in attrition observed between completers and noncompleters on lifestyle, treatment-related variables, and sociodemographic characteristics (all *P*>.05). Descriptive statistics comparing completers and noncompleters are described in Table 2.

Baseline Differences Between Study Tracks

At the baseline assessment, Hispanic survivors were more likely to be randomized to the physical activity track, and mixed race individuals were more likely to be randomized to the dietary track (*P*=.02). Descriptive statistics comparing survivors in the diet and physical activity tracks are reported in Table 3.

Table 3. Descriptive statistics of participants enrolled in ALIVE (A Lifestyle Intervention Via Email) by study tracks at baseline.

Variables	Physical activity N=34	Diet N=37	*P* value[a]
Dropout, n (%)	14 (41)	13 (35)	.60
Mean age (SD[b])	52.7 (8.4)	51.8 (8.9)	.70
Mean age at diagnosis (SD)	44.6 (7.8)	43.3 (9.9)	.52
Mean years out from diagnosis (SD)	8.2 (5.6)	8.5 (7.1)	.96
Race or ethnicity, n (%)			.02
African American	27 (79)	32 (86)	
Hispanic	7 (21)	1 (3)	
Mixed or other	0 (0)	4 (11)	
Employment, n (%)	26 (76)	25 (68)	.41
Education, n (%)			
College graduate	25 (74)	21 (57)	.14
Number of comorbidities, mean (SD)	0.8 (0.8)	0.8 (1.1)	.57
Stage, n (%)			.16
Localized	10 (29)	4 (11)	
Regional	16 (47)	22 (59)	
Distant	8 (24)	11 (30)	
Treatment, n (%)			
Surgery	31 (91)	36 (97)	.34
Radiation	23 (68)	26 (70)	.81
Chemotherapy	22 (65)	31 (84)	.07
Hormone	15 (44)	16 (43)	.94
Lifestyle behaviors, median (25%-75%) [c]			
Body mass index	29.8 (25.8-34.1)	31.0 (25.8-35.8)	.50
Fruit and vegetable intake in cup servings	2.5 (1.4-4.1)	2.8 (1.5-3.6)	.80
Fiber intake in g/day	15.8 (10.7-19.7)	15.4 (10.2-21.6)	.86
Sugar in g/day	14.8 (7.2-44.5)	24.5 (14.1-51.3)	.19
Carbohydrates in g/day	113.7 (84.8-197.5)	142.2 (106.6-186.0)	.28
Trans fat in % calories	0.4 (0.2-0.8)	0.5 (0.3-0.9)	.21
Saturated fat in % calories	8.8 (5.6-13.4)	11.2 (6.7-15.1)	.14
Minutes of moderate to vigorous physical activity/week	138 (0-390)	150 (0-390)	>.99
Discretionary minutes of sedentary time/week	1095 (660-1680)	1170 (510-1860)	.93
Other minutes of sedentary time/week	210 (150-720)	360 (120-720)	.70
Television viewing time/week	840 (420-1260)	720 (360-1200)	.62
Total sedentary minutes/week	1410 (750-2040)	1380 (630-1890)	.53

[a]Categorical *P* values are based on chi-square or Fisher exact test, whereas continuous *P* values are based on nonparametric Wilcoxon rank-sum test.

[b]SD: standard deviation.

[c]The median and 25% and 75% CIs were reported for the lifestyle variables.

Intervention Outcomes

Physical Activity

Our "completers only" and ITT analyses are reported in Tables 4 and 5, respectively. Both tracks made improvements in physical activity (all *P*<.001), but the improvements in the physical activity track were greater than that of the dietary track (all *P*<.001). In particular, the improvements in minutes of moderate physical activity per week were more than twice than that of the dietary track in the completers (+165 vs +75 min/week; *P*<.001) analysis and nearly two times greater in the ITT (+97 vs +49 min/week; *P*<.001) analysis.

Sedentary Behavior

Our analyses indicated that both groups made reductions in discretionary, television-related, and total sedentary time (all *P*<.001), but the reductions in the physical activity track were greater than that of the dietary track (all *P*<.001). In particular, the reductions in discretionary and television-related sedentary time were more than double than that of the dietary track in both the completers and ITT analyses. More importantly, the reduction in total sedentary time observed among the physical activity track was more than five times (−517 vs −91 min/week; *P*<.001) than that of the dietary track in the completers analysis and nearly five times (−304 vs −59 min/week; *P*<.001) than that of the dietary track in the ITT analysis.

Dietary Intake

Our completers case analysis indicates that only the dietary track made improvements in the intake of fiber (+4.4 g/day; *P*=.01), fruits and vegetables (+1.0 cup servings/day; *P*=.002), saturated fat (−2.8 g/day; *P*=.03), and trans fat (−0.3 g/day; *P*=.04). In the ITT analysis, only fruit and vegetable intake (+0.7 cup servings/day; *P*=.002) improved in the dietary track. The changes observed in our dietary track did not differ from the changes observed in the physical activity track in both the completers case and ITT (all *P*>.05) analyses.

Table 4. Change scores for the study outcomes in the completers case analysis (N=44).

Outcomes	Physical activity change[a] (SE[b]) N=20	Dietary intake change[a] (SE) N=24	Effect size	*P* value[c]
Minutes of moderate to vigorous physical activity/week	+165 (68)[d]	+75 (62)[d]	0.30	<.001
Discretionary minutes of sedentary time/week	−309 (138)[d]	−125 (126)[d]	0.30	<.001
Other minutes of sedentary time/week	−93 (75)[d]	+23 (68)[d]	0.35	<.001
Television viewing time/week	−216 (114)[d]	−103 (104)[d]	0.22	<.001
Total sedentary minutes/week	−517 (148)[d]	−91 (135)[d]	0.64	<.001
Sugar in g/day	+6.6 (4.4)	−2.3 (4.0)	0.45	.43
Fiber in g/day	+1.9 (1.7)	+4.4 (1.6)[e]	0.32	.40
Fruits and vegetables in cup equivalents/day	+0.6 (0.3)	+1.0 (0.3)[d]	0.28	.35
Saturated fat in g/day	−1.0 (1.3)	−0.8 (1.2)[e]	0.31	.46
Trans fat in g/day	+0.0 (0.2)	−0.3 (0.1)[e]	0.51	.99
Carbohydrates in g/day	+14.2 (11.3)	+17.6 (10.3)	0.07	.68

[a]All values represent within-group mean changes for the variables between baseline and follow-up periods.

[b]SE: standard error.

[c]Mixed-effects models were adjusted for race or ethnicity.

[d]*P*<.01.

[e]*P*<.05.

Table 5. Change scores for the study outcomes in the intention-to-treat analysis (N=71). An intention-to-treat protocol was applied where the last observations were carried forward.

Outcomes	Physical activity change[a] (SE[b]) N=34	Dietary intake change[a] (SE) N=37	Effect size	*P* value[c]
Minutes of moderate to vigorous physical activity/week	+97 (42)[d]	+49 (40)[d]	0.20	<.001
Discretionary minutes of sedentary time/week	−182 (85)[d]	−81 (81)[d]	0.20	<.001
Other minutes of sedentary time/week	−55 (45)[d]	−15 (43)[e]	0.15	<.001
Television viewing time/week	−127 (69)[d]	−66 (67)[d]	0.15	<.001
Total sedentary minutes/week	−304 (94)[d]	−59 (90)[d]	0.45	<.001
Sugar in g/day	+3.9 (2.7)	−1.5 (2.5)	0.35	.42
Fiber in g/day	+1.1 (1.1)	+2.9 (1.1)	0.27	.35
Fruits and vegetables in cup equivalents/day	+0.3 (0.2)	+0.7 (0.2)[e]	0.34	.29
Saturated fat in g/day	−0.6 (0.8)	−1.8 (0.8)	0.25	.40
Trans fat in g/day	−0.0 (0.1)	−0.2 (0.1)	0.30	.90
Carbohydrates in g/day	+8.3 (6.9)	+11.4 (6.6)	0.08	.61

[a]All values represent within-group mean changes for the variables between baseline and follow-up periods.

[b]SE: standard error.

[c]Mixed-effects models were adjusted for race or ethnicity.

[d]*P*<.01.

[e]*P*<.05.

Process Evaluation and Feasibility

Demand

Website usage did not differ between study intervention conditions. Survivors in the physical activity track visited the website on an average of 9.6 of the 12 weeks, whereas survivors in the diet track visited the website on an average of 10.7 of the 12 weeks (*P*=.15).

Satisfaction

Survivors in both tracks were mostly satisfied with the following components: tips for overcoming barriers, tips for achieving goals, goal-setting tools, and health notes. Additionally, most (97%) who completed the follow-up assessment indicated that they would recommend the ALIVE program to other cancer survivors. No statistically significant differences were observed between tracks. However, mean scores for the tracking tools were marginally lower in the physical activity track (*P*=.05). Mean satisfaction scores by track are reported in Table 6.

Implementation and Practicality

This component of feasibility was assessed via the qualitative responses obtained during our process evaluation. “Likes” reported by survivors could be grouped into six main themes: educational information (36%), email reminders (14%), goal-setting tools (12%), ease of use (9%), and motivation or encouragement (9%). The most commonly reported theme related to the educational information presented by the ALIVE program. For example, survivors indicated they liked the “information and tips,” and the “Did you know section.”

Components of ALIVE that survivors did not like could be grouped into the following themes: Functionality (48%), information (31%), tools (14%), and time (7%). For functionality, survivors indicated that they “could not enter goals,” that “links were not supported” or that they “got stuck” at some point while using the website. Examples of comments pertaining to information were “too much information” and “no relevant patient information.”

Limited Efficacy

The effect sizes measuring changes in dietary intake between tracks were mostly medium in size. In the completers case analysis (see Table 4), effect sizes ranged from 0.28 for fruit and vegetable intake to 0.45 for sugar intake. In the ITT analysis (see Table 5), effect sizes were more modest but similar in magnitude (range=0.25 for saturated fat intake to 0.35 for added sugar intake). The effect sizes measuring changes in physical activity and sedentary behavior between tracks differed by the variable of interest and analysis. In both the completers case and ITT analysis, the effect sizes were small for television viewing (0.22 for completers case and 0.15 for ITT analysis). However, for total sedentary time, the effect sizes were mostly large (0.64 for completers case and 0.45 for ITT analysis). For physical activity, the effect sizes were small (0.20) for the ITT analysis but medium for the completers case analysis (0.30).

Table 6. Process evaluation data for study participants.

Satisfaction (1=not at all, 5=very satisfied)	Total	Physical activity	Diet	*P* value[a]
Tips for overcoming barriers	4.2 (0.6)	4.1 (0.7)	4.2 (0.6)	.63
Tips for achieving goals	4.2 (0.6)	4.2 (0.7)	4.3 (0.6)	.78
Tracker of daily habits	3.7 (0.8)	3.4 (0.8)	4.0 (0.8)	.05
Progress tools—tracks current and past goals	3.9 (0.9)	3.6 (1.0)	4.2 (0.7)	.08
Simulator tools—tool to help you visualize success	4.0 (0.7)	4.0 (0.7)	4.0 (0.6)	.99
Goal-setting tools	4.2 (0.7)	4.3 (0.7)	4.1 (0.8)	.46
Automated phone coaching	3.5 (1.3)	3.4 (1.2)	3.6 (1.3)	.68
Tailored newsletters	4.0 (0.9)	4.1 (0.8)	3.9 (1.0)	.57
Health note—articles to increase knowledge and skills	4.2 (0.9)	4.2 (0.8)	4.1 (1.0)	.85
Overall satisfaction	4.1 (0.9)	3.9 (1.0)	4.3 (0.7)	.24
Effectiveness in changing behavior (1=not at all, 5=very effective)	3.8 (0.9)	3.7 (1.1)	3.8 (0.7)	.67
Recommend ALIVE[b] to other survivors, % yes	97	95	100	.47

[a]*t* tests were used to compare continuous indicators, and chi-square test of independence were used to compare the single binary item.

[b]ALIVE: A Lifestyle Intervention Via Email.

Discussion

Principal Findings

In this randomized parallel-group study, we observed that survivors randomized to the physical activity track made greater improvements in physical activity and greater reductions in sedentary behavior than those randomized to the dietary track. Despite the improvements in our activity-related constructs, these data only partially support our initial hypotheses, given that changes in the dietary variables did not differ significantly between tracks. Our process evaluation indicated that survivors were mostly satisfied with ALIVE and would recommend it to other survivors. However, concerns about ALIVE were noted. Overall, these data demonstrate that Web-based interventions such as ALIVE are feasible for racial and ethnic minority breast cancer survivors, but challenges must be addressed to improve the end user experience. The Alive program developers have recently developed and tested an updated version of the program that addresses some of the concerns identified in this study.

This is one of the first studies to examine the feasibility of a fully automated Web-based intervention in a sample of underserved breast cancer survivors. Our feasibility data were favorable, but attrition rates were high. The study's attrition rate was comparable to previous Web-based intervention studies [49-51] but higher than recent studies conducted among cancer survivors [24,26,29-31,34]. Our team discovered that functionality challenges contributed to high attrition rates. Challenges reported by survivors included repeat calls from the automated phone system and ALIVE email messages not being fully interactive within certain email domains (ie, AOL, Thunderbird, Live, Outlook, and Lotus) nor on mobile phones or tablets. Therefore, many survivors were only able to access ALIVE from a desktop computer. The challenges resulted in considerable frustration and many asked to be removed from the study. Unfortunately, our team was not aware of the technical difficulties before the study. However, we worked with NutritionQuest to address the challenges and identify solutions for participants. Encouragingly, our process evaluation was overwhelmingly positive, despite the challenges.

ALIVE was associated with significant improvements in physical activity for both tracks. Prior Web-based interventions among cancer survivors have observed significant improvements in physical activity [24,28-31,33,34], which ranged from 18 min [24] to 103 min [30]. Importantly, in our physical activity track, we observed a 165-min increase in our completers analysis and a 97-min increase in our ITT analysis. Despite these broad improvements, our effect sizes were small to medium in magnitude. The small effect sizes may be due to transfer effects [52], whereby setting goals in one's behavior increases one's confidence, intentions, and motivation to make improvements in another behavior [53-55]. Here, setting goals for diet may have transferred over to physical activity. Transfer effects may be common among cancer survivors because they capitalize on the "teachable moment" following their cancer diagnosis.

To our knowledge, this is one of the first Web-based studies among cancer survivors to observe significant changes in sedentary time. ALIVE was not designed to be a sedentary behavior intervention, yet reductions in sedentary time were observed among our physical activity track. In discussions with NutritionQuest to inquire about the sedentary behavior curriculum, we were informed that educational materials discussing sedentary behaviors were minimal. Observed improvements in sedentary activity could be the result of this minimal sedentary behavior program content. Alternatively, it could be a transfer effect, similar to what was observed in dietary track. More research is needed to determine how, when, and for whom transfer effects occur.

Few Web-based interventions for cancer survivors have intervened on dietary intake. Our completers case analysis indicated significant improvements in the intake of fiber, fruits and vegetables intake, and saturated fat for the dietary track.

These data support the results found in the original ALIVE study [36]. However, the observed changes did not differ significantly between tracks. Additionally, similar results were not observed in our ITT analysis. To our knowledge, only three Web-based intervention studies among cancer survivors have intervened on dietary intake [24,29,32], with two studies showing improvements [29,33]. It could be that 3 months were not sufficient to produce changes in dietary intake in our sample. Recently, Kanera et al [33] demonstrated an improvement in dietary intake at 12 months; a diet effect was not significant at the 6-month assessment [32]. More research is needed to determine the recommended program length required to change behavioral outcomes in Web-based intervention studies.

Limitations

Our study has limitations. Our team used a convenient sampling strategy to maximize our recruitment efforts, and our sample consisted mostly of African American survivors who were college educated. It should also be noted that eligibility was not based on baseline physical activity or dietary behaviors. In particular, some participants were meeting guidelines for physical activity or dietary intake before joining the study. This may have lowered our estimated effect size between study tracks. Prior studies have observed stronger effects among survivors not meeting guidelines to lifestyle behaviors at the baseline assessment [50]. Furthermore, our attrition rate was high, and many survivors did not return our emails or calls lowering our accrual rate. We are uncertain why participants never returned our emails or calls. Our team can only speculate that our emails with embedded links to the ALIVE websites were identified as junk mail and never received by the survivors. Other survivors who failed to complete the study were either not sufficiently engaged, were frustrated by technical challenges, or had competing priorities that reduced their interest in completing the study. Finally, our outcome measures were self-report and subject to recall and reporting biases. Self-report surveys are common in Web-based interventions, where obtaining objective estimates of physical activity and dietary intake would be costly. Despite the limitations, there are several strengths, including (1) a focus on high-priority breast cancer survivors, (2) significant or positive trends in lifestyle behavior changes, and (3) use of an evidence-based intervention tool with demonstrated efficacy in healthy adults.

Conclusions

ALIVE appears to be feasible for racial and ethnic minority breast cancer survivors and capable of improving multiple lifestyle behaviors. Although we observed favorable ratings for ALIVE, improvements to functionality and a tailoring to cancer survivors are warranted. Web-based programs should be created to minimize challenges that the end user would encounter. Since the time our study concluded, the developers of ALIVE have released an updated version of the program that includes features to increase engagement and reduce attrition. In particular, the newest version of ALIVE was designed to operate on phones, tablets, and computers; includes a stand-alone mobile phone app; and uses gamification, a points system, and other strategies to increase adherence [56]. Additional studies are needed to test the platform utilized here as well as the newest version of ALIVE in a sample of breast cancer survivors. Such studies could recruit a larger and more ethnically diverse sample to explore similarities and differences in the adoption and maintenance of lifestyle behaviors. Fully automated programs such as ALIVE are capable of being incorporated with minimal cost in clinical and community-based settings with the potential for dissemination and implementation to thousands of cancer survivors nationwide.

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Authors' Contributions

RP, RH, and PN spearhead recruitment efforts and IRB protocols at the respective institutions. RP, WC, SC, LJ, and KC conceived the study. RP, SB, and MD participated in tracking and tracing participants and entering data. All authors participated in drafting and editing the manuscript.

Conflicts of Interest

GB and TB hold the copyright on ALIVE and have financial interest in ALIVE.

Multimedia Appendix 1

CONSORT-EHEALTH checklist (v1.6.1).

[PDF File (Adobe PDF File), 548KB - cancer_v3i2e13_app1.pdf]

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Abbreviations

ALIVE: A Lifestyle Intervention Via Email
CAPS: Cross-Cultural Activity Participation Study
HRQoL: health-related quality of life
ITT: intention-to-treat
SAS: Statistical Analysis System
SE: standard error
SD: standard deviation
PAR-Q: Physical Activity Readiness Qestionnaire
PAQ: Physical Activity Questionnaire

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Original Paper

Comparison of Internet and Telephone Interventions for Weight Loss Among Cancer Survivors: Randomized Controlled Trial and Feasibility Study

Matthew Cox[1], MS, PhD; Karen Basen-Engquist[2], MPH, PhD; Cindy L Carmack[3], PhD; Janice Blalock[4], PhD; Yisheng Li[5], PhD; James Murray[6], MD; Louis Pisters[7], MD; Miguel Rodriguez-Bigas[8], MD; Jaejoon Song[2], MS; Emily Cox-Martin[9], PhD; Wendy Demark-Wahnefried[10], RD, PhD

[1]Adult and Child Consortium for Health Outcomes Research and Delivery Science, School of Medicine, University of Colorado, Aurora, CO, United States

[2]Center for Energy Balance In Cancer Prevention and Survivorship, Department of Behavioral Science, MD Anderson Cancer Center, University of Texas, Houston, TX, United States

[3]Department of Palliative Care and Rehabilitation Medicine, MD Anderson Cancer Center, University of Texas, Houston, TX, United States

[4]Tobacco Treatment Program, Department of Behavioral, MD Anderson Cancer Center, University of Texas, Houston, TX, United States

[5]Department of Biostatistics, MD Anderson Cancer Center, University of Texas, Houston, TX, United States

[6]Department of Breast Medical Oncology, MD Anderson Cancer Center, University of Texas, Houston, TX, United States

[7]Department of Urology, MD Anderson Cancer Center, University of Texas, Houston, TX, United States

[8]Department of Surgical Oncology, MD Anderson Cancer Center, University of Texas, Houston, TX, United States

[9]Division of Medical Oncology, University of Colorado, Aurora, CO, United States

[10]Department of Nutrition Sciences, University of Alabama, Birmingham, AL, United States

Corresponding Author:
Karen Basen-Engquist, MPH, PhD
Center for Energy Balance In Cancer Prevention and Survivorship
Department of Behavioral Science
MD Anderson Cancer Center, University of Texas
Unit 1330
P.O. Box 301439
Houston, TX,
United States
Phone: 1 713 745 3123
Email: kbasenen@mdanderson.org

Abstract

Background: Weight loss interventions have been successfully delivered via several modalities, but recent research has focused on more disseminable and sustainable means such as telephone- or Internet-based platforms.

Objective: The aim of this study was to compare an Internet-delivered weight loss intervention to a comparable telephone-delivered weight loss intervention.

Methods: This randomized pilot study examined the effects of 6-month telephone- and Internet-delivered social cognitive theory–based weight loss interventions among 37 cancer survivors. Measures of body composition, physical activity, diet, and physical performance were the outcomes of interest.

Results: Participants in the telephone intervention (n=13) showed greater decreases in waist circumference (–0.75 cm for telephone vs –0.09 cm for Internet, *P*=.03) than the Internet condition (n=24), and several other outcomes trended in the same direction. Measures of engagement (eg, number of telephone sessions completed and number of log-ins) suggest differences between groups which may account for the difference in outcomes.

Conclusions: Cancer survivors in the telephone group evidenced better health outcomes than the Internet group. Group differences may be due to higher engagement in the telephone group. Incorporating a telephone-based component into existing weight loss programs for cancer survivors may help enhance the reach of the intervention while minimizing costs. More research is needed on how to combine Internet and telephone weight loss intervention components so as to maximize engagement and outcomes.

Trial Registration: ClinicalTrials.gov NCT01311856; https://clinicaltrials.gov/ct2/show/NCT01311856 (Archived by WebCite at http://www.webcitation.org/6tKdklShY)

(JMIR Cancer 2017;3(2):e16) doi:10.2196/cancer.7166

KEYWORDS

weight loss intervention; cancer survivors; Internet; telephone

Introduction

Weight gain, a common and worrisome side effect of certain cancer treatments such as chemotherapy [1-3], can persist after treatment and increases the risk for chronic diseases as well as cancer recurrence and second primaries [1,4-6]. Weight gain that occurs postdiagnosis may be associated with poorer disease-specific and overall survival [7,8]. For example, a recent meta-analysis of postdiagnosis weight gain in breast cancer survivors showed that a 5% weight gain was associated with a 12% increase in all-cause mortality, and a 10% weight gain was associate with a 23% increase in all-cause mortality [9]. Two meta-analyses in breast and prostate cancer survivors showed that postdiagnosis increases in body mass index (BMI) are significantly associated with greater recurrence as well as poorer disease-free and overall survival [10,11]. Given the physical, economic, and psychological burdens that cancer survivors face, recent intervention efforts to prevent recurrence and ameliorate symptoms in posttreatment cancer survivors have shown promise.

Diet and exercise interventions may facilitate weight management in survivors [12,13]. In order to increase the reach of weight loss interventions and decrease costs, distance-based approaches using communication technology, such as telephone counseling, are receiving more attention. A recent review of weight loss interventions for breast cancer survivors identified 3 randomized controlled trials (RCT) where at least 1 component of the intervention was delivered via telephone [14]. Authors noted that only 2 of these studies compared a telephone-delivered intervention to a non–telephone-delivered intervention, and only 1 of these 2 studies reported any statistical comparisons between intervention conditions. Although this study reported that the telephone intervention condition achieved significantly more weight loss than 2 other active control conditions, Reeves et al [14] rated the risk for bias of the results as high based on a checklist created from the Consolidated Standards of Reporting Trials (CONSORT) statement and the *Cochrane Handbook for Systematic Reviews of Interventions*.

Moreover, a recent systematic review of Web-, telephone-, and print-based interventions targeting weight management in cancer survivors found only 5 studies that targeted weight management and only 2 studies that found significant improvement in weight status [15]. All 5 interventions used telephone-based intervention methods, with 1 RCT showing that a telephone intervention was significantly effective in reducing BMI among 641 older, overweight or obese colon, breast, and prostate cancer survivors [16]. As minimal as such an approach appears, it still requires dedicated staff and resources. In order to reduce these costs, less expensive means to deliver interventions are sought.

Web-based delivery is one way to reduce cost and expand the reach of weight loss interventions. There are numerous review articles and meta-analyses examining weight loss or weight control interventions delivered via the Internet. Overall, reports suggest that half of the interventions were successful in promoting weight loss or weight maintenance; however, the interventions as well as the effects were heterogeneous, limiting the ability to identify critical components. Neve et al [17] identified 7 studies for inclusion in their meta-analysis of Web-based interventions for weight loss and weight loss maintenance in overweight and obese adults; however, only 4 of the Web-based interventions were deemed effective and included in the meta-analysis. Results showed no difference between the Web-based interventions and the control condition because of substantial heterogeneity in results. In a larger meta-analysis, Kodaman et al [18] examined 23 RCTs of Web-based weight loss interventions, finding a modest but significant effect for weight loss with the Web-based intervention as compared to the control condition (–0.68 kg). The authors also found significant heterogeneity in results, which were dependent on the other components included in the intervention.

In a systematic review of reviews, Tang et al [19] found 4 meta-analyses examining Internet-based interventions for weight loss. While the authors noted heterogeneity both within and across the meta-analyses, they observed that these interventions were consistently more effective than minimal contact interventions (eg, printed material) and that interventions using self-monitoring and feedback showed promise for improving weight loss as opposed to information-only interventions.

A consistent issue noted in several review articles was the lack of use of the Internet-based materials by participants. Norma et al [20] reviewed 41 studies comparing interventions using eHealth technology to control groups and suggested that studies with higher usage rates had improved outcomes, but the authors failed to note a critical number of log-ins to achieve these results. In a review of Web-based physical activity interventions, Vandelanotte et al [21] noted that interventions with 5 or more contacts had higher levels of reported physical activity. Arem and Irwin [22] observed a similar association between log-in rates and weight loss but noted that exceptions do occur, citing one study in particular that incentivized log-ins and still did not produce clinically significant weight loss [23].

In the reviews and meta-analyses examining weight loss interventions delivered via Internet, it was found that no studies examined the impact of Internet-based approaches among cancer survivors who tend to be older [24] and less likely to use the Internet and other forms of technology [25]. Moreover, these reviews largely compared telephone- or Web-based delivery modalities with those that were face-to-face or versus waitlist

controls. No direct comparisons have been made, so claims about the comparative efficacy of telephone- versus Internet-delivered interventions cannot be made. Given that no previous study has directly compared a telephone- versus Web-based weight loss intervention in either the general population or among cancer survivors, we believe a pilot study is warranted in order to develop estimates of effect sizes for future studies.

Determining the modality that provides the largest reach with the most weight loss will help to identify the most effective intervention approach for weight loss. Our study attempts to bridge the gap in the literature by directly comparing a tailored telephone- versus Internet-delivered weight loss intervention among cancer survivors. Based on the current literature, we hypothesize that the telephone group will have greater weight loss and more improved health outcomes than the Internet group.

Methods

Ethical Approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Participants

Participants were 37 cancer survivors who had previously participated in a survey about health behavior change interventions and delivery modalities and indicated that they were willing to be contacted for participation in future studies. Participants had to have a diagnosis of either locoregional breast cancer (stages 0 to IIIA), colon cancer (stages I and II), endometrial cancer (stages I to IIIa), or prostate cancer (stages I and II) and no history of any other cancers. Participants were required to be at least 3 months postsurgery (if applicable), over the age of 18 years, have a BMI ≥25, have access to high-speed Internet and a telephone, and live in the Houston area. Survivors were excluded if they had a medical condition that prevented them from engaging in an unsupervised exercise program or low-fat diet high in fruits and vegetables. Informed consent was obtained from all individual participants included in the study. In-person assessments were completed at baseline and 6 months for all measures.

Measures

Body Composition

Percent body fat was measured using the whole body Discovery A QDR x-ray bone densitometer (Hologic Inc) (daily quality control was performed using the phantom spine). Additionally, researchers weighed participants and measured their waist circumference at both time points. Height was measured at baseline and was used with weight to calculate a BMI (kg/m^2) for each participant.

Diet

The online Automated Self-Administered 24-hour (ASA24) dietary recall was used to document participant food intake (riskfactor.cancer.gov/tools/instruments/asa24). Two assessments (1 for weekday and 1 for weekend day) were obtained and averaged. Results related to intakes of energy, saturated fat, fiber, and number of servings of fruits and vegetables were outcomes of interest.

Physical Activity

A 3-item modified version of the Godin Leisure-Time Physical Activity Questionnaire was used to measure participant usual leisure-time exercise habits. This questionnaire has been used extensively in research with cancer survivors. It is easy to administer and has good test-retest reliability (.81 for total score) and significant correlations with maximal oxygen consumption (VO_2 max) [26]. For 1 week before the baseline and 6-month assessments, participants wore a GT1M accelerometer (Actigraph LLC) and recorded their exercise in a daily diary. Participants were asked to indicate what type of exercise they performed, duration of the exercise in minutes, and the effort level during the exercise. In terms of outcomes, the Godin was used to develop a total score of physical activity minutes as well as a measure of moderate/vigorous physical activity minutes. The accelerometer was used to measure the number of sedentary minutes and the percentage of the day that participants engaged in moderate/vigorous physical activity. Cut-points for sedentary minutes and minutes of moderate/vigorous physical activity were derived using the methods of Hall et al [27].

Physical Performance

For aerobic function, a 2-minute step-in-place protocol was used. The 2-minute step-in-place protocol assesses the number of steps within 2 minutes a participant can complete in place by raising their knees to a height halfway between the iliac crest and the middle of the patella. This test correlates moderately with other common measures of aerobic capacity and is low risk [28]. For lower body strength, a 30-second chair-stand test was used [29], in which the number of full stands in a 30-second period was recorded. We used a timed arm curl task to assess upper body strength and functionality [29]. Upper body function, including arm strength and endurance, is important in activities of daily living such as carrying groceries, lifting purses, etc. Timed arm flexion tasks simulate these activities. To assess agility and dynamic balance, an 8-foot up-and-go assessment was used. The test is a modification of the 3-meter timed up-and-go test [30] and can be administered in small spaces [29]. The 6-minute walk test was used as a measure of endurance. It has been validated in older adults against treadmill walking tests resulting in a correlation of .78 [31].

Procedures

This study was approved by MD Anderson's Institutional Review Board and was registered at ClinicalTrials.gov [NCT01311856]. Following the baseline assessment, participants were randomized at a ratio of 2:1 to either the Internet-based weight loss intervention or the telephone-based version, respectively. A 2:1 ratio was used because we hypothesized that outcomes in the Internet condition would be smaller. We used a form of adaptive randomization called minimization, which is similar to stratification in that participant characteristics are used to assign them to the treatment conditions [32,33]. All

participants received resistance bands and pedometers. Participants in the telephone intervention received print materials about exercise and diet and telephone counseling calls (3 weekly, 2 semiweekly, 4 monthly; 15 to 30 minutes in length) and customized mailed progress reports every 6 weeks to encourage adherence to diet and exercise recommendations. Materials were based on the Reach Out to Enhance Wellness (RENEW) intervention [16]. Participants in the Internet-based intervention had access to the same content online by logging onto www.walkingspree.com/login/healthymoves with a personalized username and password. Participants in the Internet arm were also invited to participate in a discussion forum facilitated by intervention staff, had the opportunity to email questions directly to the intervention staff, and received customized progress reports every 6 weeks by email.

The goals for both groups were to do 15 minutes of strength exercise every other day, ≥30 minutes of walking or other moderate-intensity exercise on 5 or more days of the week, and consume a diet with 7 (for women) or 9 (for men) servings of fruits and vegetables per day and <7% of calories from saturated fat. Participants in both groups were also provided with caloric recommendations to facilitate a weight loss of 1 to 2 pounds per week (a loss of 5% body weight was used as a goal over the course of the 6-month study period) and fat gram/calorie counters or access to appropriate websites to monitor intake. Participants received 2 $25 gift cards as compensation; 1 after completing the baseline assessment and the other after completing the 6-month assessment.

Analyses

Two-sample and paired *t* tests and Fisher exact tests with a 2-sided alpha of .05 were used to (1) compare the 2 intervention groups on a number of demographic variables; (2) compare the difference scores from baseline to 6 months on diet, physical activity, physical performance, and body composition between the 2 intervention groups; (3) assess within-group changes from baseline to 6 months on the aforementioned outcome variables; and (4) compare attrition rates between intervention groups for each outcome variable. We define attrition here as any participant who completed baseline measures but stopped participating at some point following baseline (eg, the participant dropped out of the study and no further data were collected). Additionally, Cohen *d* was calculated for within-group differences between baseline and 6 months.

Results

Participants included 37 cancer survivors. A CONSORT diagram for recruitment and retention is presented in Figure 1. Baseline demographic information by intervention group is presented in Table 1. No significant differences were observed in any of these parameters. Despite the lack of statistical significance on these parameters, the distribution of ethnicities appears to be substantially different between the 2 intervention conditions, with the Web-based condition having substantially more white participants.

Attrition did not differ significantly between the 2 treatment groups. Participants who did not complete their 6-month assessment were only different in terms of their baseline percentage body fat, with those dropping out having a higher percentage of body fat than those who did not (noncompleters: mean 51.85 (SD 3.81) kg/m^2; completers: mean 41.49 (SD 4.23) kg/m^2, *P*=.002). This difference was only noted in the telephone-based intervention group. Additionally, potentially differential levels of engagement were observed between the 2 intervention groups. On average, participants completed 7.2 out of 9 telephone counseling sessions (80%) in the telephone-based group, while participants logged in 43.2 days out of a possible 160 days (27%) in the Internet-based group. Another more comparable measure of engagement was the tailored weekly online survey that participants completed. The telephone group had a higher percentage of completion than the Internet group (60% vs 42%) (see Multimedia Appendix 1 for a table of comparisons for completers vs noncompleters on baseline outcomes).

Results of the *t* tests comparing within intervention group differences between baseline and 6 months are presented in Table 2. Significant changes over time for the telephone group included decreases in weight (*D*=0.81, *P*=.04), waist circumference (*D*=1.01, *P*=.02), and 8-foot up-and-go times (*D*=0.84, *P*=.04), and while a decrease in BMI was substantial, it was not statistically significant (*D*=0.75, *P*=.06). The Internet-based group showed increases over time in body fat percentage (*D*=0.98, *P*=.004) but improvement in 2 performance tasks: the 30-second bicep curl (*D*=0.71, *P*=.02) and the 30-second sit-to-stand (*D*=0.73, *P*=.02).

Overall, between-group differences over time were only statistically significant for baseline to 6-month changes in waist circumference in favor of the telephone intervention (*P*=.03). Several other outcomes are worth noting including baseline to 6-month change in weight (*P*=.06), total body fat percentage (*P*=.09), body mass index (*P*=.08), and amount of fruit consumed (*P*=.10), all in favor of the telephone intervention. Figures 2 to 5 provide graphic depictions of these results. It is also worth noting that Figures 4 and 5 show potential differences between the intervention groups in terms of average number of sedentary minutes per day and the 6-minute walk test, respectively, with the telephone group having more sedentary minutes.

Table 1. Demographic information by treatment group.

Characteristic	Group	
	Telephone Mean (SD) or n (%) n=13	Internet Mean (SD) or n (%) n=24
Age, years, mean (SD)	59.92 (10.94)	59.62 (9.65)
Sex, n (%)		
Male	2 (15)	5 (21)
Type of cancer, n (%)		
Prostate	2 (15)	4 (17)
Colon	0 (0)	2 (8)
Endometrial	3 (23)	4 (17)
Breast	8 (62)	14 (58)
Ethnic background, n (%)		
Hispanic/Latino	3 (2.3)	3 (13)
Race, n (%)		
Asian	0 (0)	1 (4)
Black	3 (23)	3 (13)
White	8 (61)	20 (83)
Other	2 (15)	0 (0)
Level of education, n (%)		
At least bachelor's degree	7 (54)	11 (46)
Less than bachelor's degree	6 (46)	13 (54)
Employment status, n (%)		
Employed full-time	6 (46)	11 (46)
Not employed full-time	7 (54)	13 (54)
Belong to religious group, n (%)		
Yes	13 (100)	18 (75)
Present marital status, n (%)		
Married	8 (62)	14 (58)
Not currently married	5 (39)	10 (42)
Children[a], n (%)		
At least one child	9 (75)	20 (83)
Surgery, n (%)		
Yes	13 (100)	21 (88)
Chemotherapy, n (%)		
Yes	6 (46)	10 (42)
Radiation therapy, n (%)		
Yes	8 (62)	14 (58)
Hormonal therapy[a] , n (%)		
Yes	7 (58)	11 (46)

[a]One person did not respond.

Table 2. Within-group baseline and 6-month follow-up means and standard deviations for measures of body composition, diet, physical functioning, and physical activity (note: mean and standard deviations were calculated for individuals who had observations for both baseline and follow-up).

	Intervention group	Baseline Mean (SD)	Follow-up Mean (SD)	Cohen *d*	*P* value
Weight (kg)					
	Telephone	82.07 (14.04)	77.53 (12.83)	0.81	.04
	Internet	86.62 (19.35)	86.28 (19.96)	0.12	.64
Waist circumference (cm)					
	Telephone	97.23 (8.81)	92.36 (10.7)	1.01	.02
	Internet	94.13 (11.98)	93.53 (11.45)	0.28	.30
Total body fat (%)					
	Telephone	41.49 (4.23)	40.23 (6.06)	0.41	.25
	Internet	43.33 (7.56)	44.06 (7.26)	0.98	.004
Body mass index (kg/m^2)					
	Telephone	31.56 (3.07)	30.02 (4.06)	0.75	.06
	Internet	32.38 (5.05)	32.27 (5.49)	0.11	.68
ASA24[a] trans fat (g/day)					
	Telephone	66.61 (13.75)	42.05 (28.38)	0.72	.08
	Internet	60.86 (35.1)	58.69 (39.75)	0.05	.87
ASA24 saturated fat (g/day)					
	Telephone	20.41 (4.24)	12.27 (8.78)	0.75	.07
	Internet	21.17 (13.16)	18.08 (13.26)	0.19	.50
ASA24 fiber (g/day)					
	Telephone	15.15 (4.37)	17.7 (4.99)	0.53	.17
	Internet	14.39 (4.92)	15.15 (9.58)	0.08	.76
ASA24 vegetables (servings/day)					
	Telephone	1.58 (0.57)	1.9 (0.82)	0.31	.42
	Internet	1.39 (0.84)	1.44 (1.27)	0.03	.92
ASA24 fruits (servings/day)					
	Telephone	0.88 (0.73)	1.35 (0.99)	0.53	.18
	Internet	1.38 (1.13)	1.19 (1.02)	0.23	.41
ASA24 vegetables and fruits (servings/day)					
	Telephone	2.45 (0.82)	3.25 (1.58)	0.44	.25
	Internet	2.77 (1.33)	2.63 (1.86)	0.09	.74
Godin physical activity score					
	Telephone	33.33 (25.74)	48.33 (19.75)	0.56	.13
	Internet	23.6 (22.56)	25 (17.77)	0.08	.77
Godin minutes of moderate or greater activity					
	Telephone	129.44 (77.48)	156.67 (74.33)	0.34	.33
	Internet	66.88 (84.44)	88.75 (83.66)	0.27	.30
30-second bicep curl, repetitions (2 arms average)					
	Telephone	14.83 (3.81)	16.94 (2.96)	0.62	.10
	Internet	15.21 (3.25)	17.21 (3.46)	0.71	.02
30-second sit-to-stand (repetitions)					

	Intervention group	Baseline Mean (SD)	Follow-up Mean (SD)	Cohen *d*	*P* value
	Telephone	12.22 (1.99)	13.33 (1.87)	0.5	.17
	Internet	11.36 (1.6)	12.29 (1.2)	0.73	.02
8-foot up-and-go (seconds)					
	Telephone	6.65 (1.28)	6.18 (0.99)	0.84	.04
	Internet	6.23 (1.07)	6.08 (1.23)	0.15	.60
2-minute steps (count)					
	Telephone	95.67 (16.96)	95.44 (16.61)	0.02	.96
	Internet	90.23 (22.13)	93.77 (16.66)	0.23	.42
6-minute walk (meters)					
	Telephone	476.36 (130.96)	519.06 (82.12)	0.46	.20
	Internet	490.18 (69.75)	478.55 (75.28)	0.18	.52
Sedentary activity (minutes/day)					
	Telephone	60.61 (10.09)	64.95 (15.96)	0.31	.41
	Internet	68.98 (5.69)	68.71 (4.92)	0.06	.84
Moderate-to-vigorous activity (minutes/day)					
	Telephone	36.22 (31.9)	37.49 (28.65)	0.09	.80
	Internet	16.17 (11.68)	10.6 (7.95)	0.63	.07

[a]ASA24: Automated self-administered 24-hour dietary recall.

Figure 1. Consolidated Standards of Reporting Trials diagram.

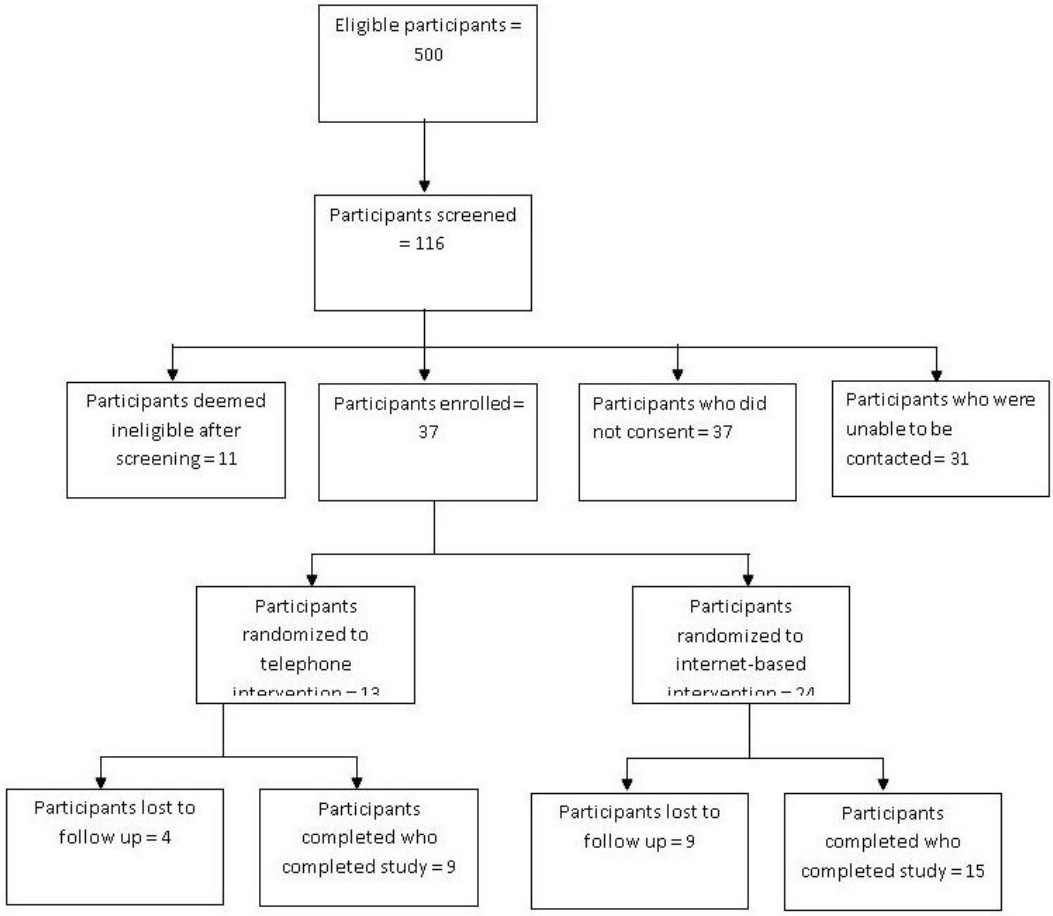


Figure 2. Boxplots for change in body composition by treatment group from baseline to 6-month follow-up.

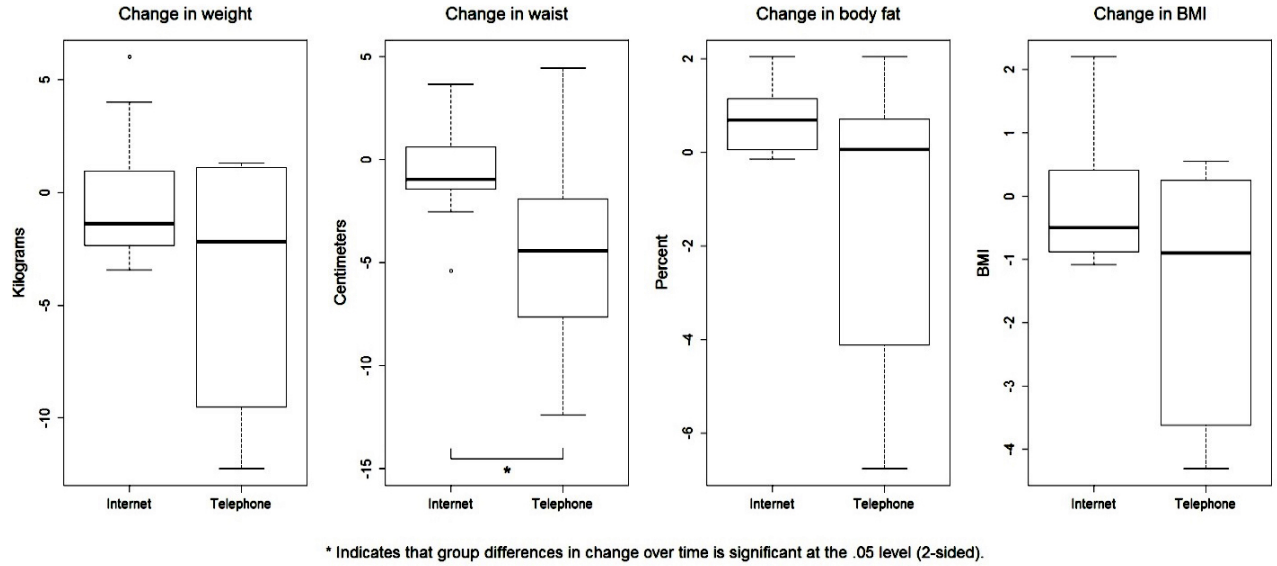


Figure 3. Boxplots for change in nutrition outcomes scores by treatment from baseline to 6-month follow-up.

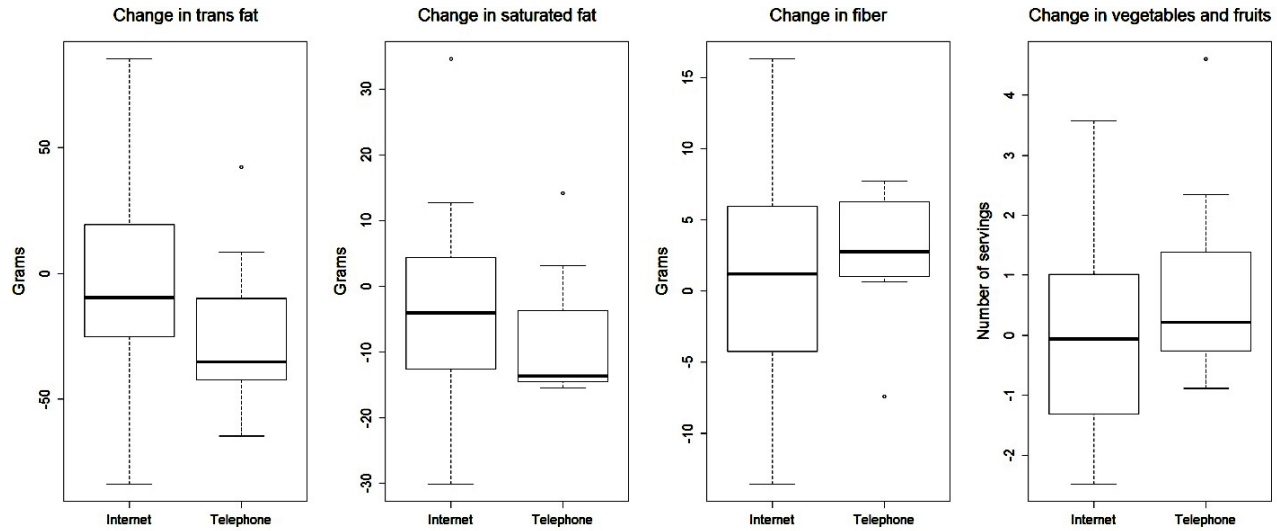


Figure 4. Boxplots of change in physical activity outcomes by treatment group from baseline to 6-month follow-up.

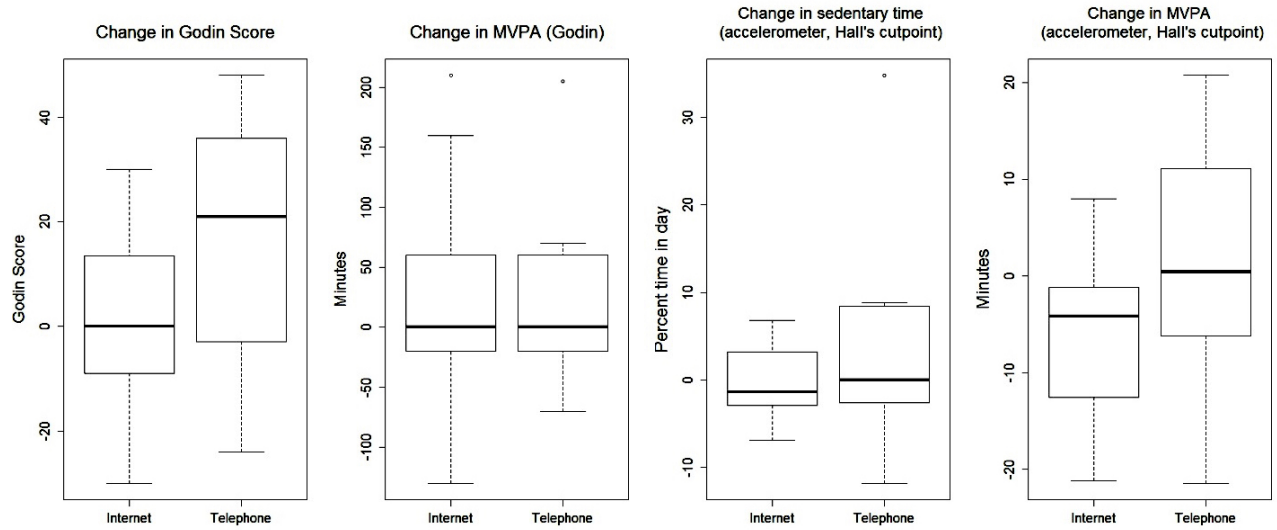
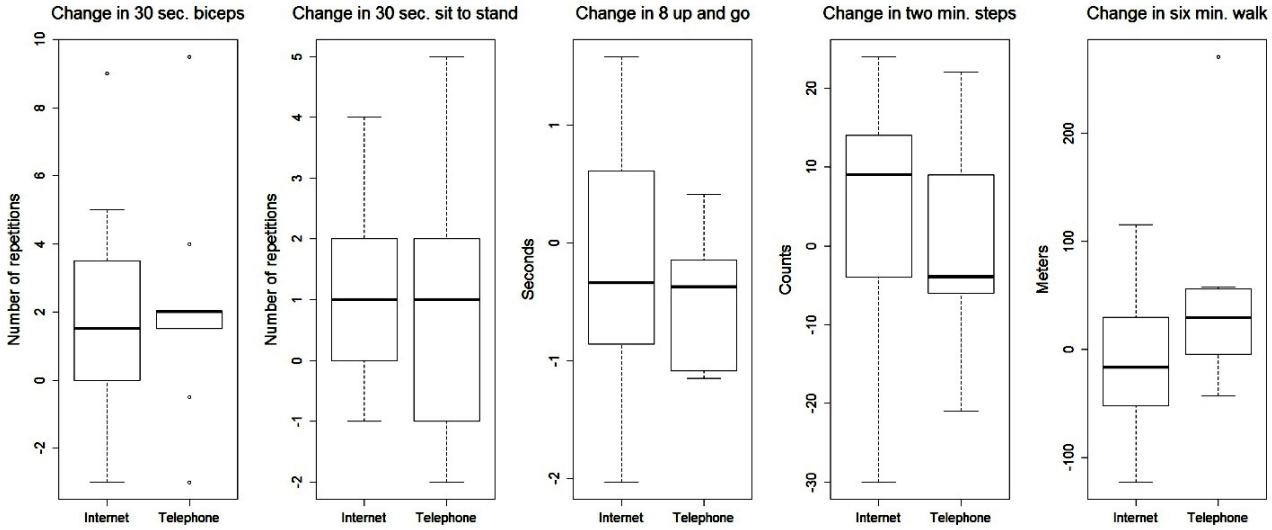


Figure 5. Boxplots of change in physical functioning outcomes by treatment group from baseline to 6-month follow-up.



Discussion

Principal Findings

This pilot RCT provides some of the first data directly comparing telephone- and Internet-delivered weight loss interventions among a sample of cancer survivors. Results suggest that the engagement was far greater with telephone intervention and consequently yielded larger improvements in several measures of body composition (especially waist circumference, which was highly significant), diet, physical activity, and physical fitness. Although outcomes generally favored the telephone group, participants with a higher percentage of body fat were more likely to drop out of this intervention group, indicating that the Internet intervention may be more acceptable for people with a high percentage of body fat. Previous research is mixed with regard to why participants drop out of weight loss interventions, but some research has found that for in-person interventions, weight or shape concerns may increase the likelihood of attrition [34].

Although our modest sample size and lack of statistical power hampered our ability to detect significant differences, several differences are worth noting as the effect sizes are clinically meaningful, including the percentage of body fat, fruits and vegetables consumed, moderate/vigorous physical activity (measured via accelerometer), and 6-minute walk test (found in Figures 2,4, and 5, respectively). Changes in these variables for participants in the telephone group were in the hypothesized direction, while participants in the Internet group showed changes in the opposite direction. In a larger sample, these differences may have been more pronounced. These findings are consistent with a recent review of telephone- and Web-based weight management interventions for cancer survivors which suggests telephone interventions may be more effective than Web-based approaches [15].

In terms of within-group change, the telephone group had more outcomes related to fitness and weight loss that changed over the 6 months than the Internet group. These included weight, waist circumference, and 8-foot up-and-go time. In terms of change in weight, participants in the telephone group experienced a 5.6% weight loss which is clinically meaningful [35]. Participants in this group also experienced a decrease of 5 cm in waist circumference, decreasing from 97.2 cm to 92.4 cm. Epidemiological research suggests an increased risk of all-cause mortality among individuals whose waist girth falls within the range of 95 to 100 cm as compared to those whose waists measure 90 to 95 cm (especially among women) [36]. Interestingly, the Internet group did have 2 measures of physical functioning change including the 30-second bicep curl and sit-to-stand, which suggest some advancements in strength training. This group also showed a significant increase in percentage of body fat; however, results indicating changes in physical functioning may be an artifact of multiple comparisons as there were no meaningful differences between interventions other than modality.

By examining the engagement data we can indirectly assess participant perceptions of usefulness or enjoyment. Engagement was assessed in the telephone group via the number of phone sessions out of 9 that they completed. In the Internet group, it was assessed as the number of days that they logged on during the intervention out of a possible 160 days. This finding is consistent with the reviews and meta-analyses of the previous literature [17,18,37], which suggest that more personal contact with participants leads to better improvements in outcomes. Moreover, these reviews reported that interventions with at least one in-person interaction resulted in greater engagement and better outcomes. In a recent systematic review of weight loss intervention for cancer survivors [38], the authors note that interventions that combined technology-based modalities (such as telephone) with in-person counseling were more effective than those using only one modality.

Engagement in Internet-delivered interventions is an ongoing area of research. One recent study found that an Internet-delivered intervention for cancer-related distress among survivors suggests that engagement tends to be higher for women, for participants who underwent chemotherapy, and when participants are recruited online [39]. The authors also note that the social networking component increased overall

engagement but may have interfered with other intervention components. In a separate weight loss study using a Web-based intervention, researchers found no difference between an information-based website and 2 supportive ones—one that provided feedback, social support, and self-monitoring and another that provided the same features plus personalized planning [40]. Despite the lack of significant differences between websites in terms of weight loss, use of the supportive websites was higher compared to the informative website, suggesting that greater engagement may not lead to greater weight loss. It should be noted that completing 9 telephone counseling sessions may not be equivalent to logging on to the website every day. Moreover, we did not have any measure of the pattern of log-ins over time or what the participant did while they were logged on, limiting our ability to infer how much of the intervention material to which they were exposed.

We compared percent completion of online surveys across the 2 groups, and while differences were not statistically significant, studies with larger sample sizes may find significant differences. In order to address this issue, standardized measures of engagement should be developed to compare across Web-based and non–Web-based interventions. One possible measure may be length of time exposed to intervention materials (eg, length of telephone sessions in minutes and number of minutes participants spent logged in to the website). Researchers should continue to evaluate different measures in order to identify the most accurate measure of adherence.

Strengths and Limitations

This study has several strengths worth noting. First, it is one of the first studies to directly compare a telephone-delivered intervention and an Internet-delivered intervention in a sample of cancer survivors. Second, several objective measures of body composition, physical activity, and physical performance were used to capture changes in important markers of health that may have occurred during the intervention. Last, the intervention that was delivered is easily disseminable and requires fewer resources compared to interventions that use supervised exercise sessions.

Although this pilot study had many strengths, there also were weaknesses. First is the small sample size. Few of the changes from pre- to postintervention were statistically significant; however, many of the between-group differences in outcomes, while not statististically significant in this study, would have likely been significant had the sample size been larger. Additionally, attrition for this study was fairly high with about 35% of participants dropping out before completing the study. Given the issues we encountered with attrition, future studies examining Web-based interventions for weight loss should account for potentially high attrition rates in the Web-based group by having proportionally more participants for this condition relative to other conditions. In the telephone group, participants with a higher percentage of body fat were more likely to drop out, and because of the small sample size, we were unable to control for this in our analyses. Finally, because many outcome variables were measured, many statistical comparisons were used, which could have increased the type I error rate; however, given that (1) this was a pilot study, (2) the goal of the pilot study was to identify relationships for future study, and (3) all comparisons were planned before the intervention was delivered, we felt that it was unnecessary to adjust for multiple comparisons.

Conclusion

The results of this pilot study are compelling and provide direction for future studies. Specifically, future studies that compare telephone- and Internet-delivered interventions would benefit from techniques to enhance adherence and examine cost differences. It may prove beneficial to augment current weight loss interventions in health care settings with personalized intervention components. Research suggests that interest in technology-based interventions is influenced by the survivors' current technology use, their age, and their current lifestyle patterns (eg, eating and physical activity behaviors) [41]. In fact, a program using both telephone and Web components may be able to maximize reach and engagement. Future studies should also focus on how to get older participants to engage more with technology so as to enhance Internet-based interventions. Over time, as younger participants who are more comfortable with technology age, there may be a shift in preference of intervention modality toward Internet-based or other technology-based interventions. A recent study involving breast cancer survivors showed moderate improvements in weight (2% weight loss), fruits/vegetable consumption (+1.5 servings/day), and physical activity (+5.75 metabolic equivalent of task hours per week) in an intervention using a multimodal mHealth approach [42]. Several outcome measures showed promise in terms of 6-month change including percentage of body fat, waist circumference, fruits and vegetables consumed, moderate/vigorous physical activity (measured via self-report), and 6-minute walk test. Future studies should focus on these outcomes.

Finally, studies should also determine the most effective intervention components and how to best combine these in order to create the most robust intervention strategy. As Hoedjes [38] notes, several promising theoretical components such as goal setting, action planning and social support may be effective for weight loss interventions for cancer survivors; however, optimizing the modality for delivery may be just as important. Future studies should use the multiphase optimization strategy to determine the most effective components [43].

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Differences in baseline assessments between drop-outs and non–drop-outs by intervention group.

[PDF File (Adobe PDF File), 30KB - cancer_v3i2e16_app1.pdf]

Multimedia Appendix 2

CONSORT Checklist.

[PDF File (Adobe PDF File), 65KB - cancer_v3i2e16_app2.pdf]

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Abbreviations

ASA24: automated self-administered 24-hour dietary recall
BMI: body mass index
CONSORT: Consolidated Standards of Reporting Trials
RCT: randomized controlled trial
RENEW: Reach Out to Enhance Wellness
VO2max: maximal oxygen consumption

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Original Paper

A Mobile Breast Cancer Survivorship Care App: Pilot Study

Janet Baseman[1], MPH, PhD; Debra Revere[2], MLIS, MA; Laura-Mae Baldwin[3], MD, MPH

[1]Department of Epidemiology, University of Washington, Seattle, WA, United States
[2]Department of Health Services, University of Washington, Seattle, WA, United States
[3]Department of Family Medicine, University of Washington, Seattle, WA, United States

Corresponding Author:
Janet Baseman, MPH, PhD
Department of Epidemiology
University of Washington
1105 NE 45th Street Suite 400
Seattle, WA, 98105
United States
Phone: 1 206 616 1495
Email: jbaseman@uw.edu

Abstract

Background: Cancer survivors living in rural areas experience unique challenges due to additional burdens, such as travel and limited access to specialists. Rural survivors of breast cancer have reported poorer outcomes, poorer mental health and physical functioning, and lower-than-average quality of life compared to urban survivors.

Objective: To explore the feasibility and acceptability of developing a mobile health survivorship care app to facilitate care coordination; support medical, psychosocial, and practical needs; and improve survivors' long-term health outcomes.

Methods: An interactive prototype app, SmartSurvivor, was developed that included recommended survivorship care plan components. The prototype's feasibility and acceptability were tested by a sample of breast cancer survivors (n=6), primary care providers (n=4), and an oncologist (n=1).

Results: Overall, both survivors and providers felt that SmartSurvivor was a potentially valuable tool to support long-term survivorship care plan objectives. Portability, accessibility, and having one place for all contact, treatment, symptom tracking, and medication summaries was highly valued.

Conclusions: Our pilot study indicates that SmartSurvivor is a feasible and acceptable approach to meeting survivorship care objectives and the needs of both breast cancer survivors and their health care providers. Exploration of mobile health options for supporting survivorship care plan needs is a promising area of research.

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KEYWORDS

breast neoplasms; data collection; feasibility studies; mobile apps; survivors; telemedicine

Introduction

Cancer patients are surviving longer. Since the early 1990s, the overall cancer death rate has steadily declined and the 5-year survival rate is now 69%, up from 49% in the 1970s [1]. Survivorship care planning aims to meet the need for ongoing, long-term surveillance and management of cancer survivors and to promote wellness and healthy lifestyle behaviors [2-4].

Most breast cancer survivors who do not die of their cancer may die from conditions that can be managed and are modifiable through lifestyle changes (eg, respiratory and heart disease) or screening (eg, colon cancer) [5]. Among breast cancer survivors, a high degree of self-efficacy—the belief that one can control challenging environmental demands by taking adaptive action—is associated with increased self-care behaviors, decreased physical and psychological symptoms, and increased quality of life after treatment [6-8]. Evidence suggests that survivor self-efficacy can be enhanced with appropriate, tailored, self-management support and making lifestyle changes to promote health, well-being, and survival [9].

One strategy to support survivors is through the development of comprehensive survivorship care plans (SCPs), which offer a blueprint for long-term management and a means to support follow-up care coordination and communication. Improvements in the quality of cancer patient-provider communication are

associated with more participatory decision making, improved medical information seeking and understanding of information, improved facilitation of information exchange, reduced depression and other negative psychosocial needs associated with survivorship, and improved quality of life [8,10-13]. Increasingly, cancer survivors are viewed as part of the population of patients considered chronically ill and in need of care that is integrated within the wider context of health, prevention, and well-being. Improved provider-provider communication and information sharing can enable cancer-related care as a component of overall prevention and wellness, empower patients with the skills and resources they need for tackling cancer-related problems, and enhance survivor self-efficacy [8].

However, SCPs are not consistently received by cancer patients or their care providers [14-16], as recommended by the Institute of Medicine (IOM) [3], the Commission on Cancer standards for survivorship care planning [17], and services such as Journey Forward's Survivorship Care Plan Builder [18]. In addition, for survivors living in rural areas there are additional and unique challenges and barriers in survivorship care planning, adherence, and coordination that lead to poorer outcomes, including higher psychological morbidity, poorer quality of life, poorer physical functioning, and increased complaints of cancer-specific symptoms [19,20]. Rural survivors also experience barriers regarding access to treatment, medical providers and health information, psychosocial adjustment and coping, and social and psychological support services, in part due to increased travel for medical services with associated burdens of time, cost, and discomfort [21-24]. The prevalence of numerous health-compromising behaviors, such as smoking, health-related unemployment, and physical inactivity, are significantly higher in rural survivors [25]. Rural survivors are also less likely to seek mental health services and cancer support groups [20,26]. In addition, specific to breast cancer survivors, those living in rural areas are more likely to report experiencing distress, high levels of depression and hopelessness/helplessness, and lower-than-average quality of life compared to urban survivors of breast cancer [27,28].

The unique challenges faced by rural survivors require unique and targeted interventions that mitigate survivorship planning and care barriers associated with residing in rural locations [3,25]. With the growth of mobile technologies in rural areas, opportunities have grown for mobile health (mHealth) venues to enhance communication between patients and providers and improve distribution of cancer SCPs [29]. For survivors living in rural settings, mHealth technologies have the potential to facilitate care coordination; support medical, psychosocial, and practical needs; and improve survivors' long-term health outcomes [30,31]. Some research has reported that rural breast cancer survivors are more likely to prefer electronic modes of communication for submitting questions about SCPs to care providers than urban survivors [8]. Research has also reported that remotely accessible mechanisms—phone, Internet, and email—may be highly effective in meeting rural breast cancer survivors' physical and psychosocial needs [11].

The most common format for distributing SCPs is as a written, hard-copy format. Characteristics of static content and lack of portability may contribute to the perception of their uncertain value and limited utility in easing the transition from active treatment into survivorship by both survivors and providers [32]. A systematic review of survivors' experiences using SCPs recommended that SCPs should be “living” documents in electronic formats that are portable and can be modified and readily available to all stakeholders [33]. Supporting the mobile delivery and “anytime” access to the SCP on a mobile phone has the potential to meet this requirement; as the survivor moves along the survivorship continuum and her or his needs change [34], updates and modifications need to be made. A flexible, reprogrammable, portable tool could accommodate these changing circumstances and needs and ultimately offer a unique approach to handling a survivor's evolving status. At the same time, this tool could facilitate time-sensitive communication of information to support collaborative decision making between survivors, their oncologists, and primary care physicians.

This study explores the feasibility and acceptability of an mHealth app, SmartSurvivor, that incorporates recommended components of a survivorship care plan into a mobile survivorship monitoring and management app for rural breast cancer survivors. It also collects system development requirements and feature enhancements for ensuring the app will enhance survivor self-efficacy, improve patient-provider communication, support adherence to SCP recommendations, and promote decision making among rural breast cancer survivors and their providers.

Between September and December 2014, we undertook a pilot study to evaluate whether converting an SCP into a mobile app that includes IOM-recommended content for survivorship care planning is a feasible and acceptable option for breast cancer patients who have completed active treatment. We also evaluated whether this mobile app could be a tool that can assist providers in their care decision making with breast cancer survivors.

Methods

Prototype Development and Design

Development was undertaken in two phases. In the first early design phase, two members of our research team and a graphic designer used paper prototyping and storyboarding to assess design ideas (see Figure 1) and to block out navigation of IOM-recommended SCP components on individual screens [35]. To situate our design as realistically as possible, in addition to a literature review, we utilized Zapka et al's *Cancer Treatment and Transition to Survivorship* Case Scenario, which was developed to highlight the multilevel issues encountered in cancer survivorship and the challenges they present to designing and testing interventions for this population [36]. Walkthroughs with the paper mock-ups and use-case scenario were conducted before a final paper prototype was approved by the research team.

In the second phase, we utilized Axure (Axure Software Solutions), a layer-based wireframe, rapid-prototyping software tool that allows linkages and dynamic interactions between pages and screens presented in a mobile phone app to simulate real-time interactions and navigation. Axure facilitated

assessment of features such as flexibility of drop-down lists and movement between screens, as well as readability, navigation, and size of text fields that could impact acceptability of the app [37]. The tool generates a downloadable mobile phone app and HTML website, creating a functional prototype with the look and feel of the actual app without requiring any coding. Based on our paper prototyping, the following were built as interactive screens into Axure (see Figure 2 for screenshots):

1. Log-in Screen and Main Menu (see Figure 2 A).
2. Medical Profile, which includes General Information; Care Team (past, current); Treatment Summary (diagnosis, radiation treatment summaries, etc); and Follow-Up Care (eg, ongoing toxicities to track, wellness/concerns, recommended follow-up schedule/frequency, etc) (see Figure 2 B).
3. Journal and Reports component, which includes a tracking tool for self-monitoring and output of logged Journal data (see Figure 2 C).
4. Calendaring link-in for Reminders, Appointments, and Notifications, including an Alerting function linked to Follow-Up Care and Journal logs to, for example, issue an alert if the survivor is dizzy for 3 days (see Figure 2 D).
5. Tips and Tools that deliver tailored tips to survivors based on data input into their Journal (Figure 2 E).
6. A mobile phone audiotaping link-in for documenting notes, appointment questions, etc.

"Mock" patient health information entered into SmartSurvivor was extracted from samples provided by Journey Forward's Survivorship Care Plan Builder [18]. For testing, the final app prototype was uploaded on a mobile phone and the HTML version was loaded onto a laptop on a website that did not require Internet connectivity.

Ethics

This study received University of Washington Institutional Review Board approval as an exempt study. Informed consent was obtained from all individual participants included in the study.

Recruitment

Given the objective of supporting communication and coordination of care, we included both breast cancer survivors and providers in our testing sample to ensure the feasibility of SmartSurvivor for meeting the needs of all end users while minimizing barriers to its utility, feasibility, and acceptability. A convenience sample of breast cancer survivors (n=6), primary care providers (n=4), and an oncologist (n=1) were recruited to participate as testers through contacts of one of the study's investigators. Survivors ranged between 2 months and 5 years postactive treatment and lived in an urban area. All primary care providers had prior experience working in rural settings in which they saw breast cancer patients for ongoing care, including cancer surveillance. All testers owned a mobile phone.

Figure 1. Prototyping development.

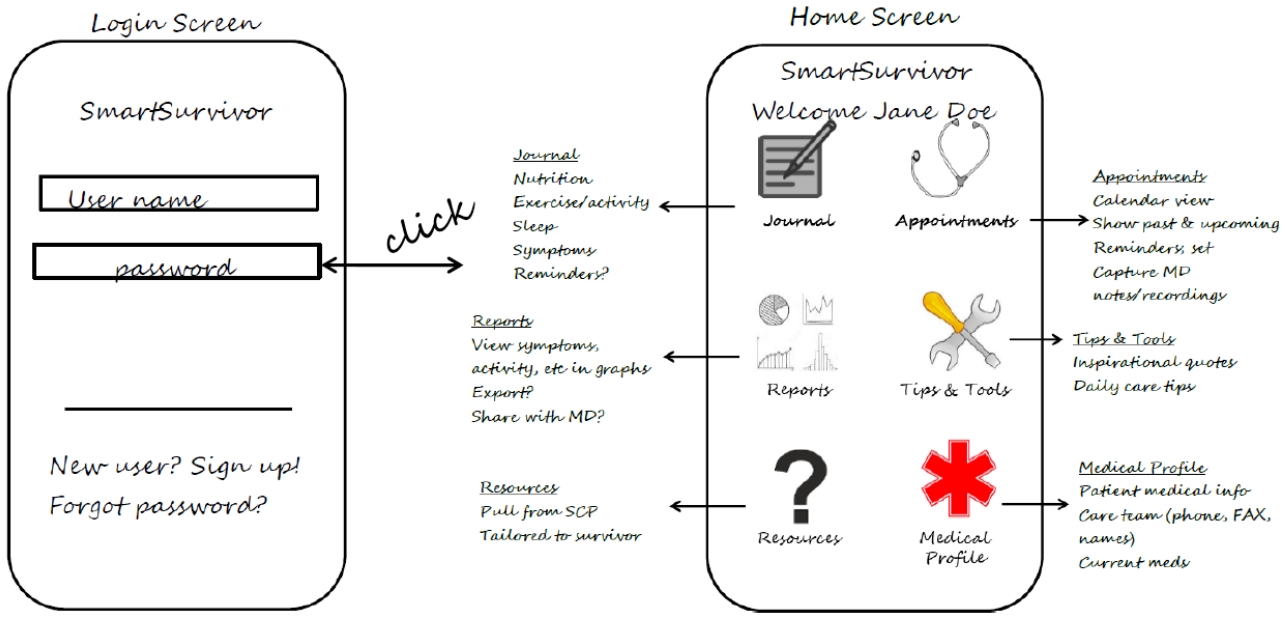
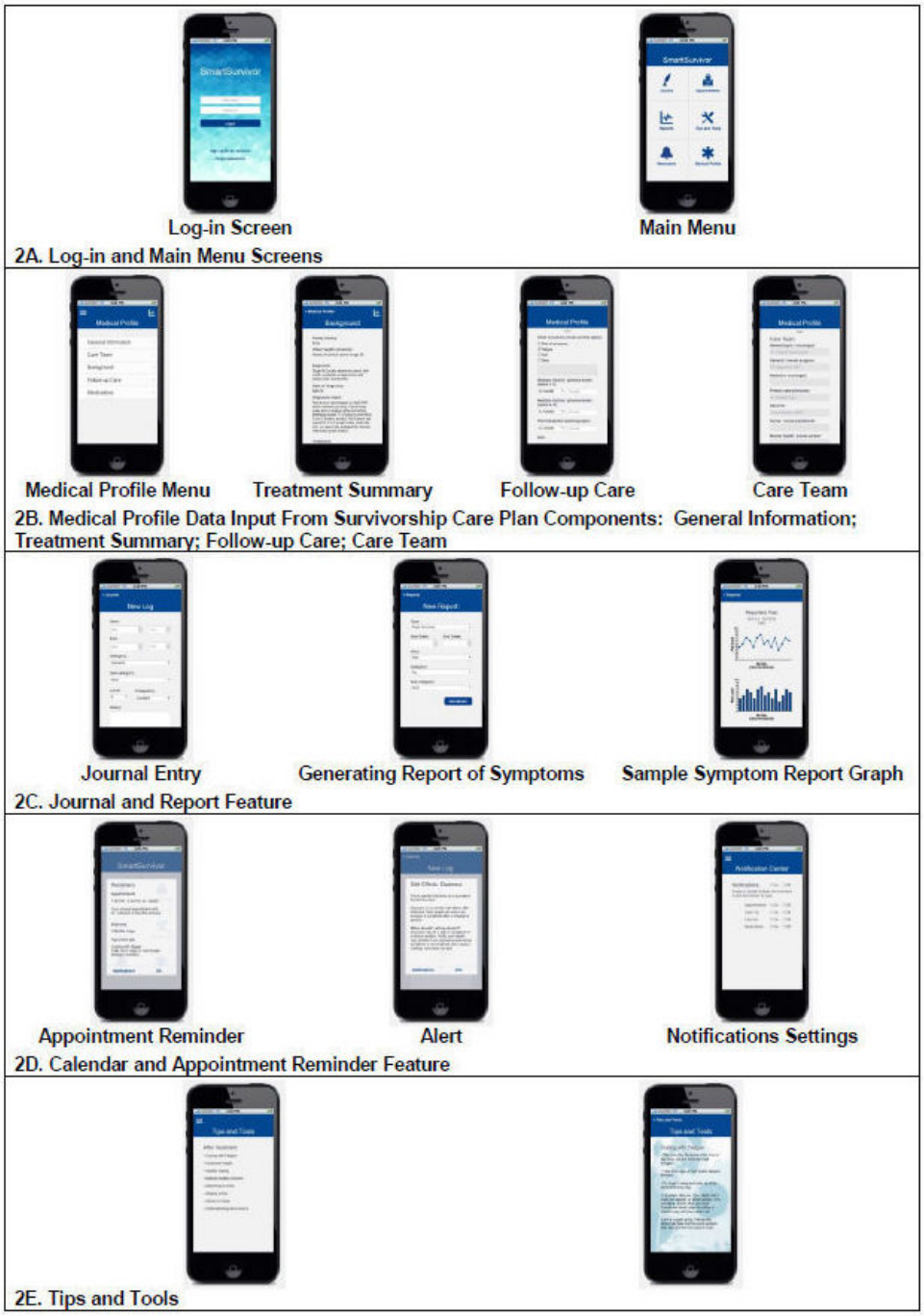


Figure 2. SmartSurvivor prototype screens.



Testing

Testing sessions lasted between 45 and 60 minutes and were led by a research team member with expertise in usability testing accompanied by a notetaker. Sessions were held at the location and time convenient for each tester and utilized the talk- or think-aloud protocol, which is a widely used method for capturing the usability of an mHealth app [38]. After a brief introduction to the project, testers were walked through the prototype and then allowed to interact with the mobile phone version. Through informal questioning, survivor and provider testers were asked to comment on SmartSurvivor's features (eg, logging and reporting); utility for supporting SCP objectives, survivorship care, and self-management; resources; and overall ease of use. While navigating through the screens, all testers were asked to talk aloud about their expectations regarding interactions with buttons and drop-down menus, navigation, and clarity of information presented in each of the components. Provider testers were also asked to comment on how SmartSurvivor might integrate with their care delivery strategies. At the conclusion of the session, testers received a US $25 gift card for their participation.

Following each session, the testing team collated their notes and observations in a debriefing session. The final set of notes was summarized and the content analysis method [39], a qualitative data analysis strategy used to generate

recommendations from moderated discussions [40], was used to evaluate and synthesize the testing sessions into themes.

Results

Thematic Outcomes

Six primary themes emerged from the analysis (see Textbox 1) and are detailed below.

Overall, both survivors and providers were positive about the value of using SmartSurvivor to support survivorship care objectives, thought it would be easy to use, and viewed SmartSurvivor as a way to make the SCP more accessible and useful. All testers were familiar with, and comfortable using, a mobile phone and regularly accessed the Internet on their mobile phones to access information, including health information.

Theme 1: SmartSurvivor Provides One-Stop Shopping

Having one place to file all contact and treatment information is supportive of coordination of care and provider-provider communication. Overall, survivors were enthusiastic about having one location as a repository for medical team contact information, treatment records, insurance numbers, etc. SmartSurvivor was seen as a good *memory aid*, as illustrated in the following quotes:

> *I have a hard time remembering all the doctors I have, when I've seen them.*
>
> *I'm always asked what medications I'm on so this would make it a lot easier.*

Providers also saw the ability to obtain treatment and medication summaries from one source as useful, stating it would streamline the fact-finding portion of an appointment:

> *If I had a patient experiencing continued dizziness, being able to see exactly what treatment she's had will help me figure out if this is a side effect of treatment or if it's unrelated.*

Providers also saw SmartSurvivor as a way to support coordination of care with specialists when consultation about the patient is needed.

Theme 2: Survivors and Providers Are Empowered by Better Tracking and Communication

The combination of Journaling symptoms and their output—Reports—may improve self-efficacy for management of survivorship needs and be supportive of improved patient-provider communication and provider decision making. Survivors not only need to track symptoms and remember appointments, they are encouraged to engage in wellness activities, monitor their sleep and eating, and track their mood. Some survivors carried notebooks, some used the *Notes* function in their mobile phones, and one had developed an elaborate system of sticky notes that were entered into a spreadsheet at the end of the day to keep track between medical visits. All survivors stated that their current methods are inadequate to their ongoing surveillance and monitoring needs. SmartSurvivor was seen as a way to improve self-management to support SCP objectives with a tool for tracking symptoms, wellness activities, mood, etc:

> *I have to be my own patient advocate all the time and this will help me track what I need to track. And then, when I see the doctor I can give her something concrete like this graph, instead of saying, "yeah, I was really tired last week," I can show her how tired, for how long.*
>
> *I'm on medication that increases my risk of ovarian cancer so I need to track any spotting. This would make it much easier than the piece of paper I'm using now.*

In addition, survivors stated that being able to see results, notice trends, and track patterns would be very useful.

Textbox 1. Key findings from pilot-testing SmartSurvivor with survivors and providers.

Theme 1: SmartSurvivor provides one-stop shopping.
Theme 2: Survivors and providers are empowered by better tracking and communication.
Theme 3: Portability is a plus.
Theme 4: Interoperability/integration of SmartSurvivor with other information sources is a concern.
Theme 5: Survivors are uncertain about being reminded.
Theme 6: SmartSurvivor needs to be tailored for rural users.

For providers, the Report function was seen as valuable for accurate and informative patient reporting, as well as for saving time during a visit:

> *Seeing a graph of what symptoms the patient is having and when is more informative.*
>
> *We have so little time during an appointment; this would help me spend more time with my patients.*

It was also seen as informing decision making about a patient's care:

> *Let's say she's experiencing pain and swelling under her right arm. It's on the graph but I also see she started a new exercise regimen. Instead of sending her back to her surgeon 250 miles away in a snowstorm, we might explore other options first, like get a CT or MRI scan locally. Plus, I could easily coordinate with her surgeon about this option since all the contact information is right here.*

Both providers and survivors stated that being able to create overlays of reports, for example, a graph that combines pain with sleep or exercise with mood, would be even more useful

than individual reports. The SmartSurvivor email function that allows the survivor to email an output of a Report in Excel or graph form in advance of a medical appointment was seen as supporting communication and coordination of care by both survivors and providers. Both survivors and providers viewed the ability to record questions and comments before or after a medical appointment as improving patient-provider communication; survivors appreciated the ability to document questions and concerns before medical visits and providers thought this feature would encourage more productive communication during visits.

Theme 3: Portability Is a Plus

Within this sample of mobile phone users, the phone is carried everywhere and used routinely as part of everyday living. In comparison, the standard, paper-based SCP is a heavy notebook that is a burden to carry, as reflected in the following quote:

> *I was told I shouldn't lift more than 5 pounds after my surgery so this [notebook] just sat on the table for months!*

Because their mobile phones are always available, survivors liked the idea of having an app that is not only convenient but very portable for meeting their survivorship care needs. Primary care providers reported their survivor patients rarely brought the entire SCP notebook to an appointment even when first transitioning from active treatment, but occasionally brought a subset of its pages.

Theme 4: Interoperability/Integration of SmartSurvivor With Other Information Sources Is a Concern

Some survivors are using mHealth tools like MyFitnessPal to track their diet and exercise. Although not developed with survivors in mind, having the capacity to link or integrate data from these different apps with SmartSurvivor would be beneficial and enhance its use as the primary support tool. Survivors who are seen in multiple health care systems also mentioned interoperability as beneficial:

> *I go to three different doctors and none of them can see the other's records so I have to coordinate my own care.*

Providers also brought up interoperability between health care systems as a possible barrier and expressed concerns about data quality if SmartSurvivor information were input by hand versus through the electronic medical record system.

Theme 5: Survivors Are Uncertain About Being Reminded

In addition to the Journal and Report features, the Reminders/Notifications/Tips functions were seen as important to ongoing surveillance for both survivors and providers. In general, reminders regarding follow-up tests and appointments were viewed as useful, but this appeared to depend on status within the survivorship continuum. Survivors less than 3 years postactive treatment were positive about Reminders. Survivors over this point stated they might turn this feature off because they did not want to be reminded about their cancer. In fact, one survivor close to her 5-year anniversary date stated, “I don’t want to obsess over my care, over my cancer. I just want to live my life.”

Overall, providers also found the Reminder function as useful, but only if recurring reminders could be recalibrated easily if an appointment is missed. This would be particularly important for rural survivors who frequently need to reschedule appointments due to transportation issues (eg, weather disruptions and distance). Providers also noted that background information would be helpful in deciding whether a routine appointment could be completed locally rather than by a specialist who practices hundreds of miles away.

Theme 6: SmartSurvivor Needs to Be Tailored for Rural Users

Several issues specific to rural survivors' needs were brought up by providers. Primary care providers reported that even though the recommended health literacy level for the SCP is around 8th grade, survivors in rural settings often have a lower literacy level and a large proportion are not native English language speakers. For patient education, providers reported using photos, visual cues, and simplified language. Another issue is tracking symptoms, wellness, mood, etc; again, survivors with lower literacy levels may have different needs. One provider stated the following:

> *It has to be simple for most of my rural patients. And I need to instruct a patient in how to record symptoms, to record simple events and at the time (or closest to the time) they're actually occurring. If the app had a way to click to capture symptoms, then you could potentially generate time of day and frequency just from that. Simpler is better for tracking; if it gets too hard, my patients won't use it.*

Discussion

Principal Findings

We successfully pilot-tested a prototype SmartSurvivor app that was both feasible and acceptable to a small sample of urban breast cancer survivors and health care providers and that could serve as the foundation for developing a tool to support rural breast cancer survivors. While some mHealth tools have been developed for survivors [29], these are limited to areas such as exercise- and diet-monitoring apps and lack concordance with comprehensive survivorship care planning.

We identified key features that will be important to include in further development, as well as exploration of the SmartSurvivor app with a larger sample of both survivors and providers, including the following:

1. Simplifying the data input process for patients by (a) improving Journaling to include drop-down menus or other features that streamline the data input process and (b) enabling auto-capture of date and time.
2. Improving the data output feature by creating the ability to build overlays of individual graphs, for example, sleep, exercise, and pain.
3. Establishing interoperability between SmartSurvivor and other tools by (a) creating linkages between SmartSurvivor

and electronic health record systems to increase confidence that clinical data (ie, appointments, medication lists and changes, and test results) are accurate and (b) enabling linkages with patient tracking tools such as Fitbit, MyFitnessPal, etc.

Those living in rural areas experience unique challenges in their survivorship care [19-28]. Although mobile health technologies have the potential to mitigate some of those challenges, the unique needs of rural survivors identified in this study, such as health literacy levels, need to be addressed in building an mHealth app for this population.

We believe that this pilot study establishes the foundation for future work on SmartSurvivor that will include a larger sample of rural survivors and providers to explore efficacy. A proposal is currently in process to conduct a randomized trial that will (1) compare SmartSurvivor use versus *usual care* (ie, paper-based SCP alone) on patient-reported self-efficacy; (2) determine the effect of SmartSurvivor use on adherence to SCP recommendations, quality of life, patient-provider communication, and care coordination as compared to usual care; and (3) explore the utility of SmartSurvivor for informing health care providers' decision making around clinical care and care coordination for their breast cancer survivor patients.

Limitations

A limitation of this work is the absence of rural breast cancer survivors, as well as inclusion of a single oncologist. However, including primary care providers with experience practicing in rural settings helped us capture some additional features to include in SmartSurvivor. This also helped identify a baseline of high-quality functional design requirements that will align the app with the needs of all its end users and minimize barriers to its use.

Comparison With Prior Work

Our findings explore an area—mobile support for rural breast cancer survivors who have completed active treatment—that has received little attention in research studies and few efforts to address. The literature recommends that SCPs become portable, flexible, and easy to access and update as survivors' needs change along the survivorship continuum [3,17]. The logical evolution of support for survivors is to identify the requirements for, and explore the feasibility and acceptability of, building an mHealth tool to meet this need. However, no work has been conducted in this area for the largest group of cancer survivors.

Feasibility and acceptability of an mHealth tool is only a first step. A factor in the development of any mHealth tool is its content. A recent review of the content available within mobile phone apps targeting cancer support reported that only 48.8% of mHealth tools surveyed had been developed by health care organizations and professionals [32]. While our work did utilize providers and cancer specialists in reviewing SmartSurvivor, we anticipate development of content after this point will also include these user groups, as well as rural breast cancer survivors.

For those in rural settings where barriers to optimal care and lower health outcomes have been well-documented [3,20-26], a mobile SCP is a promising intervention. However, it is unknown how mHealth technologies may be leveraged to support the specific and vulnerable group of breast cancer survivors living in rural settings. The work described in this paper addresses a significant gap in the cancer survivorship field.

Conclusions

Making the SCP accessible, portable, and *always available* has the potential to empower survivors to actively engage in planning, monitoring, and following health behavior guidelines throughout the survivorship trajectory. SmartSurvivor will provide a unique approach to survivorship care planning as a repository for the survivor's unique history and self-management needs, as well as a mechanism for sharing this information with her care team. This approach is responsive to a survivor's fluid and evolving needs, accommodating these changing circumstances and needs. At the same time, this approach facilitates time-sensitive communication of this information to support collaborative decision making between survivors, their oncologists, and primary care physicians.

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Conflicts of Interest

None declared.

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Abbreviations

IOM: Institute of Medicine
mHealth: mobile health
SCP: survivorship care plan

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Original Paper

Adherence to Report and Patient Perception of an Interactive App for Managing Symptoms During Radiotherapy for Prostate Cancer: Descriptive Study of Logged and Interview Data

Ann Langius-Eklöf[1], RN, PhD; Mats Christiansen[1], RN, MSc; Veronica Lindström[1], RN, PhD; Karin Blomberg[2], RN, PhD; Maria Hälleberg Nyman[2], RN, PhD; Yvonne Wengström[1], OCN, PhD; Kay Sundberg[1], RN, PhD

[1]Division of Nursing, Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Huddinge, Sweden

[2]School of Health Sciences, Örebro University, Örebro, Sweden

Corresponding Author:
Ann Langius-Eklöf, RN, PhD
Division of Nursing
Department of Neurobiology, Care Sciences and Society
Karolinska Institutet
C3
Alfred Nobels allé 23
Huddinge, 141 83
Sweden
Phone: 46 722535878
Fax: 46 852486809
Email: ann.langius-eklof@ki.se

Abstract

Background: Patients undergoing radiotherapy for prostate cancer experience symptoms related to both the cancer itself and its treatment, and it is evident that patients with prostate cancer have unmet supportive care needs related to their disease. Over the past decade, there has been an increase in the amount of research within the field of mobile health and the use of apps as tools for managing illness. The main challenge is to develop a mobile technology to its full potential of being interactive in real time. The interactive app Interaktor, which aims to identify and manage symptoms in real time includes (1) a function for patients' assessment of the occurrence, frequency, and distress of symptoms; (2) a connection to a monitoring Web interface; (3) a risk assessment model that sends alerts via text message to health care providers; (4) continuous access to evidence-based self-care advice and links to relevant websites for more information; and (5) graphs for the patients and health care providers to view the history of symptom reporting.

Objective: The aim of the study was to investigate user behavior, adherence to reporting, and the patients' experiences of using Interaktor during radiotherapy for localized advanced prostate cancer.

Methods: The patients were instructed to report daily during the time of treatment and then for an additional 3 weeks. Logged data from patients' use of the app were analyzed with descriptive statistics. Interview data about experiences of using the app were analyzed with content analysis.

Results: A total of 66 patients participated in the study. Logged data showed that adherence to daily reporting of symptoms was high (87%). The patients used all the symptoms included in the app. Of the reports, 15.6% generated alerts to the health care providers. Overall, the patients found that it was easy and not particularly time-consuming to send a daily report, and many described it as becoming a routine. Reporting symptoms facilitated reflection on their symptoms and gave them a sense of security. Few technological problems were reported.

Conclusions: The use of Interaktor increased patients' sense of security and their reflections on their own well-being and thereby served as a supportive tool for the self-management of symptoms during treatment of prostate cancer. Some further development of the app's content might be beneficial for future use.

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KEYWORDS

mobile apps; mHealth; prostate cancer; symptom assessment

Introduction

Background

Prostate cancer is the most common form of cancer in men and occurs mainly in middle and older age [1]. Depending on disease stage, patients are offered three alternative options, that is, expectation, surgery, (prostatectomy) or radiotherapy for 5 to 8 weeks [2]. Overall, there is evidence that patients with prostate cancer have unmet supportive care needs during and after treatment, as well as when they are under long-term surveillance [3]. These needs are multifocal, and they relate to physical, emotional, social, and intimacy needs and vary over time and between treatment modalities. During radiotherapy, patients with prostate cancer experience symptoms related to both the disease and the treatment, for instance, urinary symptoms, bowel symptoms, pain, and fatigue [4-6]. Patients report using different strategies to alleviate symptom burden with a variation in outcomes [7,8]. Furthermore, self-care advice from clinicians for managing symptoms during radiotherapy varies greatly in both quantity and content [4]. There is limited evidence on how to design interventions for managing symptoms [9] despite the acknowledgment that undiagnosed symptoms impact the quality of life and recovery of patients with cancer [10]. It is proposed that care and support for patients with cancer should include early recognition of signs and symptoms, support for self-care, personalized care planning, and routine use of patient-reported outcome measures (PROMs) [11]. Routine use of PROMs in cancer care seems to facilitate the identification of present problems and impact of treatment, and enhances patient-clinician communication that promotes shared decision making [12,13]. There are some promising studies that have used Web-based PROMs with interactive components to support patients with cancer to deal with their disease by monitoring symptoms, providing self-care advice, and giving access to clinicians [14-16]. Ruland et al [14] used a Web-based system that included components for patients' assessment of symptoms, provision of triggered self-management support, e-communication with expert cancer nurses, an e-forum with other patients, and access to a diary for personal notes. Furthermore, in the randomized controlled study including patients with breast and prostate cancer, there was a slight favor in the intervention group on overall symptom distress [14]. In another study, a Web-based interface for reporting symptoms related to chemotherapy was tested [15]. Patients randomized to use the Web interface before each visit to the oncology clinic showed considerable improvement in the quality of life and had fewer emergency visits and remained longer on chemotherapy than those patients receiving usual care. Another study showed that weekly Web-mediated follow-up of self-reported symptoms in a group of patients with advanced lung cancer improved overall survival in comparison with patients having routine follow-up [16]. During the last decade, there has been an increasing interest within the field of mobile health (mHealth), which has shifted from focusing on the technical development to how the use of apps can influence people and their health [17]. A review of how mHealth is used in different phases of cancer treatment revealed that most reports focus on support in medical decision making and much less on how to support patients during the entire care process [18]. A mobile phone–based remote monitoring system for real-time collection of PROMs aiming to provide structured self-care has proven to be feasible and acceptable for use by the patients but not developed for prostate cancer [19]. Paterson et al [20] tested a real-time electronic diary for prostate cancer survivors and showed high response rate and acceptability among the patients.

More studies concerning the use of apps are warranted as it is still in its initial phase [21] and its full potential is not used regarding evidence-based content, usability, security, and interactivity [22,23].

In collaboration with a Swedish company, Health Navigator, that specializes in health care management and new innovative care solutions, an interactive app (Interaktor), for smartphones and tablet computers has been developed. The theoretical underpinning in the developmental process was person-centered care [24]. In person-centered care, the importance of integrating the patients' perspective in the care process and attaining interaction between the patient and the care provider is emphasized. It is essential to enable patients to actively participate in their care rather than being passive receivers of care [25]. Interaktor includes (1) a function that allows patients' assessments of the occurrence, frequency, and distress of symptoms, which are immediately available to health care providers; (2) a connection to a monitoring Web interface and logged data storage on a secure server; (3) a risk assessment model for symptoms of concern that sends alerts via text message to the health care providers; (4) continuous access to evidence-based self-care advice related to reported symptoms and links to relevant websites for more information; and (5) graphs for the patients and health care providers to view the history of symptom reporting. Interaktor is generic and can be adjusted for different diagnoses and settings. The content of each version is developed in partnership with patients and health care professionals and by reviewing the contemporary literature.

Objectives

This study involves a prostate cancer version for use during radiotherapy. The radiotherapy is predominantly given at outpatient clinics, which means that the patients largely manage their symptoms and concerns at home based on information and advice provided by the clinic. There is a clear knowledge gap on how to support patients with prostate cancer in an effective and timely manner during radiotherapy. Therefore, testing Interaktor during treatment in outpatient care was considered appropriate to identify its potential to be beneficial for easing symptom burden.

In previous feasibility studies, the version of Interaktor for prostate cancer and a version for older adults with homecare were observed to be acceptable and user-friendly [26,27]. Patients with prostate cancer using Interaktor during radiotherapy reported reduced symptom burden compared with

those who did not use the app [28]. However, it is important to also assess the patients' experiences with using a new technology [29]. Therefore, the aim of this study was to investigate user behavior, adherence to reporting, and experiences of using Interaktor during radiotherapy for localized prostate cancer.

Methods

Study Design and Recruitment

The study was conducted at two university hospitals, one urban and one rural, where the intervention group that used Interaktor during radiotherapy was compared with a historical control group [28]. This study comprises logged data and interviews with patients in the intervention group. Patients scheduled for radiotherapy of prostate cancer at the two clinics were consecutively invited to participate in the study. The inclusion criteria were locally advanced prostate cancer planned for radiotherapy and being literate in Swedish and physically, psychologically, and cognitively able to participate in the study assessed in a conversation between the researchers and the patients. The intention of treatment was curative. Treatment was administered according to the national guidelines [30], including either external beam radiation therapy (EBRT) for 5 weeks or EBRT with a combination of iridium high-dose-rate brachytherapy for 8 weeks both with adjuvant hormone therapy based on tumor stage. Depending on the regimen, the patients had the ability to report between 56 and 77 days.

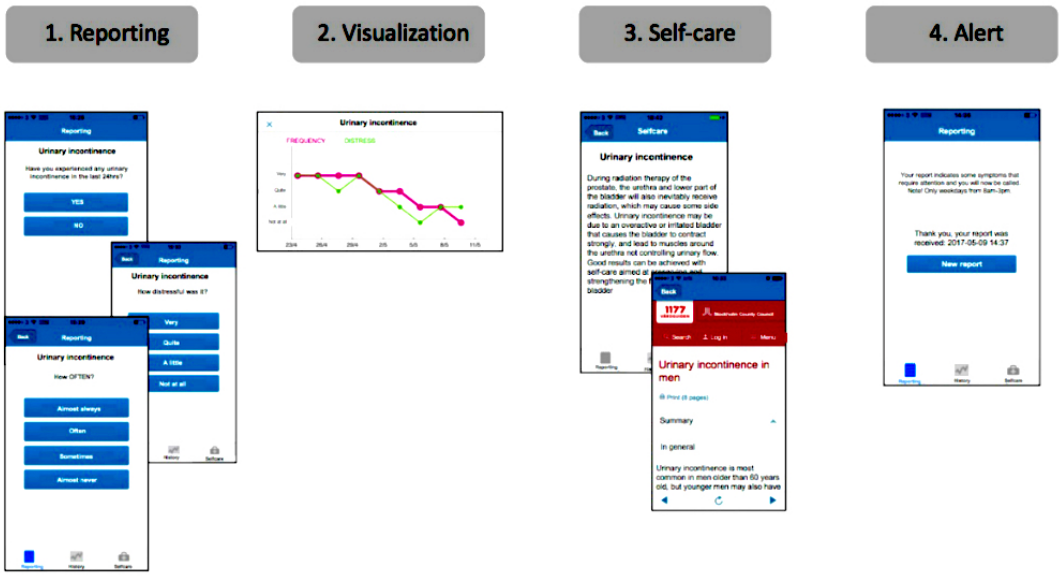
Description of the Prostate Cancer Version of Interaktor

This version includes 14 identified [4] and tested [26] symptom questions regarding bladder (urinary urgency, difficulties in urinating, urinary leakage, and hematuria) and bowel (diarrhea, stool leakage, obstipation, and blood in stool) function, fatigue, pain, worry, depression, sleep, and flushing. There is also an open comment section—Other symptoms or concerns to report—that provides opportunity to the patients to add comments. Patients are asked about the symptoms' occurrence, frequency, and the distress level based on a structure used in a standardized symptom and quality of life questionnaire [31] (eg, Do you experience urinary urgency?, and if the answer is yes, the patient is asked how often—never, sometimes, rather often, or very often—followed by how distressing—not at all, a little, rather, or very much—the symptom is). The symptoms of insomnia, obstipation, and blood in the stool are only assessed by the distress level because these symptoms are not appropriate to report regarding frequency on a daily basis.

Some of the reported symptoms generate an alert, defined by symptom frequency or distress level, to registered nurses at the respective clinics. The levels at which alerts are triggered are the same for all patients and are set according to a risk assessment model based on consultations with health care professionals caring for this group of patients. The conclusion was to differentiate symptoms into alerts that demand rather instant care (such as a prescription for a painkiller or a coaching conversation), or that represent an acute threat to the patients' health and are a direct cause of seeking emergency care if left unattended for too long. The alerts were set regarding urinary urgency, difficulties in urinating, obstipation, blood in stool, pain, worry, depression, and hematuria. There are two kinds of alerts—yellow alerts that request a nurse to contact the patient during the same day, for example, reporting having pain sometimes, and red alerts requiring contact within 1 hour, for example, reporting urinating difficulties as often or almost always.

A total of 16 self-care advice regarding symptoms related to prostate cancer and radiotherapy are included in the app together with relevant links to evidence-based Web pages. An overview of the components in Interaktor is presented in Figure 1.

Figure 1. Illustration of the Interaktor app.



Study Procedure

All of the patients were provided with a smartphone belonging to the project with the app Interaktor installed and were requested to report their symptoms daily (or more often if they wished) during office hours on weekdays throughout the radiotherapy period and for 3 weeks after. The patients were given thorough instructions by the researchers on how to use the app and a written checklist including a phone number for technical support. The patients were given an individual log-in and personal identification number (PIN) to get access to the app. They were also informed that in case of an alert, a nurse would call them during office hours on their home phone number until they could be reached. Any acute problem occurring at other time points had to be handled according to the standard procedure of the oncological clinic, that is, a certain phone number at the clinic to call for advice. A notification was sent out as a reminder to the patients to make a report in the app if they had not reported by 3 PM. The patient's self-report was sent directly via the secure server and was accessible from a Web interface for the nurses at the hospitals and the researchers at the university. The average time required for reporting was estimated to be 5 minutes [26].

Data Collection and Analysis

Data were collected from two sources, which are (1) logged data from database, and (2) telephone and face-to-face interview.

First, logged data extracted from the database, which included (1) the total number of reports, (2) the number of reports per symptom, (3) the severity and distress levels of symptoms, (4) the alerts generated, (5) patients' responses to the open-ended question, and (6) actions on alerts. The readings of self-care advice and historical graphs were not logged.

Second, data obtained from telephone and face-to-face interviews conducted by 3 members of the research team shortly after the end of using the app. The interviews followed a semistructured guide with the initial question "What was it like to report in the mobile phone?" (Table 1). The interviews lasted for 10 to 15 minutes, and during the interviews, the researchers wrote down the answers as close to verbatim as possible in a template following the interview guide.

Table 1. The semistructured interview guide.

Question		Follow-up question
1.	What was it like to report in the mobile phone?	Difficulties and benefits or opportunities?
2.	How did you experience the technology?	
3.	How did you perceive the questions?	Relevant or something missing?
4.	What was it like to report daily?	
5.	Was it relevant to report from the beginning of treatment to 3 weeks after the end of treatment?	
6.	Have you been contacted by a nurse after an alert?	If so, your experience?
7.	Can you describe what use you have had of the self-care advice?	
8.	Can you describe how you used the Internet links?	
9.	Can you describe how you used the historical graph?	
10.	Is there anything else you want to add?	

Logged data were analyzed using descriptive statistics. The statistical procedures were performed in Microsoft Office Excel 2010 (Microsoft Corporation, Redmond, WA, USA) and IBM SPSS (version 23.0 for Windows, Chicago, IL, USA). The logged symptom data were organized by frequency (1=very seldom, 2=sometimes, 3=often, or 4=almost always) and by how distressing the symptom was (1=not at all, 2=a little, 3=rather much, or 4=very much).

The analysis of the notes taken during the semistructured interviews was conducted using summative content analysis [32]. The verbatim notes from the patient interviews were read through by 2 of the authors to gain familiarity with the content. Subsequently, the authors independently identified codes that responded to the study aim. The codes were discussed between the 2 authors regarding differences and similarities and how well they covered the content of the interviews. The harmonized codes were transferred to an Excel spreadsheet, whereas their relationships were identified for organizing them into categories. The codes and categories were discussed and verified with the other authors. A quantification within the categories was also performed to visualize potential patterns [33,34].

Ethical Aspects

Ethical approval for the study was obtained from the Regional Ethical Review Board of Uppsala University (dnr 2011/256). All participants gave their oral and written consent to participate. This study was designed to meet the ethical principles for research described by the International Council of Nurses by ensuring anonymity, integrity, and confidentiality for the participants [35]. To assure that all participants had equal access and ability to participate in the study, participants were lent a smartphone.

Results

Enrollment and Sample Characteristics

There were 107 eligible patients in the intervention group, but 34 patients declined or could not be reached and 7 did not fulfill the inclusion criteria leaving 66 (61.7%) patients that

participated in the study. The patients' mean age was 69 years, and further clinical and demographic data are presented in Table 2.

A total of 53 patients participated in the interviews (face-to-face, n=9) regarding the experience of using Interaktor. There were 13 patients that did not answer repeated telephone calls from the researcher after they finished reporting through the app.

Logged Data

A total of 3 patients filled out the report once, when instructed about the app, but did not file any further reports during the study period. The logged data from the remaining 63 patients showed that adherence to reporting symptoms daily was on average 87% (median 92%, range 16%-100%). The patients had in total sent in 3536 reports during the study period, and the patients reported 10,025 specific symptoms in total. All of the symptoms included in the app were used by the patients (Table 3). The most common symptoms reported were urinary urgency (18.70%), fatigue (18.33%), hot flushes (16.17%), and difficulties in urinating (10.50%).

Of the 10,025 reported symptoms, 1566 (15.60%) generated alerts to the nurse at the oncology clinic (Table 4). Out of these alerts, 517 (33.00%) alerts were considered severe (red), and 1049 (67.00%) were considered less severe (yellow). The alerts were most commonly related to urinary urgency (yellow n=359, red n=127), pain (yellow n=287, red n=212), and difficulties in urinating (yellow n=274, red n=72). All of the alerts led to the nurses contacting the patients and adding a written note in the system such as "Telephone call to the patient – no further action," "Pain same as before – already been taken care of," "Extension of the patient's prescription," "Booked an appointment with the physician," and "Advice given on the patient's medication."

Table 2. Clinical and sociodemographic characteristics of the study participants.

Clinical and sociodemographic characteristics	Descriptive analyses (N=66)
Age, years	
Mean (SD)	69 (5.8)
Median (range)	70 (53-82)
Living situation, n (%)	
Married or living with partner	57 (86)
Living alone	9 (14)
Education level, n (%)	
Junior compulsory	9 (14)
Senior high school	23 (36)
Postgraduate or university	32 (50)
Occupation, n (%)	
Working, retired	59 (89)
Sick leave	7 (11)
Clinical tumor stage, n (%)	
1	16 (24)
2	29 (44)
3	17 (26)
Missing	4 (6)
Treatment, n (%)	
Adjuvant hormonal therapy	50 (76)
EBRT[a]	20 (30)
Brachytherapy combined with EBRT	46 (70)

[a]EBRT: external beam radiotherapy.

Table 3. Occurrences, frequency, and distress of the symptoms as reported in the app by patients with prostate cancer (N=63) during their radiotherapy.

Symptoms (number of patients reporting at least once)	Occurrence	Frequency		Distress (N=14)	
	n (%)	Mean (SD)	Range	Mean (SD)	Range
Urinary urgency (n=60)	1875 (18.70)	2.18 (0.676)	1-4	2.07 (0.437)	1-3
Fatigue (n=58)	1838 (18.33)	2.22 (0.589)	1-4	2.06 (0.577)	1-4
Hot flushes (n=43)	1621 (16.17)	1.99 (0.483)	1-4	1.89 (0.429)	1-4
Difficulties in urinating (n=47)	1053 (10.50)	2.28 (0.692)	1-4	2.22 (0.734)	1-4
Pain (n=46)	685 (6.83)	2.30 (0.714)	1-4	2.38 (0.559)	1-4
Insomnia (n=43)	651 (6.49)	N/A[a]	N/A	2.20 (0.592)	1-4
Diarrhea (n=48)	598 (5.97)	2.08 (0.525)	1-4	2.10 (0.536)	1-4
Urinary leakage (n=27)	358 (3.58)	1.94 (0.568)	1-3	2.14 (0.602)	1-4
Stool leakage (n=29)	273 (2.72)	1.59 (0.527)	1-3	2.01 (0.756)	1-4
Obstipation (n=30)	255 (2.54)	N/A	N/A	2.20 (0.689)	1-4
Depression (n=28)	253 (2.52)	2.29 (0.885)	1-4	2.39 (0.780)	1-4
Worry (n=23)	248 (2.48)	1.95 (0.724)	1-4	2.20 (0.610)	1-4
Hematuria (n=33)	175 (1.75)	2.23 (0.833)	1-4	1.79 (0.497)	1-3
Blood in stool (n=22)	142 (1.42)	N/A	N/A	1.93 (0.608)	1-4

[a]N/A: not applicable.

Table 4. Distribution of the alerts as reported in the app by patients with prostate cancer (N=63) during their radiotherapy presented on symptom and alert levels.

Symptoms (number of patients reporting)	Yellow alerts, N=1049, n (%)	Red alerts, N=517, n (%)
Urinary urgency (n=52)	359 (34.22)	127 (24.6)
Pain (n=63)	287 (27.36)	212 (41.0)
Difficulties urinating (n=44)	274 (26.12)	72 (13.9)
Depressed (n=13)	75 (7.15)	38 (7.4)
Worry (n=16)	29 (2.77)	36 (6.9)
Hematuria (n=21)	25 (2.38)	32 (6.2)
Obstipation	0 (0.00)	0 (0.0)
Blood in stool	0 (0.00)	0 (0.0)

A total of 47 (75%) patients sent 433 free-text comments through the open question. These mainly consisted of the message “You don´t need to call, my symptom is the same as yesterday.” Other free-text messages were such as “I have back pain but cannot see how this could be related to the treatment” or reporting another symptom not included in the app, for example, “I feel dizzy.” The free-text was also used for other communications with the nurses such as wishing the nurse a good weekend or describing upcoming plans for the patient’s weekend.

Patients’ Perceptions of the App

The analysis of the interviews resulted in the following six categories: reporting and content, self-care advice, historical graphs, alerts, technology, and safety and novelty. Overall, the patients reported that it was easy to use the app, even those few who were not accustomed to smartphones. It was not particularly time-consuming to send reports daily, and the patients described reporting as becoming a routine. Reporting symptoms was described as making the patients reflect over their own well-being.

Reporting and Content

According to the patients (n=44), the possibility to report daily facilitated reflection on their symptoms and illness:

> *When I answered the questions, I thought a lot about how I was feeling...It gave me perspective on my illness...I was feeling pretty good after all...* [P6, age 73 years]

The content and the design of the questions were described as relevant by the majority of the patients (n=48); however, some (n=10) said that it was sometimes difficult to nuance the answer alternatives:

> *Relevant questions, but might be a little blunt; hard to know what is meaningful to report, hard to put the level of how to respond to such as "not at all" or "a little" distress in the beginning.* [P58, age 74 years]

Some patients (n=16) wanted the possibility to say more about the symptoms, and 3 said that the app lacked symptoms such as gas in the stomach and dizziness.

The reporting sometimes became a routine for the patients (n=20) commenting that:

> *I did it every morning after listening to the news on the radio.* [P56, age 72 years]

Some patients (n=7) said that they appreciated the reminder that came at 3 PM, if they had not submitted a report earlier that day.

Self-Care Advice

The self-care advice was read by the majority of patients (n=43). Many of them (n=25) reported that the advice had been important to them, particularly concerning knowledge (n=18) and support to alleviate symptom burden (n=7). A few patients (n=5) said that they had already received the information from the nurses about self-care advice or side effects, or they had decided that they did not need or want to use that feature of the app.

Historical Graphs

A total of 21 patients reported that they followed their symptoms over time in the graphs, and they described how this function gave them and their families confirmation of their well-being:

> *I looked at the lines and it gave me in some strange way a confirmation of how I was feeling* [P24, age 69 years]

> *I used the graphs to show my family and friends that I actually felt good during the treatment.* [P21, age 73 years]

Some patients (n=13) stated that they did not follow their own graphs, mainly because they had forgotten they had the option to do so (n=7).

Alerts

To be contacted by the nurses in connection with an alert was described as positive (n=19) through the direct dialogue with the nurses:

> *It felt good to be called by the nurse... it was a confirmation that it worked...I felt like a VIP and my problem was easily solved by just talking to the nurse.* [P21, age 73 years]

There were also patients who expressed a wish to decide for themselves when to call the nurse (n=10). A total of 4 patients did not want to be contacted because of alerts, and they described how they had learned to adjust their responses to avoid a call from the nurse:

> *It took me about a week to fine tune the level at which to report symptoms. At the start the nurses called me pretty often, but then I learned how to report the symptoms so as to avoid being contacted unnecessarily.* [P29, age 55 years]

Technology

The majority of the patients (n=37) had not experienced any technological problem commenting that:

> *There was no problem at all with the phone...not at al...it was so easy to use that anyone can learn to use it...even for me as a non-technical person...* [P16, age 72 years]

The technological problems that were reported by the patients were primarily connected to the beginning of the reporting period (n=20). Technological problems such as sending the report and having problems moving on to the next question in the app were solved by the patients themselves by restarting the smartphone. Other technical issues described by the patients were related to the server (n=2), insufficient connection to the network (n=3), and the need to log-in with the PIN each time they reported (n=2).

Safety and Novelty

Several patients stated that the app gave a sense of security (n=21) in the form of being seen, monitored, and prioritized by the health care providers:

> *It felt like it was easy to get in touch with a nurse who was online all the time, it has felt really good.* [P64, age 76 years]

Some patients (n=8) described the novelty of the app for future patients and how it could be of support to both patients and staff:

> *It almost feels like having health care staff in one's home. I think there may be some kind of...perhaps less burden on the health care.* [P10, age 75 years]

A few patients (n=3) brought up a sense of lack of safety mainly related to an alert that did not result in contact from the nurse, which made them question the technology:

> *I was disappointed when no one called...it seems questionable whether the system can be trusted.* [P59, age 72 years]

Discussion

Principal Findings

This study shows high adherence to the daily reporting of symptoms through an interactive smartphone app (Interaktor) among a group of patients with prostate cancer during the entire period of radiotherapy and 3 weeks afterwards. In Borosund et al's [36] study, 64% of the patients having access to their Web-based system (described in the Introduction above) for 1 year logged in twice or more. There were no significant differences between users and nonusers but a trend of higher use among patients with prostate cancer, no comorbidity, and more computer experience. In Basch et al's study [15], the attrition rate was 73% in completing a Web-based self-report. Furthermore, patients with prostate cancer have shown high attrition rates in filling in a daily electronic diary [20]. Hence, there should be no reason to hinder further implementation of

mHealth based on the argument of fear of technology. The patients in this study did not find reporting symptoms every day to be burdensome; on the contrary, they appreciated it as it gave them a sense of security even when being at home and not in a hospital or clinic. This is in contrast to a study that reported that older adults found it intrusive to be asked about their illness on a daily basis [29]. All symptoms included in Interaktor were used during the study period, and the symptoms were relevant to the patients. Altogether, 16% of the reported symptoms generated an alert to the nurses, which confirms the literature that patients with prostate cancer may have severe symptoms during radiotherapy [4-6]. There were numerous yellow alerts for pain and problems with urinating; symptoms not necessarily perceived by the patients as distressing enough to generate an alert. Another indication that the level was set too low for some alerts is that some patients described how they learned to fine-tune their responses to avoid being contacted by the nurses. This suggests that the risk assessment model should be refined in a future study or before implementation of the app in the clinic. Furthermore, 3 alerts out of 1500 alerts did not lead to any call from the nurse. However, the reason whether this was a technical error or a human error cannot be ascertained because this was reported ex post facto in the posttrial telephone interviews. Overall, only a few patients reported technological problems, and those problems mainly related to problems connecting to the server and the Internet and the need to log in with a PIN code every time. However, it is important to be aware that there is the risk of false reassurance if the technology fails [37]. This stresses the importance of the technology and operation services being optimized and maintained. The reading of self-care advice and viewing of graphs could not be logged in this study, something that should be considered for future development of the app. The majority of the patients stated in the interviews that they read the self-care advice or followed their symptom history in the graphs, and they reported it as supportive. Borosund et al [36] found that the patients' use of all of the components in their Web-based system was related to low social support and high levels of depression in the group of patients with breast cancer but not in the group of patients with prostate cancer [36]. Whether these results relate to gender or cancer diagnosis cannot be concluded. Overall, the patients in this study appreciated the use of Interaktor and expressed feelings of being secure, which has been described before but in a smaller study [26].

It was hypothesized that Interaktor should enhance patients' participation in their own health care and that taking an active role will lead to better well-being and health. The theoretical underpinning (based on person-centered care [25]) in the development of Interaktor was to consider that patients have different needs when managing symptoms and concerns in connection with an illness. The results showed that the patients used Interaktor in different manner in line with the intention. Almost all patients reported daily, some used the graphs for their own symptom monitoring, some used the self-care advice, and some actively calibrated their responses to take own control over when to be contacted by the nurses. A study in the same sample also demonstrate that the use of Interaktor reduced symptom burden, particularly concerning urinary-related symptoms and emotional functioning [28]. One explanation could be that the patients' use of Interaktor enhance an active role in taking control over their own well-being and health. It is known that patients need and want to engage in active participation at different levels [38]. Patient participation is built upon relationships and shared knowledge [39], but this may be difficult to achieve today, as health care providers' time with patients is reduced. Angel and Frederiksen [39] state in their review that a mutual relationship is difficult to achieve if a physical and temporal space is not established. Others report that to achieve patient participation, extended conversations are not required [40]. In face-to-face interviews in the same study sample, the patients using Interaktor described how the app facilitated and increased their involvement in care and that a mutual relationship was achieved between the patient and the health care providers, which was not so apparent in the control group [41]. More studies are required before conclusions can be drawn about patient outcomes, for example, on quality of life and clinical recovering. However, Interaktor apparently offers an interactivity with the health care providers that facilitates patients to feel secure, which might be a motive to high adherence of using the app.

Methodological Considerations

The study has some methodological limitations. The patients who entered the study may have been more interested in using mHealth than nonparticipants, which might have impacted the findings. However, the participation rate, that is, 62%, is comparable with interventional clinical studies and is considered acceptable [42]. This study sample had a mean age of 69 years and thus was a cohort of older adults. In the literature, there have been discussions about the challenges older people can face with new technologies [43-45]. The lack of technical skills among older people and health care professionals has been described as hindering the implementation of information communication technology innovations [43,44]. Furthermore, lack of Internet access, problems with logging in, and unreliable wireless coverage have been described, which may decrease the participants' accessibility and interest [45]. This was not apparent in this study, and there were very few technological problems described. Technological development is rapidly moving forward and doubts around older peoples' interest and ability to use technological tools seem to be disappearing. In Sweden, 81% of the citizens are smartphone users, and it continues to rise [46]. Moreover, 58% of people over 65 years of age use a smartphone, and among those 75 years and older, 47% have a smartphone. The figures are similar in Germany [47]. Another reason for nonparticipation and dropout can be apprehension concerning cognitive accessibility or that the content is not user-friendly [22,48,49], but the patients in this study found the app to be user-friendly with relevant content, although it might not be so for all patients. Another strength of this study is the high adherence to daily reporting indicating that the use of mHealth is promising as an important tool in clinical care. Another limitation is that the interviews were not audiotaped, instead data collection was made by taking notes in a template following the interview guide. This could limit the trustworthiness of data because using notes taken by researchers may make the analysis to be based on already filtered content. However, 4 test interviews using the template

showed that it was sufficient to take notes during these short interviews. Confirmability is attained as the research members had methodological experience with content analysis and different professional backgrounds.

Conclusions

Patients with locally advanced prostate cancer adhere to, appreciate, and face few obstacles using an app for reporting and managing symptoms on a daily basis during radiotherapy. The Interaktor seems to consider patients' different needs because it has several components that the patients can choose depending on their own needs. The patients felt secure when being monitored, and using the Interaktor increased their own reflections about their own well-being. The Interaktor seems to enable self-management and serves as a facilitator to attain person-centered care, although some adjustment and further development of the content will be beneficial for future use.

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Conflicts of Interest

None declared.

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Abbreviations

EBRT: external beam radiation therapy
mHealth: mobile health
N/A: not applicable
PROMs: patient-reported outcome measures
PIN: personal identification number

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Original Paper

Health Care Providers' Knowledge of HPV Vaccination, Barriers, and Strategies in a State With Low HPV Vaccine Receipt: Mixed-Methods Study

Echo L Warner[1,2*], MPH; Qian Ding[3*], MStat; Lisa Pappas[4*], MStat; Julia Bodson[1*], BA; Brynn Fowler[1*], MPH; Ryan Mooney[1*], BS; Anne C Kirchhoff[1,5*], MPH, PhD; Deanna Kepka[1,2*], MPH, PhD

[1]Cancer Control and Population Sciences Department, Huntsman Cancer Institute, Salt Lake City, UT, United States

[2]College of Nursing, University of Utah, Salt Lake City, UT, United States

[3]Study Design and Biostatistics Center, School of Medicine, University of Utah, Salt Lake City, UT, United States

[4]Biostatistics Core, Huntsman Cancer Institute, Salt Lake City, UT, United States

[5]Department of Pediatrics, University of Utah, Salt Lake City, UT, United States

[*]all authors contributed equally

Corresponding Author:
Echo L Warner, MPH
College of Nursing
University of Utah
10 S 2000 E
Salt Lake City, UT, 84112
United States
Phone: 1 8015813413
Email: echo.warner@hci.utah.edu

Abstract

Background: Human papillomavirus (HPV) vaccination is below national goals in the United States. Health care providers are at the forefront of improving vaccination in the United States, given their close interactions with patients and parents.

Objective: The objective of this study was to assess the associations between demographic and practice characteristics of the health care providers with the knowledge of HPV vaccination and HPV vaccine guidelines. Furthermore, our aim was to contextualize the providers' perceptions of barriers to HPV vaccination and strategies for improving vaccination in a state with low HPV vaccine receipt.

Methods: In this mixed-methods study, participating providers (N=254) were recruited from statewide pediatric, family medicine, and nursing organizations in Utah. Participants completed a Web-based survey of demographics, practice characteristics, HPV vaccine knowledge (≤10 correct vs 11-12 correct answers), and knowledge of HPV vaccine guidelines (correct vs incorrect). Demographic and practice characteristics were compared using chi-square and Fisher exact tests for HPV knowledge outcomes. Four open-ended questions pertaining to the barriers and strategies for improving HPV vaccination were content analyzed.

Results: Family practice providers (52.2%, 71/136; *P*=.001), institutional or university clinics (54.0%, 20/37; *P*=.001), and busier clinics seeing 20 to 29 patients per day (50.0%, 28/56; *P*=.04) had the highest proportion of respondents with high HPV vaccination knowledge. Older providers aged 40 to 49 years (85.1%, 57/67; *P*=.04) and those who were a Vaccines for Children provider (78.7%, 133/169; *P*=.03) had the highest proportion of respondents with high knowledge of HPV vaccine recommendations. Providers perceived the lack of parental education to be the main barrier to HPV vaccination. They endorsed stronger, consistent, and more direct provider recommendations for HPV vaccination delivered to parents through printed materials available in clinical settings and public health campaigns. Hesitancy to recommend the HPV vaccine to patients persisted among some providers.

Conclusions: Providers require support to eliminate barriers to recommending HPV vaccination in clinical settings. Additionally, providers endorsed the need for parental educational materials and instructions on framing HPV vaccination as a priority cancer prevention mechanism for all adolescents.

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KEYWORDS

health care provider; human papillomavirus; human papillomavirus vaccine; mixed methods; knowledge

Introduction

In 2013, the US President's Cancer Panel identified provider recommendations as one of three priorities for improving the rates of human papillomavirus (HPV) vaccination [1]. A strong provider recommendation of the HPV vaccine reflects up to a 5-fold increase in the decision by parents to vaccinate their child [2]. Multiple national organizations have echoed their support for providers to deliver strong recommendations for the HPV vaccine to eligible adolescents, including the American Academy of Family Physicians, the American Academy of Pediatrics, the American College of Obstetricians and Gynecologists, the American College of Physicians, the Centers for Disease Control and Prevention (CDC), and the Immunization Action Coalition [3]. Research on strategies to improve the consistency and quality of provider recommendations is pivotal to achieving the Healthy People 2020 goal of 80% HPV vaccination coverage set by the CDC [4].

Knowledge about HPV vaccines influences the providers' intention to recommend HPV vaccination to their patients [5-7]. Low knowledge of the benefits of HPV vaccination among providers may contribute to low HPV vaccination rates in regions such as the Intermountain West, inclusive of Utah, Idaho, Nevada, Wyoming, Colorado, Montana, Arizona, and New Mexico [8]. In 2015, Utah was ranked the 49th state for HPV vaccine initiation among females (47.8%) and among the lowest for males (40.9%) aged 13 to 17 years [9]. Although knowledge deficits about HPV vaccines and HPV vaccine guidelines among the providers in Utah have not been described, previous research indicates that there is a high prevalence of missed opportunities for HPV vaccination in Utah [10]. Missed opportunities may reflect providers' misconceptions or lack of knowledge about HPV vaccination. In addition, contextual factors such as cultural or religious assumptions regarding adolescents' sexual practices may influence providers' perceptions of HPV and their subsequent recommendation of the vaccine to their patients [11,12]. Thus, improving provider recommendations of the HPV vaccine to their patients first requires assessments of providers' knowledge about HPV vaccines and HPV vaccine guidelines.

Theoretically informed approaches to improving HPV vaccination are necessary to advance research and practice in this area. The social ecological framework (SEF) is a health promotion model that encompasses multiple levels of influence. In the SEF, individual, interpersonal, and organizational characteristics constitute three of the five levels of influence on a public health intervention. Multilevel targeted interventions promote healthy practices such as the administration of HPV vaccines to prevent HPV-related morbidity and mortality [13]. For example, individual, interpersonal, and organizational SEF levels are represented in this study as parent and patient, health care provider, and organizational characteristics, respectively. By examining these characteristics from the health care providers' perspectives, the SEF provides the theoretical foundation for understanding how these characteristics influence providers' readiness to deliver a strong recommendation for HPV vaccination to patients and parents.

Moreover, the exposure of health care providers to the health care system, parents, and patients gives them unique perspectives on the clinical barriers and strategies for improving HPV vaccination. In this mixed-methods study, we describe providers' knowledge of HPV vaccines and HPV vaccine guidelines and their perceptions of barriers to and strategies for improving HPV vaccination in Utah, which is a state with low HPV vaccination rates. We aimed to assess associations of demographic and practice characteristics with providers' knowledge of HPV vaccination and HPV vaccination guidelines to identify provider groups with knowledge deficits. Providers' perceptions of the barriers to and strategies for improving HPV vaccination were described to contextualize the results.

Methods

Mixed-method approaches that combine qualitative and quantitative data resources provide a more complete description of a phenomenon than a single methodological approach alone [14,15]. Using a Web-based survey, our goal was to identify demographic and practice characteristics that are associated with providers' knowledge about HPV vaccination and HPV vaccination guidelines in a state with a low HPV vaccination rate. Qualitative open-ended survey questions were used to further contextualize the findings from the survey analysis by describing providers' perceptions of barriers to and strategies for improving HPV vaccination. The usability and technical functionality of the survey were assessed during pilot testing before data collection occurred. This study was deemed exempt research by the institutional review board of the University of Utah.

Participants and Data Collection

During three periods from 2014-2015, a self-administered closed survey was distributed via email listservs to 3 statewide provider organizations, with sample sizes of approximately 600, 740, and 330 for pediatrics, family medicine, and nursing, respectively. The survey comprised 58 items, with 1 to 4 questions per page. Participants received notification of a forthcoming opportunity to participate in a research study, with the option to opt out from further contact (n=1). Eligible participants who did not opt out received an additional email invitation to complete the Web-based survey within 2 weeks. Two biweekly reminder emails were then sent within 4 weeks after the initial email. Anonymous submission of the completed survey constituted consent. Participants had the option to receive a US $20 Amazon gift card or make a US $20 donation to a local children's hospital. The approximate response rates were as follows: pediatrics 18.0% (108/600), family practice 21.8% (161/740), and nurse practitioners 39.1% (129/330). Of these, 65 participants were excluded because they were not a pediatrician, family medicine physician, or nurse practitioner (eg, office staff and medical assistant), and 79 participants were

excluded because they did not see patients in a clinical setting. The final sample of 254 participants who were analyzed comprised 75 pediatricians, 136 family medicine physicians, and 43 nurse practitioners.

Independent Variables

Demographics included age, sex, race, marital status, and religion. Practice characteristics included practice location, Vaccines for Children (VFC) provider status, specialty type, practice type, practice size, number of patients per day, number of patients per week, most common form of patient payment, and provider-reported majority Hispanic population. Variable selection was guided by the SEF and included factors that represented multiple levels of influence, including individual, interpersonal, and community (eg, parents, patients, health care providers, organizations, and public policy). Variable selection was also based on extant literature and our previous research in Utah related to HPV vaccination.

Outcome Measures

On the basis of a review of the literature, two HPV knowledge measures were measured (see Table 1): knowledge of HPV vaccination and knowledge of HPV vaccination guidelines. Knowledge of HPV vaccination was measured for each participant based on their responses to 12 true or false questions resulting in a score ranging between 0 and 12. This cutoff selection was based on the distribution of the data along a natural median divide. For analysis, HPV vaccination knowledge scores summarized into a binary variable with ≤10 indicating low knowledge and 11 to 12 indicating high knowledge.

The second outcome, knowledge of HPV vaccination guidelines, was measured for each respondent based on 3 questions about the timing and age of HPV vaccination. For analysis, we aggregated responses into a binary variable, with those who incorrectly answered any of the 3 questions as lower knowledge and those who answered all 3 questions correctly as high knowledge.

Statistical Analysis

Summary statistics were reported for demographic and practice characteristics. Statistics were calculated for nonmissing data as indicated in Tables 2-5. Chi-square and Fisher exact tests were used for examining associations in univariate analyses with Stata version 14.1 (StatCorp LP). All *P* values were two-sided and considered significant at *P*=.05.

Qualitative Data and Analyses

Qualitative data were extracted from 4 open-ended questions of the Web-based survey to describe providers' perceptions of barriers to and strategies for improving HPV vaccination among males and females to "ground" the quantitative results. Grounding is a mixed-methods technique for combining qualitative and quantitative data to contextualize a phenomenon [14,15]. Responses were read and reread by 2 authors to familiarize with the data and identify themes. A deductive coding structure was created using levels of the SEF and revised as coding developed. Themes pertaining to providers' perceptions at interpersonal (parents, patients, and providers) and organizational (health care system or public policy) levels of the SEF are described herein. Pertinent differences in providers' perceptions about HPV vaccination for girls and boys are described.

Table 1. Outcome variable questions and responses.

Question	Correct response	Knowledge outcome
Vaccine leads to long-lasting immunity.	True	HPV[a]vaccination
Vaccine does not cause adverse side effects.	True	HPV vaccination
Vaccine protects against genital warts in addition to cervical cancer.	True	HPV vaccination
Condom use in patients does not decrease after vaccination.	True	HPV vaccination
Offering vaccination provides an opportunity to discuss sexuality issues with patients.	True	HPV vaccination
The likelihood of patients having sex does not increase after vaccination.	True	HPV vaccination
HPV vaccination is highly effective at preventing cervical cancer precursors.	True	HPV vaccination
Almost all cervical cancers are caused by HPV infection.	True	HPV vaccination
Women who have been diagnosed with HPV should not be given HPV vaccine.	False	HPV vaccination
The incidence of HPV in women is highest among women in their 30s.	False	HPV vaccination
Genital warts are caused by the same HPV types that cause cervical cancer.	False	HPV vaccination
A pregnancy test should be performed prior to giving HPV vaccine.	False	HPV vaccination
When is HPV vaccination recommended?	Before the beginning of sexual activity	HPV vaccine guideline
The recommended age for HPV vaccination in adolescent girls is?	Subjects aged 11-12 years	HPV vaccine guideline
The recommended age for HPV vaccination in adolescent boys is?	Subjects aged 11-12 years	HPV vaccine guideline

[a]HPV: human papillomavirus.

Results

Demographic and Practice Characteristics Associated With HPV Vaccination Knowledge and Guidelines

Participants included 136 family practice physicians, 75 pediatricians, and 43 nurse practitioners. No demographic factors were associated with providers' knowledge of HPV vaccination (see Table 2).

In Table 3, specialty was associated with knowledge; family practice physicians had the highest proportion of providers with high HPV vaccination knowledge (52.2%, 71/136), whereas pediatricians had the lowest (26.7%, 20/75 *P*=.001). Providers from institutional or university settings (54.0%, 20/37) and primary care or other (50.5%, 49/97) had higher proportions of high HPV knowledge than private care (35.7%, 30/84) and hospital or urgent care clinics (15.6%, 5/32; *P*=.001). Providers who saw ≥15 patients per day had a higher proportion of high HPV knowledge (15-19 patients: 47.8%, 33/69; 20-29 patients: 50.0%, 28/56; ≥30 patients: 44.7%, 20/50) than providers who saw <15 patients per day (27.8%, 20/72; *P*=.04).

Table 2. Univariate analysis of demographic characteristics associated with human papillomavirus vaccination knowledge (N=254).

Demographics	Human papilloma virus vaccination knowledge		*P* value
	Lower knowledge (N=148)	High knowledge (N=106)	
	n (%)	n (%)	
Age, in years			.46[a]
18-29	14 (56.0)	11 (44.0)	
30-39	47 (52.2)	43 (47.5)	
40-49	43 (64.2)	24 (35.8)	
≥50	44 (61.1)	28 (38.9)	
Sex [b]			.57[a]
Male	76 (59.8)	51 (40.2)	
Female	71 (56.3)	55 (43.7)	
Race [b]			.21[a]
White	134 (57.0)	101 (43.0)	
Other[c]	13 (72.2)	5 (27.8)	
Marital status			.87[a]
Single, divorced, widowed	22 (59.5)	15 (40.5)	
Married, living as married	126 (58.1)	91 (41.9)	
Religion			.84[a]
Latter-day Saint	70 (56.9)	53 (43.1)	
Other religion	47 (61.0)	30 (39.0)	
No religion	31 (57.4)	23 (42.6)	
Location [b]			.11[a]
Salt Lake, Utah, or Davis counties	131 (60.1)	87 (39.9)	
Other counties	16 (45.7)	19 (54.3)	

[a]Chi-square test.

[b]Missing values: Sex=1; Race=1; Location=1.

[c]Other includes black or African American, American Indian or Alaska Native, Asian, Native Hawaiian or Pacific Islander, Other.

Table 3. Univariate analysis of practice characteristics associated with human papillomavirus vaccination knowledge (N=254).

Practice characteristics	Human papillomavirus vaccination knowledge		*P* value
	Lower knowledge (N=148)	High knowledge (N=106)	
	n (%)	n (%)	
Vaccines for children provider status [a]			.06[b]
Yes	94 (55.6)	75 (44.4)	
No or Do not know	44 (60.3)	29 (39.7)	
Do not provide vaccines[c]	10 (90.9)	1 (9.1)	
Specialty			*.001* [d]
Pediatrician	55 (73.3)	20 (26.7)	
Family practice physician	65 (47.8)	71 (52.2)	
Nurse practitioner	28 (65.1)	15 (34.9)	
Practice type [a]			*.001* [d]
Private (solo or group)	54 (64.3)	30 (35.7)	
Primary care or Other[e]	48 (49.5)	49 (50.5)	
Institutional or University settings	17 (46.0)	20 (54.0)	
Hospital or Urgent care clinic	27 (84.4)	5 (15.6)	
Practice size (number of physicians) [a]			.36[d]
1-5	47 (54.0)	40 (46.0)	
6-10	37 (66.1)	19 (33.9)	
>10	60 (57.7)	44 (42.3)	
Number of patients per day [a]			*.04* [d]
<15	52 (72.2)	20 (27.8)	
15-19	36 (52.2)	33 (47.8)	
20-29	28 (50.0)	28 (50.0)	
≥30	30 (60.0)	20 (40.0)	
Number of patients per week [a]			.09[d]
<25	29 (74.4)	10 (25.6)	
25-49	53 (55.8)	42 (44.2)	
≥50	63 (55.3)	51 (44.7)	
Most common patient payment [a]			.31[d]
Private insurance	86 (54.4)	72 (45.6)	
Medicaid or Children's Health Insurance Program	35 (64.8)	19 (35.2)	
Uninsured, Self-pay, Other, or Do not know	26 (63.4)	15 (36.6)	
Patient population is Hispanic majority			.59[d]
Yes	15 (53.6)	13 (46.4)	
No	133 (58.9)	93 (41.1)	

[a]Vaccines for children provider not applicable or missing=1; Practice type not applicable or missing=4; Practice size not applicable or missing=7; Number of patients per day other, not applicable, or missing=7; Number of patients per week other, not applicable, missing=6; Most common patient payment not applicable or missing=1.

[b]Fisher exact test.

[c]Individuals who see patients but do not provide vaccinations (eg, oncology).

[d]Chi-square test. Italics indicate *P* value less than .05.

[e]Includes ambulatory care, primary care clinic, health department, federally qualified health center, and other.

Tables 4 and 5 indicate that a lower proportion of providers aged 30 to 39 years (65.6%, 59/90) correctly identified HPV vaccination guidelines than those in other age groups (18-29 years: 80.0%; 20/25, 40-49 years: 85.1%, 57/67; ≥50 years: 75.0%, 54/72; *P*=.04). More VFC providers (78.7%, 133/169) correctly identified HPV vaccination recommendations compared with other providers (*P*=.03).

Table 4. Univariate analysis for demographic characteristics associated with human papillomavirus vaccine recommendation knowledge (N=254).

Demographics	Human papillomavirus vaccine recommendation knowledge		*P* value
	Lower knowledge (N=64)	High knowledge (N=190)	
	n (%)	n (%)	
Age, in years			*.04* [a]
18-29	5 (20.0)	20 (80.0)	
30-39	31 (34.4)	59 (65.6)	
40-49	10 (14.9)	57 (85.1)	
≥50	18 (25.0)	54 (75.0)	
Sex [b]			.26[a]
Male	36 (28.3)	91 (71.7)	
Female	28 (22.2)	98 (77.8)	
Race [b]			.05[a]
White	56 (23.8)	179 (76.2)	
Other[c]	8 (44.4)	10 (55.6)	
Marital status			.27[a]
Single, divorced, widowed	12 (32.4)	25 (67.6)	
Married, living as married	52 (24.0)	165 (76.0)	
Religion			.82[a]
Latter-day Saint	29 (23.6)	94 (76.4)	
Other religion	20 (26.0)	57 (74.0)	
No religion	15 (27.8)	39 (72.2)	
Location [b]			.72[a]
Salt Lake, Utah, or Davis counties	56 (25.7)	162 (74.3)	
Other counties	8 (22.9)	27 (77.1)	

[a]Chi-square test. Italics indicate *P* value less than .05.

[b]Missing values: Sex=1, Race=1, and Location=1.

[c]Other includes black or African American, American Indian or Alaska Native, Asian, Native Hawaiian or Pacific Islander, Other.

Table 5. Univariate analysis for practice characteristics associated with human papillomavirus vaccine recommendation knowledge (N=254).

Characteristics	Human papillomavirus vaccine recommendation knowledge		*P* value
	Lower knowledge (N=64)	High knowledge (N=190)	
	n (%)	n (%)	
Vaccines for children provider status [a]			*.03* [b]
Yes	36 (21.3)	133 (78.7)	
No or Do not know	22 (30.1)	51 (69.9)	
Do not provide vaccines[c]	6 (54.6)	5 (45.4)	
Specialty			.20[d]
Pediatrician	15 (20.0)	60 (80.0)	
Family practice physician	34 (25.0)	102 (75.0)	
Nurse practitioner	15 (34.9)	28 (65.1)	
Practice type [a]			.72[d]
Private (solo or group)	22 (26.2)	62 (73.8)	
Primary care or Other[e]	21 (21.7)	76 (78.3)	
Institutional or University settings	9 (24.3)	28 (75.7)	
Hospital or Urgent care clinic	10 (31.2)	22 (68.8)	
Practice size (number of physicians) [a]			.07[d]
1-5	26 (29.9)	61 (70.1)	
6-10	17 (30.4)	39 (69.6)	
>10	18 (17.3)	86 (82.7)	
Number of patients per day [a]			.20[d]
<15	19 (26.4)	53 (73.6)	
15-19	21 (30.4)	48 (69.6)	
20-29	16 (28.6)	40 (71.4)	
≥30	7 (14.0)	43 (86.0)	
Number of patients per week [a]			.35[d]
<25	11 (28.2)	28 (71.8)	
25-49	28 (29.5)	67 (70.5)	
≥50	24 (21.0)	90 (79.0)	
Most common patient payment [a]			.07[d]
Private insurance	32 (20.2)	126 (79.8)	
Medicaid or Children's Health Insurance Program	16 (29.6)	38 (70.4)	
Uninsured, Self-pay, Other, or Do not know	15 (36.6)	26 (63.4)	
Patient population is Hispanic majority			.98[d]
Yes	7 (25.0)	21 (75.0)	
No	57 (25.2)	169 (74.8)	

[a]Vaccines for children provider not applicable or missing=1; Practice type not applicable or missing=4; Practice size not applicable or missing=7; Number of patients per day other, not applicable, or missing=7; Number of patients per week other, not applicable, or missing=6; Most common patient payment not applicable or missing=1.

[b]Fisher exact test. Italics indicate *P* value less than .05.

[c]Individuals who see patients but do not provide vaccinations (eg, oncology).

[d]Chi-square test.

[e]Includes ambulatory care, primary care clinic, health department, federally qualified health center, and other.

The following results describe health care providers' perceptions of barriers to HPV vaccination and strategies for improving HPV vaccination with accompanying illustrative quotes presented in the text and in Table 6. Each section is separated by (1) individual, (2) interpersonal, and (3) organizational constructs of the SEF, including (1) parents and patients, (2) health care providers, and (3) organizations, respectively. There were 74.4% (189/254) participants who responded to at least one of the 4 open-ended questions and 48.4% (123/254) participants who responded to all 4 questions.

Providers' Perceptions of HPV Vaccination Barriers

Barriers Related to Parents and Patients

In the open-ended questions, providers described concerns about sexual activity and promiscuity (n=69), vaccine refusal or reluctance (n=62), inadequate or incorrect parental knowledge (n=96), and low perceived risk of HPV (n=67) as the most common barriers to vaccination for parents and patients (see Table 6). To providers, parents' perceptions about their child's sexual activity influenced their decisions about HPV vaccination. One provider observed:

> *I do see a lot of moms "explain" the vaccine to their children saying, "It would be a good idea in case you were raped" rather than in case you had a sexual partner with HPV.*

Providers responded that parents believed that the HPV vaccine increases sexual promiscuity, is unnecessary because their child is not sexually active, and that their child is not at risk for HPV infection. Providers connected parents' concerns about sexuality with perceived risk of HPV infection. For example, one provider stated:

> *...if they've remained virginal, they assume the partner they marry is virginal and thus they aren't at risk [for HPV]. Not thinking their partner might not be truthful OR that this marriage might not last and they could be exposed when they remarry, which by then [they] could be past immunization age.*

Providers listed inadequate or incorrect parental knowledge as a barrier to vaccination about the purpose of HPV vaccination (Table 6). Providers felt that parental "misconceptions" were the result of parents being "very misinformed by relatives, or friends." For example, a common endorsed barrier to vaccinating boys was the perception that HPV vaccines only prevent cervical cancer.

Barriers Related to Health Care Providers

Only a few respondents identified providers' barriers to HPV vaccination. However, there were some concerns such as vaccination not being a priority (n=19). One provider stated:

> *We occasionally forget the vaccine at sick visits.*

Some providers were openly unsupportive of HPV vaccination (n=16). One provider stated:

> *Without a history of homosexuality, I do not see a great advantage to the immunization of boys.*

Whereas some providers felt HPV vaccines were not cost-effective, others expressed skepticism, stating they wanted "more science showing benefit in men" (n=13). A provider downplayed the need for HPV vaccination by stating:

> *Issues of sexually transmitted disease do not seem to be an issue in my clinical setting.*

Barriers Related to Organizations

Organizational barriers to HPV vaccination included cost (n=32), completing follow-up doses (n=22), and infrequency of vaccinating at regular well-child or primary care visits (n=16).

Perceptions of HPV Vaccination Improvement Strategies

HPV Vaccination Improvement Strategies for Parents and Patients

Parental education was the most common strategy for improving HPV vaccination (n=81). Providers felt that education should focus on reducing negative sexual connotations about the HPV vaccine. One provider relayed:

> *Basically, debunking the myth that it leads to more sex.*

Providers felt that parents could be educated directly during clinic visits and through broader community health promotion campaigns. Informing parents about the prevalence of HPV within their community was suggested. One provider stated:

> *Better understanding that it is a ubiquitous virus and infects nearly everyone in the world, regardless of sexual partner number.*

In some instances, providers' perceptions varied by gender, with different ideas for vaccinating girls and boys (n=23, Table 6). Providers felt that parents need information about the efficacy of the HPV vaccine for reducing HPV-related morbidity among males.

HPV Vaccination Improvement Strategies for Providers

The most common suggestion for improving HPV vaccination by the providers was to tailor recommendations (n=23) and to focus on preventing cancer rather than sexually transmitted infections (n=18). Providers also felt that routine HPV vaccination would reduce parental and patient hesitancy (n=17, Table 6). Providers indicated that vaccine hesitancy was related to low perceived risk among parents and patients. Therefore, providers emphasized the importance of framing HPV vaccination recommendations:

> *...discussing the fact that [patients] can be exposed from a future husband who did not know he was infected.*

Another provider echoed this perception:

> *Emphasizing that nonsexual intercourse exposure results in HPV acquisition and that there are respiratory and oral cancers associated too.*

Table 6. Thematic findings and examples by levels of the social ecological framework (SEF).

Main theme and SEF[a] level	Subtheme	Sample quotes
Perception of vaccine barriers		
Parents and Patients	Sexual activity and promiscuity (n=69)	"Their parents' opinions regarding the teen's sexuality [obviate the] legitimacy of the vaccine."
	Vaccine refusal or reluctance (n=62)	"For some reason it is okay for women to have PAP exams but it is scandalous to get the vaccine that can prevent the cancer Pap exams detect."
	Inadequate or incorrect parental knowledge (n=96)	"...very misinformed by relatives, or friends."
	Low perceived risk of human papillomavirus (HPV) infection (n=67)	"They underestimate the risks of not being vaccinated. And overestimate the risks of vaccination."
Providers	Vaccine not a priority (n=19)	"We occasionally forget the vaccine at sick visits."
	Not supportive of HPV vaccine (n=16)	"...[HPV vaccination] is a commercial success for HPV vaccines manufacturers; however, cervical cancer is not a pandemic disease and could be better controlled under personal choices than other diseases that [patients] must be vaccinated against."
		"I live in a community where most teenagers are not sexually active until they get...It is hard to recommend a series of 3 somewhat painful shots to teenagers who are not planning to be sexually active until they get married."
	More scientific evidence desired (n=13)	"...more science showing benefit in men."
Organizational	Cost (n=32)	"I recommend HPV in those that participate in VFC, but once they are 19 and older, it is too expensive."
		"I'm a big proponent of vaccines, but the cost-benefit analysis of HPV just doesn't support its widespread use. $400 is way too expensive…The HPV vaccines don't obviate the need for pap smears, so what are we gaining here? Nothing."
		"Make it free. Otherwise, I don't have any plans to recommend it."
	Completing follow-up doses (n=22)	"If it were not a series, they forget to finish it."
		"Infrequent preventive visits. Difficulty completing the series."
	Infrequency of visits (n=16)	"[There are] not enough well child visits to get in the entire series."
Perceptions of vaccine improvement strategies		
Parents and Patients	Education (n=81)	"Discussion about rates of infection in Utah especially in suburban areas and discussion about cervical cancer and its causes as a television campaign."
	Gender differences (n=23)	"Better information about genital warts, anal cancer and other diseases caused by HPV that affect boys, and can be minimized by use of the vaccine."
Providers	Cancer prevention focus (n=18)	"Focusing on cancer prevention 'later in life' is more effective—especially when the discussion can be combined with the discussion about meningococcal meningitis and tetanus/pertussis. [HPV vaccination] is just a routine part of the preteen triad of immunizations."
	Make HPV vaccination routine practice (n=17)	"To make it more routine like it is expected to get it in medical culture rather than this optional/additional vaccine."
	Tailored recommendation (n=23)	"Discussing the fact that [patients] can be exposed from a future husband who did not know he was infected."
	Educational information (n=22)	"I need some information sheets, reassurance sheets, on side effects and safety, which are easy to hand out."
Organizational	Public policy and standing orders (n=22)	"Adding it to the list of required vaccines for junior high and high school."

[a]SEF: social ecological framework.

Providers endorsed the need for better educational information to be displayed in health clinics and comprehensible educational information on HPV vaccination to share with parents (n=22, Table 6).

HPV Vaccination Improvement Strategies for Organizations and Policy

Providers expressed support for public policy requiring HPV vaccination for school enrollment (n=22, Table 6). One provider also felt that standing orders for HPV vaccination would improve consistency in HPV vaccination.

Discussion

Principal Findings

This study is the first to describe providers' knowledge of HPV vaccination and HPV vaccination guidelines, with added context of providers' perceptions related to the barriers to and facilitators of HPV vaccination. Despite Utah's very low HPV vaccination prevalence, another study with providers in Utah using similar survey items to assess providers' knowledge of HPV indicated a substantially lower proportion of providers with correct knowledge compared with our sample (mean proportion of correct responses=57.7% vs 79.4%; [16]). Yet provider endorsement of HPV vaccination varies. There are some significant correlates of lower vaccination knowledge with provider demographics, which are described hereafter to inform future efforts targeted toward providers' recommendation of HPV vaccination In addition, our qualitative results provide essential context for improving provider recommendations in states with low HPV vaccination. This study makes an important contribution to existing literature by using a mixed-methods design to describe providers' perceptions of vaccine barriers that suppress HPV vaccination in a state with low HPV vaccine receipt.

Examination of multiple levels of the SEF is integral to designing effective HPV vaccination interventions. On an individual and interpersonal level, health care practice characteristics that were associated with lower knowledge of HPV vaccination and guidelines among providers in Utah include provider specialty (eg, pediatricians and nurse practitioners), practice type (eg, private practice and hospitals or urgent care clinics), and number of patients seen per day (eg, <15 and ≥30 patients per day). Additionally, younger providers (aged 30-39 years) and older providers (aged ≥50 years) had lower knowledge compared with those who were middle aged (40-49 years). The lower level of HPV vaccination knowledge among providers aged 30 to 39 years warrants attention. Given that HPV vaccination may not have been approved at the time of their clinical training, it is possible that these individuals may not have received training on HPV vaccination as a part of their clinical curriculum. Moreover, as new clinicians, these providers may have yet to establish robust continuing education opportunities to learn about HPV vaccines and guidelines. Thus, targeted opportunities for continuing education for those who have completed their medical or nursing training within the last 10 to 15 years may be merited. Continuing education for more established providers may help improve knowledge about HPV vaccination.

Providers who saw adolescent patients but did not routinely provide vaccinations, as well as those who were not VFC providers had lower knowledge about HPV vaccination and guidelines than did VFC providers. One explanation for this finding may be that VFC providers are potentially more accustomed to routinely providing HPV vaccines and thus may be more knowledgeable about this vaccine. In addition, the differential distribution of clinicians by specialty, with more family medicine providers than physicians practicing in rural areas [17], may have influenced our results on providers' knowledge of HPV vaccination and guidelines. Although we did not examine the influence of rurality in this study, prior research has documented deficits in patient-provider communication about HPV vaccines from parents in rural areas as compared with those in urban areas [18].

Despite finding several associations between provider demographics and knowledge, the most compelling finding from this study was from our qualitative analyses demonstrating providers' overwhelming perception of an immediate need for improved parental education regarding HPV vaccines. Misinformation among parents was portrayed by providers as the strongest and most consistent barrier to vaccination. Providers described how parental beliefs regarding sexuality and HPV vaccination impede HPV vaccination and make it difficult to deliver a strong recommendation in support of HPV vaccination. Providers expressed frustration at not having access to educational materials that they need to accurately and efficiently communicate with parents and patients about HPV vaccination. However, improvements in parental knowledge alone may not eliminate hesitancy toward HPV vaccination [19]. Continued promotion of HPV vaccination on an individual, interpersonal, organizational, and community level is needed to support providers' strong recommendations for HPV vaccination to 11- to 12-year-old adolescents in Utah. Providers also endorsed public health campaigns as a strategy to inform parents of the ubiquity of HPV infection in their community by relaying local data on HPV prevalence for both males and females. In addition, providers supported framing the HPV vaccine as a cancer prevention mechanism for males and females. Lastly, providers felt that state policies requiring HPV vaccination would be the most powerful way to improve HPV vaccination. The feasibility of these strategies should be further explored.

Although health care providers' hesitancy was not explicitly noted as a barrier to HPV vaccination, our qualitative analysis revealed that some providers have persistent negative perceptions of HPV vaccination. This reticence to endorse HPV vaccination has not only been observed in Utah but has also been described in national surveys [20]. Whereas parents report variation in the quality of provider recommendations, those who receive a strong endorsement for HPV vaccination are much more likely to choose vaccination [21]. Providers' hesitancy to discuss sexual health, lack of time to address parental concerns about vaccine efficacy and safety, and perceptions of low self-efficacy to guide parents' decisions about vaccination may discourage strong recommendations for HPV vaccination

[12,22,23]. Furthermore, the lack of parental knowledge about HPV vaccination, which is noted as a barrier by providers, may be an unintended consequence of providers' low knowledge about HPV vaccination and guidelines, potentially creating a situation in which providers with lower knowledge avoid discussing the HPV vaccine with their patients. Given the powerful impact of the strength and quality of providers' HPV vaccine recommendations on parents' decisions to vaccinate [21], providers in these settings may indeed benefit from education on the costs and benefits of HPV vaccination and the consequences of an unvaccinated population. Future research is warranted that explores the association between providers' knowledge about HPV vaccination as well as guidelines and the administration of the HPV vaccine.

Limitations

Limitations of this study include sampling of providers across a single state, which could be a potential threat to external validity. However, our results may be generalizable to other states with a low HPV vaccination rate and to states in the Intermountain West region. This depiction of HPV vaccination in Utah may be incomplete because we neither investigated perceptions of parents, patients, and communities nor the policies that influence HPV vaccination in Utah. Only 48.4% of providers responded to all 4 open-ended questions, thus nonresponse bias may exist in the qualitative findings, which means that those who did not respond to the open-ended questions may hold different perspectives on HPV vaccine barriers and strategies with regard to HPV vaccination for girls and boys. Our response rate was low, which may indicate that the knowledge of HPV vaccination and guidelines among providers who chose not to participate may differ. The variation in, and overall low response rate, among the different provider groups may have introduced differential bias to the results. Additionally, given the changing nature of listserv membership, it is possible that some providers may not have had equal opportunities to participate in the survey if they were added or removed from the listserv during the data collection period. However, we have no reason to believe that knowledge and perceptions of HPV vaccination would have been different for those who were migrating into and out of the sample for this reason.

HPV vaccination knowledge is commonly operationalized using a variety of measurement tools and survey items. Whereas standardized tools have been developed for measuring parental knowledge, tools that measure health care providers' knowledge have yet to be tested. Utilization of standardized measurement tools to assess HPV vaccination knowledge among health care providers may facilitate comparisons across future studies. Lastly, we did not ask providers to report the exact location of their health care practice, which limited the data analyses.

Conclusions

Utah's vaccination rates are among the lowest in the United States. Theoretically informed interventions to improve vaccination through provider recommendations need to fully appreciate the public health benefit of HPV vaccination. This study provides evidence that provider-based HPV vaccine interventions must extend beyond improving providers' knowledge about vaccination. Our analysis revealed that providers have knowledge of HPV vaccination and guidelines, but contextual factors accentuate the need for supporting providers in administering strong, consistent, and high-quality recommendations for the HPV vaccine in Utah. Recognizing the importance of provider's experiences, we summarized their suggestions for improving HPV vaccination and recommend that providers' perspectives be considered in the development of future interventions. Specifically, providers consider parental misconceptions to be the strongest barrier to HPV vaccination in Utah. Yet, they believe that misinformation can be corrected through direct parental education and broad public health campaigns. Providers' recognize the value parents place on the dissemination of accurate information through clinical settings and appreciate the importance of a strong provider recommendation. In summary, providers in Utah have high knowledge about HPV vaccination, but they need support in correcting misinformation that persists at multiple levels of the SEF, including among patients, parents, colleagues, and communities.

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Conflicts of Interest

None declared.

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Abbreviations

CDC: Centers for Disease Control and Prevention
HPV: human papillomavirus
SEF: social ecological framework
VFC: Vaccines for Children

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130 Queens Quay East.
Toronto, ON, M5A 3Y5
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Email: support@jmir.org